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Turkish critical care nurses' views on end-of-life decision making and practices

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ABSTRACT

Background: Life-sustaining treatments are increasingly used in intensive care units (ICUs) for EOL care, but the decision to use these may cause ethical issues.

Aims and objectives: The aim of this study was to investigate the views and practices of critical care nurses in Turkey on the end-of-life (EOL) care.

Design: This was a cross-sectional study.

Methods: The research was conducted in 32 second- and third-level ICUs of 19 Ministry of Health research hospitals in Turkey. The Views of European Nurses in Intensive Care on EOL Care tool was used for data collection.

Results: The total sample size was 602. While half of the nurses stated that the withholding and withdrawal of life support were ethically different decisions, 40% felt both decisions were unethical. The expected quality of life as viewed by the patient, the medical team, the family and the nursing team (90·4%, 85·4%, and 83·4%, respectively) was an important factor in EOL decision making. The majority of the nurses (75·7%) were not directly involved in the EOL decision making and 78·4% of nurses were committed to family involvement in EOL decisions. When withdrawing treatment, 87·2% of ICU nurses agreed that the patient and family members should perform their final religious and spiritual duties. Further results showed that after withdrawing treatment, a majority of nurses (86%) agreed to continue pressure sore prevention, effective pain relief (85·5%), nutritional support (77·6%) and hydration (64·8%). Almost half (48·2%) indicated that keeping the patients in the ICU was unnecessary.

Conclusion: ICU nurses expressed a range of experiences and practices regarding EOL care. ICU nurses should be more involved in the decision-making process about EOL care.

Relevance to clinical practice: Due to their unique relationship with patients, nurses should be involved in EOL care decision making; however, patients, families or nurses are not often involved in the decision-making process in Turkey.

Key words: Decision making • End-of-life care • Intensive care nursing • Turkey

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BACKGROUND

The main objective of intensive care units (ICUs) is to provide an advanced level of life-support to assist critically ill patients in sustaining their lives. The recent advancements in medical treatment and care methods have resulted in extended life spans. As a natural consequence, ICUs have evolved into departments where challenging and vital decisions, such as withholding or withdrawing life support treatment (Keenan *et al.*, 1997; Prendergast and Luce, 1997), are discussed, and the decisions have evolved from concerning cures to concerning comfort care (Prendergast and Luce, 1997; Vincent, 1999, 2001; Carlet *et al.*, 2004; Curtis and Vincent, 2010).

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Regional, cultural and religious practices can affect decision making in regards to end-of-life (EOL) care and ICU patients are usually unable to decide whether to initiate or terminate their treatment in a critical health situation. In the event that the patient is incapable of making decisions alone, such critical and major decisions need to be made by family members, immediate friends or surrogates, in cooperation with ICU team members (Prendergast and Luce, 1997; Carlet *et al.*, 2004; Curtis and Vincent, 2010).

EOL care is a period in which dying individuals anticipate spending the rest of their lives in dignity and peace. During this period, if physical, emotional and spiritual needs of the patients are satisfied peacefully and tenderly, they can feel prepared for a dignified and peaceful death (Carlet *et al.*, 2004; Curtis and Vincent, 2010). Nurses, since they form a much longer and closer relationship with the patients and their families than the rest of the health care team, possess more comprehensive insight regarding the feelings, thoughts and wills of the patient and the family during this sensitive stage (Carlet *et al.*, 2004; Dunn *et al.*, 2005; Puntillo and McAdam, 2006; Vanderspank-Wright *et al.*, 2011). Endowed with grave responsibilities in EOL care, nurses should be the ones rendering significant contributions in the ethical decisions required in EOL care (Carlet *et al.*, 2004; Curtis and Vincent, 2010).

Despite the expectation for nurses to contribute significantly to the decision-making process in EOL care, existing research reveals that nurses' actual involvement in the decision-making process is far below the expected level (Kennard *et al.*, 1996; Akpınar, 2005; Yaguchi *et al.*, 2005; Akpinar *et al.*, 2009; Langley *et al.*, 2013). A study conducted in Turkey demonstrated that nurses lack sufficient knowledge and skills in ethical decision making (Ersoy and Göz, 2001). Likewise, other research revealed that while making ethical decisions in ICUs, there are no specific procedures or guidelines to consult and there is little shared decision making among health care team members and the patient's relatives. The biggest problems in Turkey concerning ethical decisions are communication and hierarchy (Çobanoğlu and Algıer, 2004). Adding to these issues, there are no published guidelines or statements concerning EOL care practices in Turkish ICUs (Çobanoğlu and Algıer, 2004; Akpinar *et al.*, 2009). Furthermore, topics related to ethical issues in the ICU are limited to two-hour lectures in ICU nursing certificate programs (Akpinar *et al.*, 2009).

Despite the increase in the number of intensive care patients awaiting their EOL care decisions, there are still no national policies or guidelines on this important issue. Nurses are expected to play an active role in the decision-making process, but it is unclear how ready nurses are to make EOL care decisions and provide comfort care.

METHODOLOGY

Aim

The aim of this study was to investigate the views and experiences of Turkish critical care nurses related to EOL care in ICUs.

Research questions

1. What are the views of nurses related to withholding or withdrawing EOL care?
2. According to nurses, which factors should be considered when making treatment withholding and withdrawal decisions during EOL care?
3. What are the experiences of nurses related to treatment withholding and withdrawal decision making during EOL care?
4. Are differences between the types of ICU, main practice role, length of experience in the profession and length of experience in an ICU associated with EOL care?
5. According to nurses, what are the accurate practices for EOL care?

Design

This was a cross-sectional study.

Sample

The research was conducted in second- and third-level ICUs of Ministry of Health (MoH) teaching and research hospitals ($N = 20$ hospitals) in a major metropolitan area. One hospital refused to participate and was not included in the study. The study population consisted of critical care nursing staff at all ICUs ($n = 32$ ICUs) in 19 teaching and research hospitals between March and April in 2012. A total of 866 critical care nurses were surveyed. Two hundred forty nurses refused to participate and 24 failed to complete the questionnaires correctly. Of 866 distributed surveys, 626 forms (72·3%) were returned; 24 were incomplete and the resulting total sample size was 602.

Instruments

A survey replicating the Views of European Nurses in Intensive Care on EOL Care (VENICE) tool, developed by Latour *et al.* (2009) was used for data collection. Written approval was obtained from the authors to utilize the instrument in this survey. The VENICE tool comprised four sections: (1) demographic data, (2)

16 attitudinal statements about EOL care, (3) a combination of two yes/no questions and nine statements about nurses' involvement with EOL decisions and (4) 16 statements on beliefs about EOL practice issues. A 5-point Likert-type scale was used for all statements.

Two academics, one specializing in intensive care and the other specializing in health care ethics, completed an English-Turkish translation of the survey. In the next stage, both academics reached consensus on the Turkish translation of the survey and finalized the form thereby ensuring language validity.

A pilot study was conducted on a group of 40 ICU nurses with similar features to the target population. As a result of this pilot study, four negative statements assessing the EOL-relevant experiences in the fourth part of the survey were changed into positive statements for better comprehension based on the recommendations of ICU nurses.

Data collection

The researchers delivered the surveys to the nurse educator at each participating hospital. The nurse educator distributed surveys in an envelope to the nurses and asked them to return the completed surveys in the sealed envelope to maintain anonymity.

Data analysis

Data was analysed using SPSS 18.0. In the data analysis, percentage means and standard deviations were employed in the analysis of findings concerning the demographics, and chi-square analysis was utilized to examine the relationships between independent variables.

Ethical considerations

The study was approved by the Research Ethics Board of our university. The Health Directorate of Istanbul and the head physician and chief nurse at each hospital granted permission to conduct research at the hospitals. Verbal consent was obtained from each participant after the purpose of the study was explained, and a document was given to each participant explaining their participation was voluntary and the data collected would be used solely for scientific purposes, would not be shared with any individual or institution, and would be kept anonymously and confidentially.

RESULTS

Of 866 distributed surveys, 626 forms (72·3%) were returned; 24 of those were incomplete and excluded from the analysis. Of the 602 ICU nurses, 82·2% were female, 60·1% were below age 30 (range 18–52, mean 28·4 ± 4·7), 52·3% were university graduates and 94·2% were directly responsible for patient care. A wide majority (73·3%) had less than 5 years of experience in ICUs (Table 1).

Table 1 Demographics of critical care nurses ($n = 602$)

Characteristics	*n*	%
Female	495	82·2
Male	107	17·8
Age groups (Mean 28·42 ± 4·69) (Range: 18–52)		
<30	362	60·1
30–39	230	38·2
>40	10	1·7
Educational background		
Vocational health school & associate degree	248	41·2
Baccalaureate degree	315	52·3
Master's degree	39	6·5
Working environment		
General medical/surgical ICU	367	61
Coronary ICU and cardiovascular surgical ICU	235	39
Main practice role		
Clinical practice	566	94·2
Management	24	4·00
Education	3	1·5
Total experience in nursing (Mean 6·56 ± 4·89) (Range 0·4–33)		
≤5 years	309	51·3
6–10 years	193	32·1
11–15 years	66	11·0
≥16	34	5·6
Total experience in ICU (Mean 4·29 ± 3·82) (Range: 0·1– 33)		
≤5 years	441	73·3
6–10 years	122	20·3
11–15 years	23	3·8
≥16	16	2·7
Total	**602**	**100**

Views of nurses on withholding and withdrawing treatment

Almost half of the nurses (49·5%) claimed 'withholding life-support treatments' and 'withdrawing life-support treatments' were not the same ethical decision; however, 40·2% reported that both decisions were unethical, and 35·4% of the nurses reported that neither of the decisions were unethical. More than half (59·5%) claimed that 'withdrawing life-support treatments' was more ethical than 'withholding life-support treatments.'

Factors deemed important when making decisions about withholding or withdrawing life support

The vast majority of ICU nurses (90·4%) reported that not only was the quality of life the patient expected

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

Criteria	Not important	Quite important	Neither not important nor very important	Important/ very important
Expected quality of life as viewed by the patient	15 (2·5)	23 (3·8)	20 (3·3)	544 (90·4)
Expected quality of life as viewed by the medical team	17 (2·8)	31 (5·1)	40 (6·6)	514 (85·4)
Expected quality of life as viewed by the family	13 (2·2)	49 (8·1)	38 (6·3)	502 (83·4)
Expected quality of life as viewed by your nursing colleagues	19 (3·2)	37 (6·1)	44 (7·3)	502 (83·4)
Fear of litigation or breaking the law	35 (5·8)	47 (7·8)	51 (8·5)	469 (77·9)
The medical/nursing team has assessed that if the patient does survive, his/her neurological outcome is expected to be very poor	78 (13·0)	69 (11·5)	58 (9·6)	397 (65·9)
The medical/nursing team has assessed that the patient is unlikely to survive, even with ICU treatment	64 (10·6)	57 (9·5)	85 (14·1)	396 (65·8)
The medical/nursing team has assessed that if the patient does survive, his/her quality of life with a chronic disorder is expected to be very poor	73 (12·1)	81 (13·5)	74 (12·3)	374 (62·2)
Religious views of the patient	142 (23·6)	35 (5·8)	67 (11·1)	358 (59·5)
The ICU bed is needed for another critically ill patient	97 (16·1)	88 (14·6)	69 (11·5)	348 (57·8)
Religious views of the patient's family	161 (26·7)	42 (7·0)	71 (11·8)	328 (54·5)
Religious views of the nursing team	311 (51·7)	63 (10·5)	73 (12·1)	155 (25·7)
Religious views of the medical team	312 (51·8)	64 (10·6)	71 (11·8)	155 (25·7)

for him/herself important, but the quality of life the relatives and nurses (83·4%), and the medical team (85·4%) expected for the patient, was also important (Table 2).

In making EOL decisions, 59·5% of ICU nurses felt the religious views of the patient were important and 54·5% of nurses reported feeling the religious beliefs of the patient's relatives were important while 51·8% of physicians and 51·7% of nurses reported that religious views were an insignificant factor (Table 2).

In making EOL decisions, the factors identified as important when deciding to withdraw or withhold treatment were: the potential legal consequences of EOL decisions (77·9%); the potentially critical neurological damages the patient could incur (65·9%); the fact that even if the patient was monitored in the ICU, there would be no chance of recovery (65·8%); the possibility of tremendous deterioration of a patient's quality of life due to a chronic disease/condition if he/she survived (62·2%), and whether the ICU bed was needed by another patient in critical condition (57·8%) (Table 2).

Nurses' experiences and views in decision making with respect to withholding and/or withdrawing

While all ICU nurses stated that they had had direct involvement in EOL care of patients, 75·7% of ICU nurses had not had any active involvement in decision making regarding withholding or withdrawing treatment for patients. 55·6% of ICU nurses reported that their medical colleagues did not ask them to participate in the decision-making process regarding EOL care. However, 53·5% of ICU nurses reported that active involvement in the decision-making process would positively affect their job satisfaction (Table 3).

Of 237 ICU nurses, 39·4% reported that discussions usually took place at the right time, 47·5% stated the patient or their relatives were not involved in EOL care discussions, and 78·4% claimed that prior to EOL decisions, an extensive body of counselling should be provided to the patient and/or the family (Table 3).

There was a significant difference in those who reported actively participating in the EOL process and those who did not participate in the process ($p < 0{\cdot}001$, $X^2 = 26{\cdot}115$, df = 2). 22·8% of bedside ICU nurses, but 49·6% of ICU nurses in management or education positions agreed that the medical team always ask for nurses' participation in EOL care decisions. However, no difference was seen between participation in the EOL care decision-making process and the type of ICU the nurses were employed in (e.g. general medical/surgical vs. cardiovascular/coronary care unit), or the total number of years of experience they had in the nursing profession ($X^2 = 3{\cdot}878$, $p = 0{\cdot}144$, df = 2; $X^2 = 2{\cdot}552$, $p = 0{\cdot}279$, df = 2, respectively).

Table 3 Nurses' experiences and views in decision making with respect to withholding and/or withdrawing life-supporting treatment

Nurses' experiences in decision making	Strongly disagree /disagree	Neither agree nor disagree	Agree/strongly agree
I think the patient and/or their family always needs to be fully consulted before a decision to withhold or withdraw treatment from a patient is made.	66 (11)	64 (10·6)	472 (78·4)
Involvement in ethical decision making of issues such as withholding or withdrawing treatment positively influences my job satisfaction.	128 (21·3)	152 (25·2)	322 (53·5)
In my experience, the timing of discussions about the decision to withhold or withdraw treatment of a patient is often just right.	146 (24·2)	219 (36·4)	237 (39·4)
In my experience, the patient and/or their family is always involved in discussions about end-of-life care of a patient.	286 (47·5)	147 (24·4)	169 (28·1)
In my experience, I have always been actively involved in discussions with doctors about end-of-life decisions.	317 (52·6)	133 (22·1)	152 (25·2)
In my experience, the timing of discussions about the decision to withhold or withdraw treatment from a patient is often too late.	244 (40·5)	210 (34·9)	148 (24·6)
I am always asked by my medical colleagues to participate in the decision-making process regarding end-of-life care for a patient.	335 (55·6)	130 (21·6)	137 (22·8)
In my experience, the timing of discussions about the decision to withhold or withdraw life support treatment from a patient is often too early.	354 (58·8)	127 (21·1)	121 (20·1)
I have often initiated discussions with doctors about end-of-life care for patients.	415 (68·9)	109 (18·1)	78 (13)

Of the ICU nurses with 5 or more years of work experience, 55·3% agreed that involvement with the ethical decision-making process would affect their job satisfaction positively. A discrepancy was detected in the comparison with respect to their length of experience ($p = 0{\cdot}034$, $X^2 = 6{\cdot}735$, df = 2). Roughly half of the nurses employed in general medical and surgical ICUs (55·3%) and 50·6% of ICU nurses employed in cardiovascular surgery/coronary care units reported that involvement with the ethical decision-making process would affect their job satisfaction positively. A difference has been detected with respect to the type of ICU they worked in ($X^2 = 8{\cdot}614$, $p = 0{\cdot}013$, df = 2). On this statement, no difference was found between the responses provided by bedside nurses and nurses employed in management and education with regard to actively participating or not participating in the EOL process ($X^2 = 2{\cdot}031$, $p = 0{\cdot}362$, df = 2; $X^2 = 4{\cdot}051$, $p = 0{\cdot}132$, df = 2; respectively).

EOL practices and procedures

With regard to EOL care practices, 87·2% of ICU nurses expressed the need to let the patient and their family members perform their last religious and spiritual duties and ensure the patient is comfortable by performing the following duties (in order of importance): initiatives to prevent pressure ulcers (86%), administration of effective pain relief (85·5%), oral or endotracheal aspiration (82·2%) nutritional support (77·6%), fluid therapy (64·8%), passive range of motion exercises (64·3%), removal of endotracheal tubes (61·3%) if the patient can breathe spontaneously (Table 4). While 27% ICU nurses supported a restriction of visits by the patient's relatives, 57·5% of ICU nurses argued that these patients should be cared for in the ICU.

DISCUSSION

The findings of current research illustrate the views of Turkish ICU nurses related to withdrawal and withholding decisions, the factors deemed to be important in making such crucial ethical decisions, the experiences of nurses in the process of making EOL decision making and basic practices and procedures in EOL care.

Clinicians argue that in terms of ethical responsibility, there is no difference between withholding or withdrawing treatment (Carlet *et al.*, 2004; Curtis and Vincent, 2010), but in our study, half of the nurses reported there is an ethical difference between the

Table 4 End-of-life practices and procedures

	Strongly disagree/disagree	Neither agree nor disagree	Agree/strongly agree
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.	31 (5·2)	46 (7·6)	525 (87·2)
The patient should continue to receive all interventions to prevent pressure sores.	36 (6)	48 (8·0)	518 (86·0)
The patient should be provided with effective pain relief.	37 (6·2)	50 (8·3)	515 (85·5)
During end-of-life care, oro/endotracheal suction should be continued to maintain the airway of the patient.	51 (8·5)	56 (9·3)	495 (82·2)
During end-of-life care, the nutritional support of the patient should be continued.	46 (7·6)	89 (14·8)	467 (77·6)
During end-of-life care, the patient should continue to receive fluids to maintain hydration.	101 (16·8)	111 (18·4)	390 (64·8)
The patient should continue to receive a full range of passive limb exercises.	92 (15·3)	123 (20·4)	387 (64·3)
If the patient is able to breathe spontaneously, the endotracheal tube should be removed.	104 (17·3)	129 (21·4)	369 (61·3)
The patient should continue to receive care in the intensive care unit.	100 (16·6)	156 (25·9)	346 (57·5)
The family and friends of the patient should be permitted to visit the patient at the bedside without a restriction on the number of family members and friends.	163 (27)	149 (24·8)	290 (48·2)
If ventilated, the patient's inspired oxygen level should be reduced to 21% (air).	198 (32·9)	209 (34·7)	195 (32·4)

two. This finding can be explained with the fact that concepts on ethical decisions are unclear. Previous studies (Burns *et al.*, 2001; Akpinar *et al.*, 2009; Latour *et al.*, 2009; Langley *et al.*, 2013) have also reported nurses experiencing similar dilemmas.

It is clear that expected quality of life is an ethically considered criterion in this study and it may vary with respect to the values, beliefs, and culture of each individual (Keenan *et al.*, 1997; Carlet *et al.*, 2004; Curtis and Vincent, 2010). The fact that nurses value the quality of life expected by the patient and their relatives as equal to that expected by the health professionals, is an encouraging and stimulating finding in terms of making shared decisions in the EOL process. In a Turkey-based study aiming to investigate the criteria in patient admission and discharge in ICUs, the quality of life that the patient expected for him/herself was set as a vital criterion (Akpınar and Ersoy, 2011). In this study, 25·7% of the nurses deemed the nurses' and medical teams' religious beliefs as relevant to the EOL decision-making process. These findings signify an ethical concern in that the interference of the nurses' and medical team's religious beliefs may handicap professional independence and clash with professionalism (Keenan *et al.*, 1997; Burns *et al.*, 2001; Latour *et al.*, 2009; Langley *et al.*, 2013). In making life sustaining treatment decisions from an ethical viewpoint, the consideration of the quality of life for the patient, the prognosis for the disease, the likelihood of further damages to the patient, deterioration of his/her condition, and legal issues all justify a sense of responsible professionalism (Burns *et al.*, 2001; Akpınar and Ersoy, 2011).

Almost half of the participants reported that EOL discussions are not conducted at the appropriate time. Other research (Latour *et al.*, 2009; Langley *et al.*, 2013) reported only one third of EOL decisions take place at the right time. This might be explained by the absence of national policies and unit-based procedures on EOL decisions. In the available guidelines, there are no clear-cut prognoses on ICU patients, which mean that there are no clear guidelines on when the ideal timing is to start EOL discussions. It is suggested that as soon as a patient is admitted to the ICU, EOL decisions should be discussed cooperatively with the team members, the patient, and his/her relatives, and regular meetings among the parties should be held to enable the patient to die in dignity and peace (Carlet *et al.*, 2004; Medina and Puntillo, 2006; Truog *et al.*, 2008; Curtis and Vincent 2010).

Nurses' involvement in EOL decisions is vital for effective communication between the physicians and the family (Carlet *et al.*, 2004; Medina and Puntillo, 2006; Puntillo and McAdam, 2006). In this study, while all of ICU nurses actively participated in EOL care practices, almost one fourth had participated

in the EOL decision-making process. In the study of Langley *et al.* (2013), 76% of the participants directly involved in EOL care practices, while 35% were involved with the decision-making process. Despite the expectation for nurses to contribute significantly to the decision-making process in EOL care, existing research reveals that nurses' actual involvement in the decision-making process is far below the expected level (Kennard *et al.*, 1996; Akpınar, 2005; Yaguchi *et al.*, 2005; Akpinar *et al.*, 2009). Nurses who have management and educator roles in ICU were more actively involved with EOL care decisions with physicians than ICU nurses, which might be explained by the demands of their managerial roles to participate in the decision-making process. A result of the study revealed that 22·8% of ICU nurses stated they were always asked by medical colleagues to be involved in EOL discussions and decisions. In a multi-centre study, 41% Turkish ICU physicians reported that they would involve ICU nurses in an ethical decision-making process (Yaguchi *et al.*, 2005). In a study by Ferrand *et al.* (2003), more than 90% of caregivers reported that the decision-making process should be a commonly shared stage, only 50% of the physicians believed that nurses should actively partake in this process, and only 27% of the nurses felt they had actively participated in this process. In research by Latour *et al.* (2009) covering European countries, 63·6% of the nurses reported having started discussions on EOL decisions. However, in the ETHICUS study, integrating 37 centres from 17 European countries, physicians reported only 2% of the nurses initiated EOL discussions (Benbenishty *et al.*, 2006). Likewise, in studies conducted in New Zealand and South Africa, it was found that only 15·4% (Ho *et al.*, 2005), and 22% (Langley *et al.*, 2013) of the nurses, respectively, had initiated these discussions. It is a source of ethical concern that the majority of nurses failed to initiate EOL care discussions; in order to ensure quality care in the EOL process, it is important that nurses monitor, learn and meet the needs and expectations of their patients, who seek to meet a peaceful and dignified death. In addition, it is a vital requirement for nurses to play the role of a patient's rights advocate.

Nurses who are recognized as playing a pivotal role in the EOL care decision-making process (Carlet *et al.*, 2004; Puntillo and McAdam, 2006; Curtis and Vincent, 2010) describe participation in this emotionally challenging process as a privilege and honour (Ranse *et al.*, 2012) and accept its positive effect on their job satisfaction (Ho *et al.*, 2005; Latour *et al.*, 2009; Langley *et al.*, 2013). While this study presented similar results, only a small portion of nurses took part in the decision-making process (24·3%), while half reported their job satisfaction would be positively affected if they were involved with the decision-making stage.

A mere 28·1% of the ICU nurses reported being involved in patients' and relatives' discussions on EOL care, the principle of shared decision making for EOL care is not being applied in all cases. In reality, it is an ethical and legal requirement to receive consent from the patient, the family, or surrogates, prior to withholding or withdrawing life support treatment in ICUs in Turkey (Akpir, 2010).

EOL practices

Skilled and caring ICU nurses should focus on specific interventions for EOL care such as symptom management (pain and other distressing symptoms), withholding and withdrawal of life support, spiritual and psychological care, comfort care for the patient until death, and grief and bereavement interventions for the patient's relatives (Carlet *et al.* 2004; Medina and Puntillo, 2006; Truog *et al.*, 2008).

More than half of ICU nurses advocated continuing nutrition and hydration (77·6% and 64·8%, respectively) which indicates that ICU nurses feel confused about the transition from cure to comfort. This could be explained by the fact that palliative care is a newly emerging concept in Turkey as evidenced by the absence of palliative care centres. Although there is limited evidence available, once the transition from cure to comfort has been negotiated, all ICU therapies should be evaluated in terms of whether they make a positive contribution to the comfort of the patient (Medina and Puntillo, 2006; Truog *et al.*, 2008). One of the key objectives in EOL care is providing a pain-free death; it is an ethically important finding that the majority of nurses in this study (82·2%) advocated administering effective pain relief treatment during EOL care. Similarly, the studies conducted by Latour *et al.* (2009) and Langley *et al.* (2013) showed the majority of ICU nurses agreed that administering effective pain relief in EOL care is important (Latour *et al.*, 2009; Langley *et al.*, 2013).

In reality, the significance of multidisciplinary care in providing optimum comfort care to patients, and the placement of nurses as team leaders, in particular, is a widely acknowledged approach today. The nurse plays a pivotal role in securing trust and an integrity-based relationship between the health care team, the patient, and the family (Carlet *et al.*, 2004; Medina and Puntillo, 2006). Despite having such an important responsibility, the participants in this study believed in the necessity of imposing limits on family visits, which is a practice that contradicts the empowerment of patients and family-centred health care. Our results were in contrast with Latour *et al.* (2009) and Langley

et al. (2013) which concluded that a large percentage of nurses believed no restrictions should be imposed in either length or number of visitors for patients for whom EOL decisions have already been made. It is argued that such open-visit policies provide a strengthening effect in patient and family-centred care (Slota *et al.*, 2003; Ciufo *et al.*, 2011; Whitton and Pittiglio, 2011). In Turkey, however, although visitor acceptance is included in the guideline of patient rights (MoH, 1998), there are strictly structured visitation rules with regard to visitation hours and the number of visitors one can have in ICUs. In reality, it is a basic human need for a patient to feel safe and surrounded with loved ones when s/he is near death (Truog *et al.*, 2001; Carlet *et al.*, 2004; Curtis and Vincent, 2010).

Limitations of this study

There were potential limitations to this study. First, this study was limited to research hospitals in a metropolitan area in Turkey; it did not address ICU nurses in smaller towns or ICU nurses in non-teaching and research hospitals. Second, the percentage of the sample had only a small number of nurses that had actually participated in EOL decision making. Thus, perhaps it is possible that some of the data were pulled from a small dataset. Third, quantitative and qualitative method (mix method) could be used to obtain more objective and detailed data about nursing practice on EOL care rather than based on perceptions of nurses.

CONCLUSIONS

The results of this study indicate that there is an ambiguity regarding the concepts of withholding and withdrawal and a lack of nurse involvement in EOL discussions and decisions, which suggests a need to improve communication between health care professionals and the patients and their families. ICU nurses desire greater involvement with EOL care decision making and discussions and feel it would improve their job satisfaction. They also wish for more patient and family involvement, continued respect for the patients' religious beliefs, and keeping patients pain-free and as comfortable as possible with dignity.

Due to their unique relationship with patients, nurses should be involved in EOL care decision making. There is a need to develop national EOL care practice guidelines and policies which define the EOL care process including the roles and responsibilities of each member of the health care team and the involvement of the patient and their family members. Further research should focus on patient and families' views and experiences regarding ethical decisions in EOL care in Turkey.

WHAT IS KNOWN ABOUT THIS TOPIC

- There are currently no policies or guidelines on EOL care in Turkish ICUs.
- Patients, families or nurses are not often involved in the decision-making process.

WHAT THIS PAPER ADDS

- Nurses desire greater involvement in EOL care decision making and feel it would improve their job satisfaction.
- Most nurses feel that the priorities should be having the patients and families involved, respecting the patients' religious beliefs, and taking actions to keep patients comfortable.
- There is a need for ethics training for Turkish ICU nurses.

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