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Certainty and uncertainty about end of life care nursing practices in New Zealand Intensive Care

Units: a mixed methods study

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55 **Keywords:**
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57 Death and dying, end of life care, intensive care, intensive care nurse, treatment withdrawal,
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60 nursing care
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3 **ABSTRACT**

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5 **Background:** With end-of-life (EOL) central to the nursing role in intensive care, few studies have
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7
8 been undertaken to explore EOL care in the context of New Zealand (NZ) intensive care nursing.

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

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

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

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

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

1. Introduction

Over the past two decades, the central position that end of life (EOL) holds within intensive care has become clear.¹ The tension between the delivery of life sustaining therapies in an environment with high mortality rates has been well-explored,² and the processes used to manage EOL have been described.³ During this sensitive time, the demands placed on family members have been identified⁴ and interventions developed to support those grieving.⁵

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-making³ and then negotiating how the clinical decisions are delivered at the bedside.⁶

EOL care is therefore an intrinsic part of intensive care nursing practice. However, there is limited nursing work published about EOL in ICU from a New Zealand (NZ) perspective. Empirical work to date has explored EOL service development⁷ and ethical decision making by intensive care nurses in this setting.⁸ 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 professional⁹ and cultural¹⁰ 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

1
2 This sequential two phased mixed methods study used a cross sectional survey with follow-on
3
4 focus groups to identify NZ ICU nurses experiences of, and attitudes towards EOL care.
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9 In Phase One a cross sectional descriptive survey was undertaken with a sample of registered
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11 nurses in four large tertiary ICUs in NZ. This survey replicated European work that explored
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13 attitudes and beliefs towards EOL care of European ICU nurses (n= 164) across 22 countries.¹¹
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15 Permission was given by the original authors for use of the survey. The survey instrument was
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18 piloted on 14 ICU nurses from a non-tertiary ICU in NZ to determine cultural relevance to NZ.
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21 Minor amendments were made to clarify clinical phrases commonly used.
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28 In preparation for data collection, the study was presented to staff in each of the four study sites
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30 during staff meetings. An email invitation with survey information and survey link (through Survey
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32 Monkey) was sent out by nurse managers to all ICU nurses (N=465). Consent was understood as
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34 implicit by completion of the survey with all responses anonymised and confidential. Two
35
36 reminders were sent out at three weekly intervals. Survey data were analysed using Statistical
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38 Package for Social Scientists (SPSS, version 21). Statistical examination replicated analysis in the
39
40 European study.¹¹ Data were coded numerically and subjected to descriptive and inferential
41
42 statistical analysis. Chi square tests (with Yates Continuity Correction for 2 by 2 tables) were used
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44 to measure the association between categorical variables; with Phi or Cramer's V, as appropriate,
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47 used to calculate effect size. Association between ordinal variables was assessed using
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50 Spearman's Rho.
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1 Results from Phase I were reviewed by MC and PF and areas of similarity and difference in
2 experiences and attitudes towards EOL between European and NZ ICU nurses were identified.
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4 Based on this, a focus group guide was developed and used in Phase 2.
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10 In Phase Two, follow-on focus groups were undertaken using a developed focus group guide to
11 explore: EOL in ICU, use of fluids, nutritional support and passive limb exercises during EOL care.
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13 Participants were drawn from participants in Phase One. Consent was gained prior to focus group
14 commencement. Focus groups were digitally recorded, transcribed and then underwent directed
15 content analysis¹² by RT and MC.
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26 **3. Results**

27 *3.1 Phase One - survey demographics*

28 From the pool of 465 nurses in four NZ ICUs, 220 surveys were returned, giving a response rate of
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31 47.3%. However, only 203 respondents completed the survey tool fully. The demographics of the
32 respondents are shown in Table 1.
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45 *3.2 Survey results: Beliefs and attitudes about EOL care*

46 Over half of nurses surveyed (55%, n = 111) disagreed that withholding and withdrawing life
47 support treatment were ethically the same. Although the majority (93%, n = 189) agreed that
48 withholding OR withdrawing life support treatment was ethical, 78% (n = 159) of nurses felt that
49 withholding life supporting treatment was more ethically acceptable than withdrawing it. Based
50 on their experiences, most respondents (88%, n = 179) disagreed that decisions to withdraw life
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1 support were taken too early, and although a third (33%, n = 68) felt that decisions were made
2 too late, two thirds (68%, n = 139) felt that the timing was just right.
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8 A large proportion of the sample (45%, n = 98) indicated that their religious beliefs were
9 not at all important with regard to influencing their views about EOL care. When those
10 who declared themselves agnostic or atheist were compared to others, a Chi square test
11 (with Yates Continuity Correction) indicated a significant association between religious
12 belief and the influence of religious view on EOL care [χ^2 (1, n = 220) = 25.42, p < 0.001,
13 phi = 0.35].
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23 When making decisions to withhold or withdraw life support, consideration of the
24 expected quality of life as perceived by the patient and their family were reported as the
25 most important factors, with most nurses (96%, n = 194 and 90%, n = 183; respectively) in
26 agreement. The expected quality of life from the medical and nursing teams' perspectives
27 were considered to be much less important (63%, n = 128 and 44%, n = 90; respectively).
28 Most respondents indicated that the patient's (68%, n = 138) and family's (55%, n = 111)
29 religious view were important/very important. However, considerably fewer considered
30 the religious views of medical or nursing staff to be as important (see Table 2.) Most
31 important was considered to be the medical and nursing teams' assessment that the
32 patient is unlikely to survive despite medical treatment (93%, n = 189) of nurses in
33 agreement. Considered least important by the majority (90%, n = 183) was the need for a
34 bed for another ICU patient. Nurses were divided regarding fear of litigation as a factor
35 with similar proportions agreeing (36%, n = 74) and disagreeing (40%, n = 81) about its
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3.3 Survey results: Nurses' involvement in EOL care and decision-making

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3 The majority of nurses who had been directly involved in EOL care of a patient had also actively
4 participated in decision-making about withholding or withdrawing treatment (70%, n = 137).
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6 Furthermore, there was a significant association between active involvement in EOL-decision-
7
8 making and ICU years of experience, with more experienced nurses more actively involved [χ^2 (5,
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10 n = 203) = 12.68, $p = 0.027$, Cramer's V = 0.25]. A large proportion of respondents (44%, n = 89)
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12 reported that they often initiated the EOL discussions with their medical colleagues with the
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14 majority of nurses (91%, n = 185) stating that the patient's family should always be involved in the
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16 EOL decision-making process.
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25 Around half of respondents (45%, n = 91) stated that they were always actively involved
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27 in EOL discussions with physicians, but considerably fewer (30%, n = 60) reported that
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29 they were always asked to participate in the decision-making process by medical
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31 colleagues. A large proportion (44%, n = 89) reported that they often initiated the EOL
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33 discussions with their medical colleagues. Spearman's Rho indicated a strong positive
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35 correlation between nurses *always* being active in decision-making and their medical
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37 colleagues *always* requesting to involve them [r_s (203) = 0.59, $p < 0.01$]. Also, nurses'
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39 initiation of EOL discussions with doctors was moderately correlated with their view that
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41 they were *always* involved in EOL discussions with doctors [r_s (203) = 0.42, $p < 0.01$]. The
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43 majority (77%, n = 157) indicated that participating in EOL decision-making positively
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45 influenced their job satisfaction.
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3.4 Survey results: Perspectives on EOL practices

1 Respondents were asked to rank their level of agreement with 16 statements about EOL
2 procedures and treatments. Table 3 presents their responses, ranked in order of strength of
3 opinion. During EOL care, all participants agreed that attending to religious and spiritual beliefs
4 and patient and family support were important factors. Equally significant was the provision of
5 effective pain relief (99.5%, n=195), although nurses were divided about whether the patient
6 should be deeply sedated, with 41% (n=80) in support.
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12 If the patient was able to breathe spontaneously, most nurses (89%, n=175) felt that the
13 endotracheal tube should be removed. If ventilated, the majority agreed that the inspired oxygen
14 should be reduced to air (71%, n=139) and, whether ventilated or not, suction should be provided
15 to maintain the patient's airway (60%, n=118).
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31 **INSERT Table 3**

32 There was less evidence of consensus regarding continued hydration and nutrition. A small
33 majority (43%, n=84) felt that fluids should be continued but a similar proportion disagreed (41%
34 n=83). Just over half (56%, n=110) did not support continued nutritional support. The need to
35 provide continued pressure injury prevention was supported (79%, n=154) however passive limb
36 exercises were not (47%, n=92).
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50 *3.5 Phase Two - Focus group demographics*

51 A total of 18 nurses were involved in the four focus groups (range 47 – 60 minutes). Participants
52 were generally experienced nurses with a mean of 11.14 (range 1-22) years of ICU experience
53 with a range of clinical and educational qualifications.
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3.6 Phase Two - Focus group results

EOL in ICU

Across the focus groups, there was a perception that EOL care was generally well organised in ICUs in NZ. Comments were made about the importance of culturally sensitive, person centred EOL care in NZ: *'nursing is underpinned by the Treaty (of Waitangi). New Zealanders have a very high awareness of the uniqueness of people'* (FG4) and that from this position NZ was *'more forward thinking in accommodating the family/whānau, held more open conversation about death, and delivered more holistic care at end of life'* (FG3).

The nursing role at EOL was described as: *'the glue on the unit and you're also the one who works in between all the multidisciplinary teams and kind of negotiating between the family and what they want'* (FG3). However, it was acknowledged that whilst the nursing contribution to EOL care brought great rewards, it also brought great challenges: *'it's something I've never been comfortable with and I will tend to avoid unless I think I've worked a lot with that patient and family'* (FG1). However, working in collaborative team environments was seen as supporting nurses in this role: *'we're probably quite lucky in ICU because we do work so closely with the medical staff which has probably passed on a sense of cohesion'* (FG4).

Perspectives on EOL practices

Focus group participants held varying views on the use of intravenous fluids and nutrition at EOL. Some identified that there was confusion around their purpose and that *'dehydration was a natural part of dying'* (FG4) with some ICUs advised against continuation of hydration and nutritional fluids by specialist palliative care teams. The use of fluids and nutrition at EOL were seen as comfort measures by some (FG2) with others expressed concern regarding increasing respiratory secretions causing distress for both patient and family/ whānau (FG3). Whilst there

1 was a widely held view that *'when the end of life decision is made, it feels right to turn everything*
2 *off and get all the lines out'*, ultimately context and duration of EOL care were important factors in
3 this area: *'I think hydration and nutrition I mean it's a very fine line there isn't it? We're not talking*
4 *about that as a process of weeks, its very relatively short periods of time. It depends on who's on,*
5 *about that as a process of weeks, its very relatively short periods of time. It depends on who's on,*
6 *what their views are and the underlying context'*. (FG3)
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14 Whilst participants were broadly unanimous that passive limb exercises were *'not within the*
15 *scope of EOL cares'* (FG4), there was a range of views held. Whilst some participants felt that such
16 exercises could be undertaken to make the patient more comfortable (FG3), others expressed
17 concern that moving a patient's limbs at EOL may be painful (FG3). It was acknowledged that
18 passive limb exercises may be continued if families wished to be actively involved in care so that
19 families *'felt that they were doing something'* (FG2); thereby meeting family as opposed to patient
20 need. Although these areas demonstrated uncertainties about aspects of EOL care provided, a key
21 theme to emerge was that patient comfort was paramount: *'If you've made the decision that we*
22 *are going to let the patient pass away peacefully then we should not intervene in any way that can*
23 *prolong death.'*
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42 **4. Discussion**

43 Results from this study demonstrate broad areas of agreement between attitudes and beliefs of
44 NZ and other international intensive care nursing communities about EOL care. The nursing role
45 at EOL and the importance of working in collaborative and supportive teams is similar to findings
46 reported in the international literature.^{13,14} Similarly, the emotional pressures described by NZ
47 nurses during EOL care resonates strongly with the literature on moral distress in this area.¹⁵
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In reviewing survey results from European¹¹ and NZ nurses, similar attitudes were held about EOL care. However, the view of NZ nurses, that withholding life support treatment was ethically more acceptable than withdrawal, was not held by European nurses. Whilst treatment withdrawal and treatment withholding has been noted as having equal moral weighting,¹⁶ the passive withholding of treatment is often, as reflected in this study, seen as more preferable to the active withdrawal of treatment.¹⁷

The nursing role during EOL care has been detailed from different perspectives. Family members have described how the concern, rapport, professionalism, support for decision making and information given by nurses during EOL care were key for family preparation at this time.¹³

However, the nursing role during EOL is not solely concerned with provision of emotional and psychosocial support. The bedside nurse is also central to undertaking aspects of the treatment withdrawal process.¹⁸ This includes symptom management and the weaning and withdrawal of specific therapies e.g. mechanical ventilation. Whilst such aspects have been reported as being performed by nursing staff,¹³ there is no established consensus on how these should be undertaken. Results from this New Zealand study demonstrate divided opinion on specific EOL nursing practices: this merits further discussion.

Whilst NZ nurses were generally supportive of reducing inspired oxygen to air for ventilated patients, this was also an area with one of the highest levels of uncertainty (don't know) responses. Other EOL practices dividing opinion and with high levels of uncertainty included use of fluids, nutrition, sedation and passive limb exercises at EOL. Interestingly in a recent study¹⁹ reporting on South African (SA) critical care nurses views of EOL decision making, SA nurses were more certain about such interventions. Perhaps such uncertainty is expected given that in recent review papers, use of fluids and nutrition²⁰ and sedation²¹ at EOL is acknowledged to be contentious areas requiring more guidance needed for staff, patients and families. The lack of

1 evidence base to guide use of passive limb exercises at EOL is unsurprising given that current
2 evidence based recommendations¹⁷ are mainly medically led and focussed on medical
3 interventions. Further nursing debate that leads to development of clinical guidance may address
4 the uncertainty raised by these aspects of care. Empirical work that describes nursing activities
5 concerned with symptom management and weaning of interventions during EOL care will enable
6 any guidance documents to be empirically developed and evaluated.
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17 **5. Limitations**

18 Although results of this study cannot be generalised, the survey response rate suggests that Phase
19 One results can reasonably be assumed to broadly represent the views of tertiary New Zealand
20 ICU nurses. The study was designed to gather the experiences and attitudes of ICU nurses about
21 EOL care and may not be representative of actual patient care.
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33 **6. Conclusions**

34 EOL views and experiences held by NZ ICU nurses are broadly reflective of EOL views and
35 experiences held by their international colleagues. As such, international literature within this
36 area has transferability to the NZ setting. However, as identified in the results of this mixed
37 methods study, some differences and uncertainties in care exist. Further debate and guidance on
38 specific aspects of nursing care at EOL is required.
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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)

Table 2: Criteria for making EOL decisions: ranked by importance (n = 203)

Rank	Criterion	Not important n (%)	Quite important n (%)	Not sure n (%)	Important n (%)	Very important n (%)
1	Patient is unlikely to survive despite medical treatment	0 (0)	10 (4.9)	4 (2.0)	59 (29.1)	130 (64.0)
2	Poor neurological outcome despite survival	0 (0)	17 (8.4)	3 (1.5)	81 (39.9)	102 (50.2)
3	If patient survives quality of life with chronic disease is expected to be poor	0 (0)	20 (9.9)	11 (5.4)	89 (43.8)	83 (40.9)
4	Religious views of the patient	18 (8.9)	33 (16.3)	14 (6.9)	70 (34.5)	68 (33.5)
5	Religious views of the patient's family	22 (10.8)	51 (25.1)	19 (9.4)	76 (37.4)	35 (17.2)
6	Fear of litigation or breaking the law	43 (21.2)	38 (18.7)	48 (23.6)	42 (20.7)	32 (15.8)
7	Religious views of medical team	157 (77.3)	13 (6.4)	23 (11.3)	8 (3.9)	2 (1.0)
8	Religious views of nursing team	157 (77.3)	13 (6.4)	23 (11.3)	8 (3.9)	2 (1.0)
9	ICU bed needed for another critically ill patient	168 (82.8)	15 (7.4)	11 (5.4)	7 (3.4)	2 (1.0)

Table 3: Nurses' perspectives on EOL care practice (ranked) n = 196

Rank	Statements	Strongly disagree/ disagree n (%)	Do not know n (%)	Strongly agree/ agree n (%)
1	The patient SHOULD always be given the opportunity to receive last rituals that are appropriate to the religious and spiritual beliefs of the patient and their family	0 (0)	0 (0)	196 (100)
2	The patient SHOULD be provided with effective pain relief	1 (0.5)	0 (0)	195 (99.5)
3	The family or friends of the patient SHOULD be permitted to visit any time, day or night	6 (3.1)	0 (0)	190 (96.9)
4	The family and friends of the patient SHOULD NOT be permitted to visit for as long as they want	185 (94.4)	6 (3.1)	5 (2.5)
5	The family and friends of the patient SHOULD be permitted to visit the patient at the bed side without restriction on the number of family members and friends	6 (3.1)	5 (2.6)	185 (94.4)
6	The patient SHOULD NOT be cared for in the privacy of a private room	185 (94.4)	2 (1.0)	9 (4.6)
7	If the patient is able to breathe spontaneously, the endotracheal tube SHOULD be removed	6 (3.1)	15 (7.7)	175 (89.3)
8	The patient SHOULD continue to receive care from nurses who know the patient and family	20 (10.2)	5 (2.6)	171 (87.3)
9	The patient SHOULD NOT continue to receive all interventions to prevent pressure injury	154 (78.6)	14 (7.1)	28 (14.3)
10	The patient SHOULD NOT continue to receive care in the intensive care unit	140 (71.4)	35 (17.9)	21 (10.8)
11	If ventilated the patients' oxygen level SHOULD be reduced to 21% (air)	16 (8.2)	41 (20.9)	139 (70.9)
12	During EOL care oro/endotracheal suction SHOULD be continued to maintain the airway of the patient	50 (25.5)	28 (14.3)	118 (60.2)
13	During EOL care, the nutritional support of the patient SHOULD be continued	110 (56.1)	46 (23.5)	40 (20.4)
14	The patient SHOULD NOT continue to receive a full range or passive limb exercises	61 (31.1)	43 (21.9)	92 (46.9)

