

# South African critical care nurses' views on end-of-life decision-making and practices

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## ABSTRACT

**Background:** Care of patients at the end-of-life (EOL) may be influenced by the experiences, attitudes and beliefs of nurses involved in their direct care.

**Aim:** To investigate South African critical care nurses' experiences and perceptions of EOL care.

**Design:** Cross-sectional survey.

**Methods:** South African critical care nurses completed a modified version of the 'VENICE' survey tool. Data were collected concerning: attitudes towards EOL care; involvement in EOL decision-making; and beliefs about EOL practices.

**Results:** Of 149 surveys distributed, 100 were returned (response rate 67%). Seventy-six percent stated that they had had direct involvement in EOL care of patients, but a minority (29%) had participated in EOL decision-making processes. Whilst most nurses (86%) were committed to family involvement in EOL decisions, less than two thirds (62%) reported this as routine practice. When withdrawing treatment, around half (54%) of the respondents indicated they would decrease the inspired oxygen level to room air, and the majority (84%) recommended giving effective pain relief. Continued nutritional support (84%) and hydration (85%) were advocated, with most nurses (62%) indicating that they were against keeping patients deeply sedated. Most respondents (68%) felt patients should remain in intensive care at the end of life, with the majority (72%) supporting open-visiting, no restriction on number of family members visiting (70%), and the practising of religious or traditional cultural EOL rituals (93%).

**Conclusions:** The involvement of Johannesburg critical nurses in EOL care discussions and decisions is infrequent despite their participation in care delivery and definite views about the process.

**Relevance to clinical practice:** Use of formal guidelines and education is recommended to increase the nurses' involvement in and their confidence in participating in EOL decisions. Educators, managers, senior nurses and other members of the multi-disciplinary team should collaborate to enable critical care nurses to become more involved in EOL care.

**Key words:** End-of-life • Intensive care • South Africa

## BACKGROUND

South Africa is unique because third and first world health conditions are found in the population. The high incidence of acute and chronic disease (notably, HIV/AIDS), and high levels of violence dramatically

affect morbidity and mortality. Interpersonal and community violence and traffic accidents affect primarily the 35–49-year-old male population (Statistics South Africa, 2009). As a consequence of these factors, and the acuity of the illness (total mean SAPS II score

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34.83 overall and 42.75 in trauma patients) (Kisorio *et al.*, 2009), the average age of intensive care unit (ICU) patients (48.2 years) is significantly less than that of Western countries, e.g. 59.1 and 61.7 years in Europe and USA, respectively (Iapichino *et al.*, 2001; Zimmerman *et al.*, 2006).

Despite its advanced technology and specialized workforce, many patients die in ICU and end-of-life (EOL) care is practised commonly (Wunsch *et al.*, 2005; Norton *et al.*, 2011). Practices vary between critical care units (CCUs) and nurses' involvement in EOL care is variable (Latour *et al.*, 2009). Although attempts have been made to raise awareness and improve EOL care in Europe by developing consensus-wide statements (Carlet *et al.*, 2004; Dellinger *et al.*, 2008), the extent of their influence upon nursing practice is unclear.

The drive for standardized health care practices within Europe was the impetus for the *VENICE* (Views of European Nurses in Intensive Care on End-of-life-care) study, which investigated similarities and differences in EOL care (Latour, *et al.*, 2009). One hundred and sixty-four nurses participated from all over Europe. The results demonstrated that the majority (73%) was actively involved in EOL decision-making processes, 79% were committed to family involvement in EOL care but only 59% felt this was routine. Regarding decisions to withdraw or withhold therapy, 65% indicated that they would decrease the flow of inspired oxygen, 99% would provide continuous pain relief and 91% endorsed open visiting. A division of view was observed in views regarding sedation and nutritional support.

Faced with a rising death rate, a different patient profile, as well as a broader diversity of religious beliefs than that found in most western countries, it was speculated that South African nurses might hold different views from those of their counterparts in Europe.

## METHODOLOGY

### Aim and objectives

The aim of this study was to investigate the experiences and views of South African critical care nurses. The objectives were to:

- determine the attitudes of CCU nurses towards EOL care, and describe the similarities and differences in EOL care practices;
- investigate the experiences of South African CCU nurses of involvement in EOL decision-making; and
- contrast the results with those of the European ICU nurses.

### Ethical considerations

The study was approved by the University Human Research Ethics Committee (Medical) (reference MO9117) and, in two hospitals, permission to conduct the study was given by the Provincial Health Directorate, the hospital chief executives, and the CCU nurse managers. Potential participants were informed about the study via an oral presentation supplemented with a written information/invitation letter. Consent was implied by completion of the survey.

### Design

A survey was used; replicating the original study by Latour *et al.* (2009). A modified version of the *VENICE* survey tool (see below) was administered to a convenience sample of CCU nurses.

### Sample

The sample was drawn from a population of nurses ( $n = 149$ ) working in general, neurological, cardiothoracic and trauma CCUs in two Johannesburg university-affiliated, public hospitals. All critical care registered nurses were invited to participate. The survey tool was provided to participants via the CCUs, and was also distributed at a *Critical Care Society of South Africa* meeting. Critical care in South Africa, is generally considered in the broader sense incorporating the sub-speciality areas of emergency, coronary care, high-dependency, cardiothoracic and general ICUs.

### Instrument

The *VENICE* tool was developed from the literature by its authors (Latour *et al.*, 2009). It comprises four sections: (1) biographical details; (2) 16 statements about nurses' personal attitudes towards EOL care; (3) two questions and 9 statements about nurses' involvement with EOL care decisions and (4) 16 statements of beliefs about EOL practice issues. A 5-point Likert scale is used for all statements. Operational definitions including EOL care, EOL decisions, withholding treatment and withdrawing treatment are provided to clarify terms for participants.

For use in the South African context, several modifications to the original tool were required. An additional question regarding participants' home language was inserted (there are 11 official languages). The question regarding religious background was expanded under 'Christian' to include Roman Catholic, Protestant mainstream (e.g. Anglican, Methodist, Presbyterian) and Protestant Evangelical, African Traditional Christian Churches (these meld traditional cultural belief systems within predominantly Christian worship), and African traditional belief systems (which

emphasize traditional cultural understandings and practices of the supernatural).

### Data analysis

The data were coded numerically and subjected to descriptive and inferential statistical analysis using statistical software (SPSS version 19). Significance was set at  $p < 0.05$ .

## RESULTS

### Demographic information

Of the 149 surveys distributed, 100 (67%) were completed. The majority of participants was women (84%), and just over half (51%) was aged 40 years or older (Table 1). Most were engaged in clinical practice ( $n = 63$ ; 67%) or management ( $n = 16$ ; 17%); the majority had more than 5 years' nursing experience ( $n = 78$ ; 79%). The largest group ( $n = 40$ ; 42%) had no ICU experience, with the second largest group ( $n = 30$ ; 31%) having less than 5 years. The majority belonged to the various black South African ethnic groups and religious background fell into six main groups (Table 1). The majority ( $n = 65$ ; 67%) indicated that their religious beliefs were important or very important with regard to influencing their views about EOL care. However, there was no statistically significant association between any particular religious group and their EOL beliefs.

### Ethical views

Nearly half of the nurses ( $n = 44$ ; 46%) agreed that withholding and withdrawing life support treatment were ethically the same, however, the same number ( $n = 44$ ; 46%) disagreed. Similarly, the same number of nurses ( $n = 43$ ; 46%) disagreed that withholding OR withdrawing life support treatment was unethical to those who felt it was ethical ( $n = 43$ ; 46%). Around half of the nurses ( $n = 45$ ; 48%) felt that withholding life supporting treatment was more ethically acceptable than withdrawing life support treatment with only slightly fewer disagreeing ( $n = 40$ ; 43%).

### Withholding or withdrawing active treatment

The criteria considered important for making the decision to withhold or withdraw treatment are summarized in Table 2. Assessment by the medical/nursing team that the patient is not expected to survive was considered to be important/very important by the majority of the nurses ( $n = 67$ ; 71%). The next largest factor was fear of litigation/breaking the law, which a majority of respondents ( $n = 63$ ; 68%) indicated was important/very important. Most nurses also

**Table 1** Demographics of respondents ( $n = 100$ )

Characteristics	<i>n</i> (%)
Gender	
Female	84 (84.0)
Male	16 (16.0)
Age group (years)	
<30	14 (14.14)
30–39	34 (34.34)
40–49	34 (34.35)
50–59	11 (11.11)
>60	6 (6.06)
Home language	
English	17 (17.0)
Isikosa	10 (10.0)
Sipedi	14 (14.0)
Sesotho	10 (10.0)
Setswana	16 (16.0)
Tshivenda	4 (4.0)
IsiZulu	16 (16.0)
Xitsonga	11 (11.0)
IsiNdebele	1 (1.0)
Religious background	
Catholic	13 (13.0)
Protestant—Mainstream	28 (28.0)
Protestant—Evangelical	16 (16.0)
African Christian	20 (20.0)
African Traditional	20 (20.0)
Jehovah Witness	4 (4.0)
Critical care unit	
Adult ICU	24 (26.37)
PICU	5 (5.49)
NICU	2 (2.20)
Coronary care unit	12 (13.19)
Cardiothoracic	4 (4.40)
Neurological	20 (21.98)
Trauma ICU	6 (6.59)
Trauma admissions (accident & emergency)	18 (19.78)
Main practice role	
Clinical practice	63 (67.02)
Education	7 (7.45)
Management	16 (67.02)
Research	4 (4.26)
Other	4 (4.26)
Years of experience in nursing (years)	
0–5	21 (21.21)
6–10	18 (18.18)
11–15	18 (18.18)
16–20	19 (19.19)
≥21	23 (23.23)
Years of experience in ICU nursing (years)	
None	40 (41.67)
0–5	30 (31.25)
6–10	15 (15.63)
11–15	4 (4.17)
16–20	7 (7.29)
≥21	

ICU, intensive care unit; NICU, neonatal ICU; PICU, paediatric ICU.

**Table 2** Criteria deemed important when making decision to withhold or withdraw treatment

Criterion	Responses (n)	Not important n (%)	Quite important n (%)	Not sure n (%)	Important n (%)	Very important n (%)
Patient is unlikely to survive despite medical treatment	94	9 (9.6)	9 (9.6)	9 (9.6)	50 (53.2)	17 (18.1)
Fear of litigation or breaking the law	93	3 (3.2)	18 (19.4)	9 (9.7)	21 (22.6)	42 (45.2)
Poor quality of life despite survival	95	14 (14.7)	17 (17.9)	7 (7.4)	42 (44.2)	15 (15.8)
Poor neurological outcome despite survival	99	7 (7.1)	22 (22.2)	18 (18.2)	40 (40.4)	12 (12.1)
ICU bed needed for another critically ill patient	93	44 (47.3)	17 (18.3)	3 (3.2)	23 (24.7)	6 (6.5)

**Table 3** Quality of life as viewed by affected persons as a criterion for instituting EOL measures

Criterion	Responses (n)	Not important n (%)	Quite important n (%)	Not sure n (%)	Important n (%)	Very important n (%)
Expected quality of life as viewed by the patient's family	96	6 (6.3)	15 (15.6)	6 (6.3)	40 (41.7)	29 (30.2)
Expected quality of life as viewed by the medical team	96	9 (9.4)	14 (14.6)	9 (9.4)	40 (41.7)	24 (25.0)
Expected quality of life as viewed by the patient	99	7 (7.1)	15 (15.2)	13 (13.1)	34 (34.3)	30 (30.3)
Expected quality of life as viewed by nurses	96	14 (14.6)	19 (19.8)	7 (7.3)	26 (27.1)	30 (31.3)

EOL, end-of-life

considered that the quality of life prognosis and neurological prognosis were important/very important ( $n=57$ ; 60% and  $n=52$ ; 53%, respectively). The need of a bed for another ICU patient was considered least important ( $n=29$ ; 31%).

### Quality of life

When making decisions to withhold or withdraw life support, consideration of the expected quality of life as perceived by the patient's family was reported as the most important factor, with most nurses ( $n=69$ ; 72%) considering this to be important/very important. The expected quality of life from the patient's and medical team's perspectives was considered to be almost as important ( $n=64$ ; 65% and  $n=64$ ; 67%, respectively). Although most nurses felt that nursing assessment of expected quality was important/very important ( $n=56$ ; 58%), this was the least important factor (Table 3).

### Religious view

All respondents identified an affiliation with either a Christian or African traditional religion; none identified themselves as Islamic, agnostic or atheist.

When making decisions to withhold or withdraw life support, the patient's religious view was considered to be most important, with most respondents ( $n=71$ ; 75%) indicating this was either important or very important. Fewer respondents ( $n=59$ ; 63%) considered the family's view to be important/very important and even fewer considered the religious views of nursing or

medical staff to be very important/important ( $n=42$ ; 44% and  $n=39$ ; 42%, respectively) (Table 4).

### Involvement in direct patient care and decision-making

The majority ( $n=68$ ; 76%) of respondents stated that they had been directly involved in the care of a patient where treatment had been withheld or withdrawn. Of these, a third ( $n=24$ ; 35%) indicated that they had been actively involved in the decision-making process. A Chi-square test (with Yates Continuity Correction) indicated that this association was significant [ $\chi^2$  (1,  $n=90$ ) = 4.35,  $p=0.037$ ]. Furthermore, there was a significant difference in the active involvement in EOL-decision-making between nurses with ICU experience and those without. Thirty-nine percent of ICU-experienced nurses had been involved, compared to only 14% of those without ICU experience. This association was significant [ $\chi^2$  (1,  $n=88$ ) = 5.76,  $p=0.016$ ].

A quarter of respondents ( $n=23$ ; 24%) stated that they were always actively involved in EOL discussions with physicians, but fewer ( $n=13$ ; 13%) reported that they were always asked to participate in the decision-making process by medical colleagues. Around a quarter ( $n=22$ ; 22%) reported that they often initiated the EOL discussions with their medical colleagues. Spearman's Rho indicated a statistically significant strong correlation between nurses' active involvement in decision-making and their medical colleagues' request to involve them [ $r_s$  (91) = 0.76,  $p<0.001$ ]. Nurses' initiation of EOL discussions with doctors was

**Table 4** Religious view as a criterion for making EOL decisions

Criterion	Responses (n)	Not important n (%)	Quite important n (%)	Not sure n (%)	Important n (%)	Very important n (%)
Religious views of the patient	95	9 (9.5)	8 (8.4)	7 (7.4)	41 (43.2)	30 (31.6)
Religious views of the family	94	9 (9.6)	15 (16.0)	11 (11.7)	40 (42.6)	19 (20.2)
Religious views of the nursing team	95	21 (22.1)	19 (20.0)	13 (13.7)	26 (27.4)	16 (16.8)
Religious views of the medical team	93	20 (21.5)	16 (17.2)	18 (19.4)	24 (25.8)	15 (16.1)

EOL, end-of-life.

moderately correlated with their view that they were *always* involved in EOL discussions with doctors [ $r_s(92) = 0.49, p < 0.001$ ].

Despite the relatively low participation rate in EOL discussions/decision-making, most respondents ( $n = 65$ ; 68%) indicated that involvement in EOL decision-making positively influenced their job satisfaction.

### Family involvement

The majority ( $n = 85$ ; 86%) stated that the patient's family should always be involved in the EOL decision-making process, but fewer stated that they always were ( $n = 58$ ; 62%). There was a significantly higher percentage of non-ICU-experienced nurses ( $n = 36$ ; 90%) compared to those with ICU experience ( $n = 45$ ; 82%) who agreed that the patient or family should always be consulted before making an EOL decision. This difference was significant ( $U = 853, z = -2.62, p = 0.024$ ).

### Timing

Fifty (51%) respondents disagreed with the statement that decisions to withdraw life support were taken too early with a smaller proportion feeling that it was made too late ( $n = 31$ ; 33%). A similar number indicated that the EOL decision was made at just the right time ( $n = 31$ ; 29%).

### Practices and procedures

Respondents were asked to rank their level of agreement with 16 statements about EOL procedures and treatments. Table 5 presents their responses, ranked in order of strength of opinion.

During EOL care, most ( $n = 61$ ; 62%) agreed that if the patient could breathe spontaneously, the endotracheal tube should be removed. However, over half ( $n = 52$ ; 54%) did not support reducing the oxygen level of ventilated patients to room air ( $FiO_2$  0.21) and the majority ( $n = 82$ ; 83%) felt that oral or endotracheal suction should be continued to maintain airways. Most nurses felt that hydration and nutrition should continue ( $n = 84$ ; 85%, and  $n = 79$ ; 84%, respectively).

The need to continue with essential nursing care during EOL was supported the majority of respondents, who stated that the patient should continue to receive pressure injury prevention interventions ( $n = 85$ ; 89%) and a full range of passive limb exercises ( $n = 70$ ; 74%). Most nurses ( $n = 81$ ; 84%) agreed that the patient should be provided with effective pain relief, and two thirds ( $n = 60$ ; 62%) believed the patient should not be deeply sedated.

Most respondents ( $n = 60$ ; 65%) felt that the patient should continue to receive care from nurses who know the patient and family, within the ICU ( $n = 65$ ; 68%) in a private room ( $n = 69$ ; 73%). The majority ( $n = 68$ ; 70%) indicated that the family and friends of the patient should be permitted to visit the patient at the bedside without restriction on the number of family members and friends. Nor should there be any restriction on the length of time of their visit ( $n = 80$ ; 82%), or the time of day or night ( $n = 82$ ; 84%).

Almost all respondents ( $n = 91$ ; 93%) agreed that the patient should always be offered the opportunity to receive the last rites and rituals appropriate to their religious and spiritual beliefs.

## DISCUSSION

The study aim was to identify South African CCU nurses' beliefs and attitudes about EOL care. Overall, despite the relatively small sample, our results are similar to those of European ICU nurses (Latour *et al.*, 2009).

### Withholding and withdrawing treatment

With regard to the ethics of withholding or withdrawing treatment, 46% of nurses agreed that withholding and withdrawing life support treatment were ethically the same, with a similar percentage disagreeing (46%). This is similar to the VENICE study where 51% disagreed that they were ethically the same. When phrased negatively and asked whether withholding or withdrawing life support treatment was unethical, 46% of nurses agreed, with the same proportion disagreeing. The findings indicate a clearly divided



**Table 5** Nurses' beliefs and opinions on EOL care practice (ranked)

Statements	n	Strongly agree/agree n (%)	Do not know n (%)	Strongly disagree/disagree n (%)
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	98	91 (93)	1 (1)	6 (6)
The patient SHOULD NOT continue to receive all interventions to prevent pressure sores	95	8 (8)	2 (2)	85 (89)
During EOL care the patient SHOULD NOT continue to receive fluids to maintain hydration	99	12 (12)	3 (3)	84 (85)
The family or friends of the patient SHOULD be permitted to visit any time, day or night	98	82 (84)	0 (0)	16 (16)
The patient SHOULD be provided with effective pain relief	97	81 (84)	4 (4)	12 (12)
During EOL care, the nutritional support of the patient SHOULD be continued	94	79 (84)	3 (3)	12 (13)
During EOL care oro/endotracheal suction SHOULD be continued to maintain the airway of the patient	99	82 (83)	3 (3)	14 (14)
The patient SHOULD NOT continue to receive a full range or passive limb exercises	95	17 (18)	8 (8)	70 (74)
The patient SHOULD NOT be cared for in the privacy of a private room	95	21 (22)	5 (5)	69 (73)
The family and friends of the patient SHOULD NOT be permitted to visit for as long as they want	97	15 (15)	2 (2)	70 (72)
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	97	68 (70)	2 (2)	27 (28)
The patient SHOULD NOT continue to receive care in the intensive care unit	96	28 (29)	3 (3)	65 (68)
The patient SHOULD continue to receive care from nurses who know the patient and family	92	60 (65)	4 (4)	28 (30)
If the patient is able to breathe spontaneously, the endotracheal tube SHOULD be removed	99	61 (62)	12 (12)	26 (26)
The patient SHOULD NOT be kept deeply sedated	97	28 (29)	9 (9)	60 (62)
If ventilated the patients' oxygen level SHOULD be reduced to 21% (air)	97	52 (54)	11 (11)	34 (35)

EOL, end-of-life.

view. However, given the multiplicity of first, second and third languages of many of the respondents in South Africa, this division may be indicative of semantic differences. Nevertheless, these results suggest that this is an area where further education aimed at improving nurses' ethical understanding and helping them to clarify their own values would be of benefit. This, in turn, would help to increase their confidence to participate in EOL discussions.

When it came to EOL, nurses reported that despite their direct involvement in the care of the patient, to a large extent, they were not involved in decision-making. Although they indicated that involvement in EOL decision-making positively influenced their job satisfaction, most reported that they were never asked to participate in this process by their medical colleagues and seldom initiated discussions with doctors about EOL care of a patient, nor were actively involved in EOL discussions with physicians. This lack of nursing involvement in decision-making is confirmed in several studies (Ho *et al.*, 2005; Yaguchi *et al.*, 2005; Benbenishty *et al.*, 2006; Latour *et al.*, 2009). This is an area that will benefit from further study.

The European ICU EOL care guidelines (Carlet *et al.*, 2004) advocate that nurses play an active role within the multidisciplinary team. An important aspect is relationship building, to support and guide the patient and family during an emotionally and physically demanding time. Understanding the family is vital when it comes to decision-making. While the ultimate

responsibility for the EOL decision remains with the physician, the nurse is frequently tasked with the duty of effecting the decision and, where the family is unable to understand the language used by the team members or the consultant reporting the decision, is often both interpreter and explainer. Professional collaboration in this difficult area helps to allay moral distress and dissatisfaction (Hamric and Blackhall, 2007), confers a measure of support to the nurse, and emphasizes the importance of the family's inclusion in the team.

In this study, factors influencing decisions about withholding or withdrawing life support during EOL care were investigated. When it came to the patient's quality of life, nurses rated the expected quality of life as viewed by the family as a very important factor to consider, more so than the quality of life expectations held by the patient, nursing colleagues or the medical team. Accordingly, the majority (86%) agreed that the family of the patient should always be involved in EOL decisions and consulted before an EOL decision is made. This is congruent with the generally accepted ethical viewpoint which is supported by the European EOL recommendation (Carlet *et al.*, 2004) that the health care team builds a close relationship with the patient and family, which improves understanding of family values and needs and enhances satisfaction (Gries *et al.*, 2008).

Nurses interact with family members throughout the whole day in both formal and informal circumstances. Their involvement in EOL decision-making is

important to ensure effective communication between the medical team and the family (Puntillo and McAdam, 2006); poor communication may prolong the decision-making process (Fridh *et al.*, 2009). Strategies to improve communication between the family and the multi-disciplinary team have been implemented with some success (Lautrette *et al.*, 2007) but research of effective strategies to improve communication between ICU nurses and relatives is a priority (Blackwood *et al.*, 2011). Much depends on the presence of the family, as well as written information, to expand and reinforce their understanding of the situation and the choices available to them. However, in South Africa, the presence of the family is not guaranteed due to a number of reasons such as the migrant labour system, a high number of 'illegal' refugees in the urban areas, the restriction of visiting in response to violence directed against staff in public hospitals, and poverty which may preclude regular family visiting.

### Religious affiliation

Unlike the VENICE study, none of the respondents were agnostic or atheist, with the majority (28%) identifying their affiliation to Protestant Churches. Nurses rated their religious backgrounds, and those of the medical team, as unimportant factors in making EOL decisions. Similarly to the results found in the Europe, the religious views of the patients were regarded as more important than those of the families when making EOL decisions. The only difference of note pertains to the respondents' religious affiliation and the anomaly found that, despite the majority claiming to be members of the mainstream Protestant churches, African Traditional or Christian denominations, the use of rituals around death and dying was strongly supported. This is at odds with the commonly held view that these religions—and certainly the evangelical or African traditional religious denominations—do not usually endorse the practice of religious rituals such as Last Rites (anointing the patient with oil; also known as Extreme Unction) and Viaticum (administering communion to the dying patient). Such rituals are more commonly associated with the liturgical churches, e.g. Roman Catholic, Anglican and Lutheran. However, the African Christian traditions and African Traditional belief systems, which, if the two are considered together, accounted for a significant number of the respondents (39%) of whom most were black women. There is a very strong tradition in traditional black cultures of rituals performed to 'cleanse' the area after a death. This raises the possibility that the rituals alluded to were those carried out in the more traditional ancestor-aware belief systems.

The respondents were all employed in the public hospital system where the majority of patients are likely to be black persons who are either indigent or who are not covered by private medical insurance schemes. These patients are also more likely to adhere to more traditional forms of worship and, as such, the nursing staff would be aware of and responsive to their patients' and family members' wishes. This aspect would benefit from further study.

### EOL practices

In this study, half of the nurses (51%) disagreed that the timing of EOL discussion was made too early, and a third indicated it was frequently instituted too late. Concerning beliefs about EOL care practices in ICU, nurses supported nursing the patient in the unit (in a private room) with a known nurse. This is consistent with the VENICE study results. Unlimited visiting without restriction of numbers was also supported by nurses. Visiting policies are under debate in many countries and recent reviews have established that open-visiting enhances patient- and family-centred care, is supported by patients and visitors, but most critical care nurses feel that it impedes patient care (Ciuffo *et al.*, 2011; Whitton, 2011). However, the benefits to the patient and their family outweigh any negative impacts on the patient (Whitton, 2011) and evidence generated through an Institute for Health care Improvement initiative in the USA indicated that the three major concerns expressed by clinicians (stress for the patient, interference with care provision and physical/mental exhaustion of relatives) were largely unfounded (Berwick, 2004).

Maintenance of patients' respiration, hydration and the continuing of comfort care in the ICU were supported by the majority of respondents (85% and 68%, respectively). Nurses also believed that nutrition should be continued during EOL care (80%). The VENICE study differed in that views on fluid and nutritional support for patients were polarized (Latour *et al.*, 2009). This is an aspect that needs further study as there is limited evidence regarding the provision of nutrition and fluids to dying patients (Truog *et al.*, 2008).

Most respondents (84%) stated that the endotracheal tube should be left *in situ* to ensure a patent airway despite a recommendation or prescription to extubate. The majority (83%) also supported continued suctioning of the oro/endotracheal tube to maintain the airway of the patient. This concurs with the European nurses' (81%) view that suctioning was required to maintain the patient's airway. However, only 35%

agreed that the level of oxygen administration should be decreased, compared to 54% who disagreed. In the VENICE survey, three quarters of respondents (75%) advocated removal of the endotracheal tube if the patient was breathing spontaneously and agreed that their fractional inspired oxygen should be reduced to room air.

Pain management, passive exercises and pressure area care were supported by the majority of nurses (84%, 74% and 89%, respectively), similar to that found in the VENICE study (99%, 82% and 89%, respectively). Deep sedation was advocated by two thirds of South African respondents, whereas European nurses either agreed with decreasing sedation (44%) or were undecided (19%). Factors such as the potential loss of the patient's ability to interact, the clinician's or unit's policy, choice of sedatives and time influence the choice of deep sedation (Latour *et al.*, 2009). In our study setting, the CCU policy is to limit sedation, and this may have influenced respondents' opinions.

## LIMITATIONS

The response rate of 67% is respectable. However, the results of the study cannot be generalized, as only those members of the professional group and members currently practising in CCUs of the major academic affiliated hospitals were invited to participate.

The lack of ICU experience of 42% of the sample, as well as the possibility that respondents who elected to participate in the survey may have had a particular interest in EOL care, may have biased the results. This is one of the limitations of using a self-selecting sample. However, when individual items of the survey instrument were examined, there were only two statistically significant differences in opinion between ICU-experienced nurses and those with no ICU experience.

The survey tool was designed to gather the experiences and attitudes of critical care nurses towards EOL care may not be representative of actual patient care. Content validity and reliability were not assessed specifically in relation to the South African health service providers.

## CONCLUSIONS

The results from our study indicate a lack of nurse involvement in EOL discussions and decisions, which suggests a need to improve communication between medical and nursing teams and the patient and their family. However, these results must be considered in relation to the sample, of which 42% had no ICU experience. In this context, it would be helpful to develop formal guidelines or policies around EOL care, with the aim of enhancing communication. Furthermore, inter-professional and family communication are areas that would benefit from further research to examine the South African context and patterns of communication in clinical practice.

Differences in the attitudes and beliefs regarding rituals around death and dying were identified, possibly due to religious and cultural norms. Whilst it appears that religious backgrounds and beliefs impact on EOL practices and decision-making, further research is required.

Most nurses who responded to this survey expressed views similar to those of European nurses regarding withdrawing and withholding treatments and procedures, with the exception of the belief that nutrition and hydration should be continued when withdrawing treatment.

Further research is recommended, expanding the study to elicit the beliefs and views of nurses in private hospitals, in the wider provincial, public hospital context and in different level ICUs and high care units.

### WHAT IS KNOWN ABOUT THIS TOPIC

- Guidelines are available on EOL and provide definitions towards EOL decisions and care.
- EOL practices vary between ICUs and there are differences in terms of nurses' involvement in this area.

### WHAT THIS PAPER ADDS

- This study provides insight into the involvement of South African intensive care nurses in EOL, decisions particularly with respect to their cultural and religious beliefs.
- Issues of clinical practice, after EOL decisions are made, described and discussed based on the views of South African intensive care nurses.
- This is a starting point to identify knowledge gaps and areas for further research in the pursuit of effective EOL care in critical care.



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