

# Intensive care unit nurses' perceptions of the obstacles to the end of life care in Saudi Arabia

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## ABSTRACT

**الأهداف:** استكشاف تصورات الممرضات من العقبات التي تحول دون توفير رعاية نهاية الحياة (EoLC) في العناية المركزة (ICU) في المملكة العربية السعودية.

**الطريقة:** قمنا بتوزيع نسخة معدلة من الاستبيان المطور من بيكستراند وكيرشوف تدار في مدينة الرياض، المملكة العربية السعودية خلال الفترة من مارس و أبريل 2015م.

**النتائج:** أعيد ما مجموعه 87 استبيان من 140 مستجيبا محتملا يمثلون 62% معدل الاستجابة. أبرزت النتائج المخاوف المرتبطة بأسرة المريض، والأطباء الذين يختلفون في الآراء والاختلافات الثقافية وحاجز اللغة. وأشارت الممرضات أيضا إلى الوعي والمشاركة في التعليم حول رعاية نهاية الحياة والرعاية غير المجدية.

**الخاتمة:** تسلط النتائج الضوء على عدد من المفاتيح والعقبات التي تعترض توفير الجودة في مركز رعاية المرضى في وحدات العناية المركزة للممرضات. نوصي بمواصلة تطوير المبادئ لرعاية نهاية الحياة والتنشيف حول رعاية نهاية الحياة في وحدات العناية المركزة.

**Objectives:** To explore nurses' perceptions of obstacles to the provision of end of life care (EoLC) in the intensive care unit (ICU) in Saudi Arabia.

**Methods:** A modified version of a questionnaire developed by Beckstrand and Kirchoff was administered in one setting at Riyadh, Saudi Arabia between March and April 2015.

**Results:** A total of 87 questionnaires were returned from 140 potential respondents, representing a 62% response rate. Findings highlighted concerns associated with patient's family, physicians who differed in opinions, cultural differences and language barriers. The nurses also noted issues in awareness and involvement in education about EoLC and futile care.

**Conclusion:** Findings highlight a number of key obstacles to the provision of quality EoLC in ICUs for nurses. Further development of both EoLC guidelines and education about EoLC in ICUs is recommended.

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Research suggests that many people die in hospital,<sup>1</sup> and as many as one in 5 of these deaths occurs in the intensive care unit (ICU),<sup>2,3</sup> or a place of aggressive medical treatment.<sup>4,5</sup> Intensive care unit nurses may become emotionally stressed and experienced feelings of helplessness, frustration, anger, and sadness when providing end of life care (EoLC).<sup>6,7</sup> Nurses expressed different feelings on the realization of EoLC.<sup>8</sup> Nurses appear to prefer a holistic model of providing EoLC in ICUs, whereas physicians appear to focus on illness and treatment.<sup>3</sup> The Kingdom of Saudi Arabia (KSA), often referred to as Saudi Arabia, is known as an Islamic homeland.<sup>9</sup> The total population of the KSA is 29,195,895; and average life expectancy is 73.8 years.<sup>10</sup> In Islam, it is believed that everything will happen according to the will of Allah.<sup>11</sup> Faithful Muslims consider the guidance of the Qur'an and Sunnah for their life habits and actions to reach the ultimate goal, which is to be in Heaven, because they are always conscious that they can die at any time and they should be well prepared for the hereafter.<sup>12</sup> In the Muslim faith, beliefs and preferences in the dying process include being sure there is someone to prompt the patient with (Shahadah) "bearing witness that there is no true God but Allah and Muhammad is verily His Servant and His Messenger",<sup>13</sup> as the last statement of faith. The

presence of somebody to recite chapters from the Holy Qur'an at the bedside and to place the dying person in a position facing Meccah is important.<sup>13</sup> The availability of facilities and the approach to care in the KSA is determined by policies and regulations. The General Presidency of Scholarly Research and Ifta set a group of statements 'called Fat was' related to medical issues and regulations regarding the care of sick patients.<sup>14</sup> The multiple cultural influences may further influence EoLC provision due to different cultures and beliefs. These situations may hinder an ICU nurse's ability to meet the needs of dying patients. This phenomenon is very little discussed in the KS A where multiple cultural influences may further influence EoLC provision. Therefore, this study aimed to explore nurses' perceptions of the obstacles to providing EoLC in ICUs in the KSA

**Methods. Study design.** A quantitative questionnaire method was used in this study. The questionnaire was developed by Beckstrand and Kirchhoff (2005) was used in this study. This questionnaire was created to evaluate nurses' perceptions of the intensity and frequency of obstacles and helpful behaviors in providing EoLC to patients and their families in ICU.

**Instrument.** Minor modifications in demographics questions were made and it was conducted in English language. A pilot test was conducted in the KSA with ICU nurses to ensure that the questionnaire's wording was appropriate.

The study utilized the Beckstrand and Kirchhoff<sup>5</sup> questionnaire related to obstacles to meet the study aim. Twenty-nine obstacle items focused on the intensity and frequency of obstacles to the provision of EoLC in ICU. Additionally demographic questions were also included. The obstacle items were presented in the form of Likert scales ranging from 0-5, where zero represented no value, and 5 extreme or significant value. An open-ended question enabled participants to provide additional information related to obstacles to EoLC in the ICU if they chose to; another asked participants about aspects of EoLC they would change, and there was also provision for participants to make further comments. The final 10 questions were designed to collect participants' demographic information.<sup>15</sup> Internal consistency and reliability of this questionnaire items ranged from 0.81 to 0.8915.

**Disclosure.** Authors have no conflict of interests, and the work was not supported or funded by any drug company.

**Setting.** The study was conducted in a 936 bed specialist hospital in Riyadh between March and April 2015 and it considered to be one of the leading hospitals in KS A. There were 129 adult ICU beds in 6 specialist ICUs, including medical, hematological, oncological, surgical, and cardiac (Ibrahim, personal communication, May 14, 2015).

**Sample and inclusion criteria.** Convenience sampling was used to recruit participants for the study and included nurses who worked in intensive care at the hospital and who had provided care for dying patients on at least one occasion in an ICU. This sampling approach is appropriate for small exploratory quantitative studies.<sup>16</sup> Nurses who did not work in ICU and who had not cared for patients requiring EoLC were excluded.

**Data collection.** An independent staff member of the hospital was appointed as the liaison and was responsible for data collection. The investigators of the study were not involved in participants recruitment, distribution or collection of questionnaires. This approach was considered to reduce potential coercion and investigators bias.

Potential participants were provided with a copy of the explanatory statement about the study and a hard copy of the questionnaire. The questionnaires were distributed with an open envelope and participants were asked to complete the questionnaire, place it in the envelope, seal it and place it in a questionnaire collection box located in each of the 6 ICUs. At the end of the data collection period, approximately four weeks, the questionnaires were collected.

**Data analysis.** All questionnaire data, except for the open-ended responses, were converted to numeric codes to enable data entry into Microsoft Excel and SPSS Version 20 for analysis.<sup>17</sup> Ten percent of data entry was checked at random by researcher to ensure accuracy in data entry. Data analysis for the questionnaire content in this study was modelled on the analysis undertaken by Beckstrand and Kirchhoff (2005).

**Ethical considerations.** Approval to conduct the research was granted by the Monash University Human Research Ethics Committee (Human Ethics Certificate of Approval CF15/518 – 2015000245). The Office of Research Affairs of the hospital required the investigators to complete an online ethics course (National Institutes of Health, 2015). Ethics approval was subsequently obtained (Number ORA/1011/37).

**Consent.** Participants were encouraged to read the Explanatory Statement before deciding to participate in this study. It provides confidentiality and anonymity of the data, participant has the right to refuse to participate

in the study without any penalty. The Explanatory Statement clarified that returning a completed questionnaire would be considered implied consent.

**Results.** From 140 potential participants, 87 questionnaires were returned, representing a 62% response rate. Of the returned questionnaires, 10 were excluded as they were incomplete, leaving 77 questionnaires to be included in the analysis. Participants' ages, years of experience and working hours per week varied considerably (Table 1). The majority of participants were females, had some level of post-graduate qualification, provided direct bedside care, worked in specialist ICUs, and had cared for a number of patients and their families at the end of life (Table 2).

**Obstacles items for end of life care.** The means of all obstacle intensity items ranged from 1.27 to 4.26. The top obstacle intensities, based on the highest means, were determined by their means in a descending order (Table 3). Open-ended questions for obstacles in EoLC. For the open-ended question regarding any further obstacles, nurses commented on many obstacles regarding EoLC. One nurse noted that EoLC was not available and another nurse stated that most of the time, painkillers and sedation for dying patients were not considered. This may indicate the need for EoLC awareness. One nurse noted that there was a lack of knowledge on the dying process. Another nurse stated that there were cultural barriers to providing EoLC such as some patients being subjected to measures that did not provide relief. A further obstacle raised by another nurse was the difficulty in providing EoLC for brain-dead patients who were considered potential organ donors. Nurses also commented that language barriers affected EoLC conversations about patient wishes. One nurse noted that even the Arabic translators were considered a primary barrier to perform EoLC.

Some comments indicated that physicians did not involve or inform family regarding the decision about the patient's resuscitation status, leaving them without explanation or preparation for do not resuscitate (DNR)

orders. Thus, when death occurred, the family was confused and blamed the nurses. A nurse commented that physicians might have ignored palliative care needs, and considered more aggressive interventions or futile care instead. Another nurse also stated that sometimes physicians appeared to delay the patient death by passing the patient to another physician's shift. One comment suggested that physicians often did not inform the patients' families regarding the patient's situation because of their beliefs, particularly when a patient had a poor prognosis. One nurse stated that physicians and the community did not acknowledge nurses as knowledgeable independent professionals. Some nurses felt that they were seen in a support role and not appreciated for their specialist skills and knowledge.

The open-ended question regarding an aspect participants would like to change in EoLC showed further comments such as the following. Nurses noted that unnecessarily intensive care and painful

**Table 2 -** Questionnaire participant demographics.

Characteristics	n	(%)
<i>Gender</i>		
Male	13	(17.1)
Female	63	(82.9)
<b>Total</b>	<b>76</b>	<b>(100)</b>
<i>Qualifications</i>		
Undergraduate nursing	26	(35.1)
Postgraduate critical care nursing	22	(29.7)
Postgraduate nursing (other than critical care)	24	(32.4)
Other	2	(2.7)
<b>Total</b>	<b>74</b>	<b>(100)</b>
<i>No. of times EoLC has been provided</i>		
More than 30 patients	30	(42.3)
Between 21 and 30 patients	15	(21.1)
Between 11 and 20 patients	15	(21.1)
Between 5 and 10 patients	7	(9.9)
Less than 5	4	(5.6)
<b>Total</b>	<b>71</b>	<b>(100)</b>
<i>Participant's role</i>		
Bedside/Staff nurse	40	(57.1)
Charge nurse/ Staff nurse	28	(40.0)
Other	2	(2.9)
<b>Total</b>	<b>70</b>	<b>(100)</b>
<i>Type of ICU</i>		
Intensive Care Unit	54	(74.0)
Combined ICU/CCU	8	(11.0)
Other	6	(8.2)
Coronary Care Unit	5	(6.8)
<b>Total</b>	<b>73</b>	<b>(100)</b>

**Table 1 -** Questionnaire participants' age and years of experience.

Characteristic	Range	Mean±SD
Age (years)	25 - 63	34.39 ± 8.21
Years of experience as a RN (years)	3 - 30	10.8 ± 5.77
Years of experience in ICU (years)	1 - 20	8.6 ± 4.51
Working hours per week (hours)	12 - 84	48.6 ± 11.52
The number of beds in each of the ICU	7 - 30	18.2 ± 4.01

Table 3 - Obstacle items including both intensity and frequency

Obstacle Items	Intensity			Frequency		
	Mean	SD	Rank	Mean	SD	Rank
1. Families not accepting what the physician is telling them about the patient's poor prognosis.	4.26	0.90	1	3.90	1.05	2
2. The nurse having to deal with angry family members.	4.13	1.08	2	3.73	1.11	5
3. Family and friends who continually call the nurse wanting an update on the patient's condition rather than calling the designated family member for information.	4.06	1.11	3	4.08	1.07	1
4. Family members not understanding what 'life-saving measures' really mean, i.e., that multiple needle sticks cause pain and bruising, that an ET tube will not allow the patient to talk, or that ribs may be broken during chest compression.	3.95	1.18	4	3.72	1.26	6
5. Multiple physicians, involved with one patient, who differ in opinion about the direction care should go.	3.91	1.26	5	3.55	1.27	8
6. The nurse having to deal with distraught family members while still providing care for the patient.	3.81	1.22	6	3.81	1.17	4
7. Unit visiting hours that are too liberal.	3.71	1.53	7	3.84	1.56	3
8. Continuing intensive care for a patient with a poor prognosis because of the real or imagined threat of future legal action by the patient's family.	3.56	1.40	8	3.45	1.30	9
9. Physicians who are evasive and avoid having conversations with family members.	3.54	1.31	9	3.00	1.40	15
10. Continuing treatment for a dying patient even though the treatment causes the patient pain or discomfort.	3.42	1.63	10	3.26	1.47	10
11. The nurse not knowing the patient's wishes regarding continuing with treatments and tests because of the inability to communicate due to a depressed neurological status or due to pharmacologic sedation.	3.42	1.49	11	3.18	1.48	13
12. Not enough time to provide quality end-of-life care because the nurse is consumed with activities that are trying to save the patient's life.	3.38	1.50	12	3.26	1.44	11
13. When the nurses' opinion about the direction patient care should go is not requested, not valued, or not considered.	3.30	1.26	13	2.89	1.26	16
14. Employing life-sustaining measures at the families' request even though the patient had signed advanced directives requesting no such treatment.	3.29	1.48	14	2.82	1.60	18
15. Intra-family fighting about whether to continue or stop life support.	3.25	1.60	15	2.86	1.41	17
16. Physicians who are overly optimistic to the family about the patient surviving.	3.20	1.35	16	3.19	1.09	12
17. Physicians who will not allow the patient to die from the disease process.	3.08	1.35	17	2.78	1.34	19
18. The family, for whatever reason, is not with the patient when he or she is dying.	3.06	1.43	18	2.70	1.27	21
19. Dealing with the cultural differences that families employ in grieving for their dying family member.	3.05	1.46	19	3.13	1.42	14
20. The unavailability of an ethics board or committee to review difficult patient cases.	3.03	1.46	20	2.59	1.55	22
21. Being called away from the patient and family because of the need to help with a new admission or to help another nurse care for his/her patients.	2.94	1.38	21	2.75	1.33	20
22. The nurse knowing about the patient's poor prognosis before the family is told the prognosis.	2.79	1.90	22	3.63	1.56	7
23. Continuing to provide advanced treatments to dying patients because of financial benefits to the hospital.	2.69	1.94	23	2.20	1.86	27
24. Lack of nursing education and training regarding family grieving and quality end-of-life care.	2.66	1.48	24	2.33	1.36	25
25. The patient having pain that is difficult to control or alleviate.	2.65	1.63	25	2.57	1.38	23
26. Poor design of units which do not allow for privacy of dying patients or grieving family members.	2.61	1.75	26	2.55	1.61	24
27. No available support person for the family such as a social worker or religious leader.	2.35	1.64	27	2.26	1.59	26
28. Pressure to limit family grieving after the patient's death to accommodate a new admission to that room.	2.31	1.76	28	2.00	1.62	28
29. Unit visiting hours that are too restrictive.	1.27	1.61	29	1.50	1.66	29

interventions should be avoided. Other nurses commented that the idea of keeping the patients with brain death on ventilators should be changed.

Nurses commented that EoLC should be provided for all dying patients, to respect patient's dignity and to facilitate peaceful death, as well as enhancing the acceptance of the patient's family for their patient's condition. Further comments stated that organizing a meeting with the family for education and to discuss the

ICU team's expectations about the patient's situation, the health care plan and family understanding of their patient situation, might prepare family members for accepting the death of their beloved patient and improve EoLC. Comments indicated that clear communication between health professionals and families about a patient's situation was recommended by nurses. Further comments implied that telling the truth, allowing family members to be present, giving realistic details

about the patient's condition, including the situation of impending death and how treatment might prolong suffering, should be considered.

**Discussion.** Family issues were the highest-ranking concerns for nurses in providing quality EoLC in this study. This finding is similar to previous studies on the topic.<sup>15,18</sup> Major family issues identified by participants in providing EoLC included that family not accepting the patient's poor prognosis, dealing with difficult family reactions, continual requests for updates on the patient's condition from family members, and the family not understanding what constitutes life-saving measures. This may indicate that the patient's family in the ICU in KSA should be considered and cared for during EoLC.

The current study showed contrasting findings in relation to ICU visiting hours in KSA. While the obstacles created by liberal visiting hours scored highly in this study, other research scored this item as less of an obstacle to care.<sup>15,18</sup> Visiting those who are sick is highly regarded in the Islamic culture of the KSA.<sup>19</sup> Thus, when liberal visiting hours were considered by nurses as an obstacle, this may indicate that further arrangements and processes for visitors should be well implemented to facilitate nurse's care and meet the dying patient and their family needs.

The findings demonstrated that having a designated family member might be less effective because other family members continue to ask for updates and there can be a lack of consensus between family members. This issue has also been noted in two other studies.<sup>15,18</sup> Another study indicated that communication with families in EoL crisis situations is difficult because they may not grasp the reality of the situation.<sup>20</sup> Therefore, it seems that how to communicate with family in ICU should be well considered and improved.

This study has revealed concerns about nurses' involvement in the EoLC process. One comment stated that nurses are not treated as knowledgeable independent professionals. Furthermore, the current results and other research scored that nurses' opinions are not valued and there is not enough time to give EoLC as obstacles to EoLC provision.<sup>15,18</sup> Nurses know the patients best but physicians often do not involve nurses in decision-making regarding the care.<sup>3</sup> The nurses highlighted some issues related to physicians' roles in EoLC during the study. This concern has also been noted in other research about EoLC in ICUs<sup>15,18</sup>. The issues referred to physicians who differ in opinions from each other, do not communicate a poor prognosis

to family members, and intensive care being continued due to fear of the future threat of legal action. All these issues were revealed as obstacles to EoLC provision in ICU in KSA.

Some nurses thought that patients diagnosed with brain death should be removed from mechanical ventilation. Another study found out that this was not against the doctrine of Islam and it even might be approached to reduce patient and family suffering and also saved resources for other patients.<sup>21</sup>

**Study limitation.** The findings of this study cannot be generalized because it was conducted in one health care setting with a relatively small sample size. The another limitation of this study is that the questionnaire tool was modified from the original.

In conclusion, the findings of this study show a number of obstacles to the provision of end-of-life care in intensive care units, which may affect nurses' ability to maintain quality end-of-life care. Dying patients continue to receive aggressive medical treatments in KSA even when this may be futile. Research regarding EoLC protocols and guideline in ICU should be implemented in accordance to the population culture and belief in KSA.

It is recommended that health policy makers should develop EoLC in ICU in according to the KSA culture and overcome its obstacles. Health care providers such as nurses and physicians should have a clear EoLC guidelines. Further studies including physicians and dying patient's family perspectives regarding EoLC in ICU are recommended.

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