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ABSTRACT

Objective: To determine perceptions of Jordanian critical care staff about obstacles and facilitators to end-of-life care.

Research Methodology: The “National Survey of Critical Care Nurses' Perceptions of End-of-Life Care” was adapted and distributed to 143 critical care nurses (n=110) and physicians (n=33) in two Jordanian hospitals. Nurses and physicians completed items about perceived obstacles to end-of-life care. Nurses only completed items about facilitators to end-of-life care.

Results: The overall response rate was 72.7% (n = 104/143). Seventy–six nurses (69.1%) and 28 physicians (84.5%) responded. Nurses and physicians agreed that the highest scoring obstacles were: ‘family members who do not understand what life-saving measures mean’ and the ‘poor design of critical care units’. Other highly scoring obstacles related to clinicians’ behaviours, characteristics and attitudes. Nurses perceived the highest scoring facilitator was ‘family members who accepted that the patient was dying’.

Conclusion: There is a need to further explore the issues underlying perceptions about clinicians’ behaviours, which were perceived to be key barriers to quality end-of-life care, and to find acceptable solutions that fit with Islamic culture. It is the first time that the survey has been used to gather perceptions of doctors and nurses and in a non-western culture.

KEY WORDS

Critical care; end-of-life care; facilitators; Jordan; obstacles; nurses; physicians.

IMPLICATIONS FOR CLINICAL PRACTICE:

- Jordanian nurses and physicians working in critical care perceive misunderstandings of family members and the poor physical design of units to be most intense and frequent obstacles to end-of-life care.
- Other key obstacles to end-of-life care relate to physicians' communication and decision-making practices resulting in futile continuation of life support.
- Improving end-of-life care in critical care in Jordan requires a focus on family-staff communication, multi-disciplinary team work and development of a palliative care approach.
- More understanding is needed of the cultural milieu within which end-of-life care practice occurs in Jordan.

INTRODUCTION

End-of-life care (EOLC) in critical care units is challenging (Coombs et al., 2017; Kisorio and Langley, 2016). Physicians experience uncertainty in decision-making (Blomberg and Sahlberg-Blom, 2007; McCann et al., 2013), and problems related to: prognostication, delivering bad news and communication with families and colleagues (Ahern et al., 2012; Piers et al., 2014; McAndrew and Leske, 2015). For nurses, Espinosa et al. (2008) provide a systematic review of 22 studies (13 quantitative and nine qualitative) highlighting: lack involvement in EOLC planning, disagreement with physicians, lack of knowledge, unrealistic expectations from families, staff shortages, and environmental problems. One of the studies reviewed by Espinosa et al. (2008) designed a tool (The National Survey of Critical Care Nurses' Perception of End-of-life Care) to measure American critical care nurses' perceptions of obstacles and supportive behaviours in EOLC (Beckstrand and Kirchhoff, 2005). The biggest obstacles perceived were: behaviours of patients' families that removed nurses from caring for patients, behaviours that prolonged patients' suffering, and physicians' disagreement about the plan of care.

This paper reports a study that employed the survey of critical care nurses' perception of EOLC in Jordanian critical care units. The study is drawn from a mixed methods project which also employed qualitative interviews. It aimed to understand staff experiences about the transition to, and provision of, EOLC (Almansour, 2015).

METHODS

Aim

To determine Jordanian critical care staffs' perceptions of the intensity and frequency of obstacles and facilitators in providing EOLC.

Design

We used an exploratory, descriptive survey design, employing an existing questionnaire (Beckstrand and Kirchhoff, 2005) previously employed only with nurses. We adapted the survey for measuring nurses' and physicians' perceptions about the intensity (i.e. importance or magnitude) and frequency of obstacles to EOLC and nurses' perceptions about intensity and frequency of facilitators. We did not gather physicians' perceptions of facilitators to EOLC; this would have required a fundamental revision of the questionnaire.

Survey

The 'National Survey of Critical Care Nurses' Perceptions of End-of-life Care' (Beckstrand and Kirchhoff, 2005) has good reliability with a Cronbach alpha of 0.82-0.89 (Beckstrand and Kirchhoff, 2005; Crump et al., 2010). In this study, the reliability for the nurses' data (obstacles and facilitators) items was good with a Cronbach alpha of 0.86-0.88 (George and Mallery, 2012). For the physicians' data about obstacles, the reliability of the intensity scores was good with a Cronbach alpha of 0.81 and the reliability of the frequency items was moderate with a Cronbach alpha of 0.54 (George and Mallery, 2012).

The survey has three sections. The first uses a 5-point Likert scale to measure perceptions of intensity of 29 obstacles to EOLC ranging from 0 (not an obstacle) to 5 (an extremely large obstacles) and the frequency of their occurrence, ranging from 0 (never occurs) to 5 (always occurs). The second section uses a 5-point Likert scale to assess perceptions about the intensity

of 24 facilitators to EOLC, ranging from 0 (not a help) to 5 (extremely large) and the frequency of occurrence, ranging from 0 (never occurs) to 5 (always occurs). The third section gathers respondents' demographic characteristics.

Approval for questionnaire use and adaptation was gained from one of the original authors (R. Beckstrand). Firstly, the title and the introductory message were formulated to address nurses and physicians. Secondly, obstacle items were formulated to be appropriate for nurses and physicians. For example, the item: "Nurse not trained regarding family grieving and quality end-of-life care" was altered to read: "Lack of clinicians' education and training regarding family grieving and quality end-of-life care." The adapted questionnaire was sent to three Jordanian staff for comment; small additional changes to language were made.

Setting

The study took place in two teaching hospitals and in five critical care units. The hospitals have western style health care. As in the west, leading causes of death in Jordan relate to chronic cardiovascular and circulatory disease, followed by cancer (Nazer and Tuffaha, 2017). These patterns of disease were reflected in the caseload of the units in the study. Cultural issues related Islamic society in Jordan have an impact on EOLC, with physicians often reluctant to discuss

EOLC issues, and the strong emphasis on the importance of the family as the unit of care (Da Costa et al., 2002).

Participants' selection

One hundred and forty three critical care staff (Nurses n=110; Physicians n=33) were invited to complete the survey. Staff were eligible if they were involved in providing care for dying patients and employed in the units at the time of the study. There were no other inclusion criteria.

Data collection

Lists of staff were obtained from clinical directors. The lead author arranged meetings with staff, and sought permission to have their contact details, including mobile phone numbers. Hard copy questionnaires were administered with a cover letter providing study information and thanks. A self-addressed envelope was included for return. Completion and return of the questionnaire were taken to imply consent. There were no identifiable personal details on the questionnaires. Staff were informed that they would all receive three text messages, at weekly intervals, to: remind them about the questionnaire, where to put completed questionnaires, and to thank them. Potential participants were told there was no need to respond to the messages. Data were collected between November 2013 and July 2014.

Ethical considerations

The study was reviewed by the Faculty of Medicine and Health Sciences Research Ethics Committee, University of Nottingham (Ethical Review Number: A07062012OVS SNMP) and

by the Ethics Committees of the study hospitals (Ethical Review Numbers: 10/2/5/2465 and JUH/10/2012/11022).

Data analysis

Data were analysed using Statistical Package for Social Science software 19.0 (SPSS Inc., Chicago, IL). For comparative purposes, we employed the same approach to analysis as the survey developers, with the Likert scale data treated as continuous (Beckstrand et al., 2017; Beckstrand and Kirchhoff, 2005; Iglesias et al., 2013). Analysing Likert data using mean (M) and standard deviation (\pm) is acceptable if the data is normally distributed and there are a minimum of five to 10 observations per group (Sullivan and Artino, 2013). Mean intensity scores for each obstacle item were multiplied by mean frequency scores to produce a ‘perceived intensity score’ (PIS) for obstacles, and ‘perceived facilitator score’ (PFS) for facilitators. Items were ranked according to their PIS and PFS to determine which had both the most intensity and the most frequent occurrence. An independent-samples t-test (t) was conducted to compare nurses’ and physicians’ perceptions of obstacle intensity.

RESULTS

Demographic Data

Data of 104 critical care staff including 76 nurses (69.1% response rate) and 28 physicians (84.5% response rate) were collected and analysed. Table 1 reports the demographic characteristics of the respondents.

Obstacles

Nurses and physicians perceived that the most intense obstacle to EOLC was: “family members not understanding what life-saving measures really mean” (Nurses: $M= 4.12 \pm 0.93$; Physicians:

M= 3.92±1.32) (see Table 2). Nurses and physicians agreed on another five items in their top ten most intense obstacles. One was associated with the behaviours of physicians: “clinicians who are evasive and avoid having conversations with family members” (Nurses: M= 3.71±1.16; Physicians: M= 3.46±1.36). Another was associated with family members: “clinicians’ having to deal with angry family members” (Nurses: M= 3.76±0.90; Physicians: M=3.77±1.1). The remaining three items were supports to care provision: “poor design of units which do not allow for privacy of dying patients or grieving family members” (Nurses: M= 3.89 ±1.36; Physicians: M= 3.65±1.57); “lack of clinician education and training regarding family grieving and quality EOLC care” (Nurses: M= 3.84±1.31; Physicians: M= 3.42±1.44), and “the unavailability of an ethics board or committee to review difficult patient cases” (Nurses: M= 3.57±1.31; Physicians: M= 3.5±1.10).

Nurses and physicians agreed the most frequently occurring obstacles were: “poor design of units which do not allow for privacy of dying patients or grieving family members” (Nurses: M= 4±1.43; Physicians: M= 3.77±1.55) and “family members not understanding what life-saving measures really mean” (Nurses: M= 3.89±0.90; Physicians: M= 3.85±0.83) (see Table 2). Nurses and physicians agreed on four other items in their top ten most frequent obstacles. Two related primarily to physicians’ practice: “continuing treatments for a dying patient even though the treatments cause the patient pain or discomfort” (Nurses: M= 3.33±1.20; Physicians: M= 3.5±1.14), and: “clinician not knowing the patient’s wishes regarding continuing with treatments and tests due to the patient’s inability to communicate” (Nurses: M= 3.37±1.19; Physicians: M= 3.31±1.12). The third related to education and training: “lack of clinician education and training regarding family grieving and quality EOLC care” (Nurses: M= 3.38±1.18; Physicians: M= 3.23±1.58). The fourth item involved staff-family interaction:

“family continually call the clinician wanting an update rather than calling the designated family member” (Nurses: $M= 3.42\pm 1.31$; Physicians: $M= 3.69\pm 1.35$).

Nurses and physicians ranked the same two obstacles as both most intense and most frequently occurring: “family members not understanding what life-saving measures really mean” (Nurses: PIS= 16.02; Physicians PIS= 15.09) and “poor design of units which do not allow for privacy of dying patients or grieving family members” (Nurses: PIS= 15.56; Physicians PIS= 13.76) (see Table 2). Obstacles relating primarily to: physicians’ behaviours, availability of education or ethics advice, and family communication, were among the ten items with highest PIS scores for both sets of respondents.

There were small statistically significant differences in the intensity scores of three obstacles between nurses and physicians (see Table 2). Nurses rated two items to be more intense obstacles than did physicians: “employing life sustaining measures at the families’ request even though the patient had signed advanced directives requesting no such care” ($t(102) = 1.57, p = 0.02$) and “multiple clinicians, involved with one patient, who differ in opinion about the direction of care” ($t(102) = 1.85, p = 0.02$). Physicians rated “clinicians who won’t allow the patient to die” as more of an obstacle than nurses ($t(102) = 0.19, p = 0.01$).

Compared to physicians, three items were perceived by nurses to have higher frequency scores: (1) “pressure to limit family grieving after the patient’s death to accommodate a new admission to that room” ($t(102) = 1.4, p = 0.04$); (2) “lack of clinician education and training regarding family grieving and quality end-of-life care” ($t(102) = 0.51, p = 0.01$); and (3) “opinions of other critical care staff about the direction of patient care not being requested, valued, or considered” ($t(102) = 0.78, p = 0.02$) (see Table 2).

Nurses' perceptions of facilitators to EOLC

The most intense facilitator to EOLC perceived by nurses was “having family members accept that the patient is dying” (M= 4.12±1.01) (see Table 3). Of the top ten items, six items related to behaviours after the patient’s death and under nurses’ control: “allowing family members adequate time to be alone with the patient after he or she has died” (M= 3.83±0.94); “having the physician meet in person with the family after the patient’s death to offer support and validate that all possible care was done” (M= 3.75±1.20), “providing a peaceful, dignified bedside scene for family members once the patient has died” (M= 3.53±1.21); “a unit designed so that the family has a place to go to grieve in private” (M= 3.51±1.38); “having family members thank you or in some other way show appreciation for your care of the patient who has died” (M= 3.75±1.12); and “having a fellow nurse tell you that, you did all you could for the patient" or some other word of support” (M= 3.63±1.10).

The two most frequent facilitators perceived by nurses were “allowing family members adequate time to be alone with the patient after he or she has died” (M= 3.03±1.31) and “having family members accept that the patient is dying” (M= 2.82±0.93). Of the remaining top ten facilitators that received high frequency mean scores, three relate to providing support to nurses after a patient’s death, for example: “having family members thank you or in some other way show appreciation for your care of the patient who has died” (M= 2.54±1.08). The remaining five items in the top ten relate to providing support and access to families, drawing on personal experience and physicians establishing agreement about the direction of care.

The nurses ranked the item of “family members accept that the patient is dying” as the most intense and most frequently occurring facilitators (PFSs=11.61) (see Table 3). Facilitators

relating to behaviours that happened after patient death and to some degree support from nurses and families were among the ten items with highest PFS scores.

DISCUSSION

This study determined the views of Jordanian critical care staff about the intensity and frequency of obstacles and facilitators to EOLC using an existing survey tool. It is the first time that the survey has been used to gather perceptions of doctors and nurses and in a non-western culture. We found that nurses and physicians agreed that the most intense and frequent obstacles to EOLC relate to misunderstandings of family members and the poor physical design of units making it difficult to support grieving relatives. Other key obstacles were perceived to relate to physicians' communication and decision-making practices resulting in futile continuation of life support and poor quality interactions with family members and other members of the health care team. Nurses were also asked about facilitators to EOLC, ranking the item "family members who accepted that the patient was dying" as the top facilitator. Other facilitator items highly ranked by nurses relate to aspects of practice that nurses can usually control, such as providing a dignified bedside scene.

Insights into some of the mechanisms that may be behind our findings are provided by a qualitative study of physicians in the Middle East (Al-Awamer and Downar, 2014), which shows that it is the cultural norm in the Middle East for practitioners to avoid direct conversations about EOLC with relatives and to continue with interventionist treatment for as long as possible; this is partly because it is perceived that this is what the family desires but also due to lack of legal clarity, which leads to defensive practice. In addition, the notion of shared decision-making and consultation is not widely accepted. In the wider study from which this paper is drawn, qualitative data show that these cultural complexities combine to ensure

that aggressive modalities of treatments are usually pursued for most terminally ill patients, with both nurses and doctors perceiving there to be no planned transition to EOLC. There is little knowledge about family perceptions of EOLC in the Middle East that could be drawn upon to develop evidence based approaches to family care and communication in critical care.

Our study focused on obstacles and barriers to EOLC at the level of the critical care unit, but the units operate within a wider institutional, cultural and legal context. A review of multidisciplinary team (MDT) working in the Middle East in cancer care (Silbermann et al., 2013) highlights the lack of frameworks for team interaction and the challenge of entrenched patterns of hierarchal interaction. Even though progress has been made in Jordan with regard to the status and education of nurses, initiatives are needed to promote interdisciplinary exchange and understanding.

Although our study was in a non-western culture, its findings resonate with other studies using the same survey in the west, suggesting many similarities between western and Middle Eastern concerns. A study comparing data gathered using the survey over 17 years in the USA (Beckstrand et al., 2017) shows that in 2015 the item: “family members not understanding what life-saving measures really mean” was the greatest obstacle to EOLC, and that this item had moved up from 4th position in an earlier 1999 study. Beckstrand et al. also demonstrated that an item related to physicians: “physician disagreement about the direction of patient care” ranked as the second top obstacle to EOLC by American nurses in 2015, although two other items related to physicians dropped from their top five position between 1999 and 2015, suggesting that communicative and decision-making practice has improved over time. Family members’ misunderstandings and poor physical environments of care have also been perceived as top obstacles to providing a peaceful and dignified death by emergency nurses working in

the USA (Heaston et al., 2006). Concerns about environments for EOLC have been a recurrent theme in critical care research (Espinosa et al., 2008; Hanson et al., 2009; McCallum and McConigley, 2013), although American nurses surveyed in 2015 did not rank unit design as highly (Beckstrand et al. 2017), suggesting that this is an area that can also be improved.

In addition to attention to MDT work and to the perspectives of family members about EOLC, focusing on the development of nursing practice in palliative care could lead to beneficial impacts on the quality of EOLC in critical care. Although there is currently a lack of knowledge about how to effectively integrate palliative care with critical care practice (Aslakon et al., 2014), key principles have been agreed and include effective management of distress, timely and sensitive communication about goals of care and prognosis, attention to family needs and support for clinicians. Many of these principles relate to the obstacles and facilitators to EOLC reported here and elsewhere.

LIMITATIONS

Comparability with other research may have been limited by changes made to the survey, and the responses to the survey do not necessarily reflect the views of all critical care staff in Jordan. Some staff perceived the survey as being too long and the sample may reflect only the views of those highly motivated to take part.

CONCLUSION

The findings from this survey suggest a need for international evidence to inform the implementation of palliative care in critical care units and to explore ways to adapt the physical environment to preserve the privacy of patients and family members. There is a need to further explore the issues underlying perceptions about clinicians' behaviours and family

communication, which Jordanian staff perceived to be key barriers to quality EOLC, and to find acceptable solutions to these that fit with Islamic culture.

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Conflicts of interest: none

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Table 1. The participant's demographic characteristics (N=104)

| Characteristic | Nurses | Physicians |
|---|---------------|-------------------|
| Gender - n (%) | | |
| Male | 38 (50) | 18 (64.3) |
| Female | 38 (50) | 10 (35.7) |
| Age (years) - M± | 26.4±2.9 | 27.25±0.96 |
| Years as registered nurse/physician - M± | 4.1±2.4 | 3.14±1.06 |
| Years in critical care units - M± | 3.4±2.0 | 1.39±0.81 |
| Hours worked per week - M± | 45±3.8 | 62.78±14.65 |
| Number of bed in unit - M± | 9.2±3.2 | - |
| Highest Academic Degree - n (%) | | |
| Bachelor's degree | 65 (85.5) | 28 (100) |
| Master degree | 11 (14.5) | - |
| Working area - n (%) | | |
| Intensive Care Units (ICUs) | 35.5 (27) | 1 (3.6) |
| Coronary Care Units (CCUs) | 35.5 (27) | 3 (10.7) |
| Combined ICUs/CCUs | 7.9 (6) | 22 (78.6) |
| Medical Intensive Care Units | 12 (15.8) | 2 (7.1) |

RUNNING HEAD: END-OF-LIFE CARE IN CRITICAL CARE UNITS

| | | |
|---|---------|-----------|
| Surgical Intensive Care Units | 2 (2.6) | 0 |
| Other | 2 (2.6) | 0 |
| Position - n (%) | | |
| Direct Care/ Bedside Staff | 60 (79) | - |
| Charge Nurse/ Staff Nurse | 16 (21) | - |
| Senior physician (>3 years of experience) | - | 53.6 (15) |
| Junior physician (<3 years of experience) | - | 46.4 (13) |

Table 2. Intensity, frequency and perceived intensity scores (PIS) for obstacles in end-of-life care for the respondent staff

| Obstacles | Physicians (n=28) | | | | | Nurses (n=76) | | | | | Significance | |
|---|-------------------|------|-----------|------|-------|---------------|------|-----------|------|-------|--------------|------------|
| | Intensity | | Frequency | | PIS | Intensity | | Frequency | | PIS | Intensity | Frequency |
| | M± | Rank | M± | Rank | | M± | Rank | M± | Rank | | t (p) | t (p) |
| Family members not understanding what “life-saving measures” really mean | 3.92±1.23 | 1 | 3.85±0.83 | 1 | 15.09 | 4.12±0.93 | 1 | 3.89±0.90 | 2 | 16.02 | -.57 (.14) | .01 (.94) |
| Poor design of units which do not allow for privacy of dying patients or grieving family members. | 3.65±1.57 | 5 | 3.77±1.55 | 2 | 13.76 | 3.89±1.36 | 2 | 4±1.43 | 1 | 15.56 | -.86 (.29) | .64 (.56) |
| Continuing treatments for a dying patient even though | 3.85±0.92 | 2 | 3.5±1.14 | 4 | 13.47 | 3.45±1.22 | 13 | 3.33±1.20 | 10 | 11.48 | 1.99 (.052) | -.80 (.52) |

| | | | | | | | | | | | | | |
|---|-----------|---|-----------|----|-------|-----------|----|-----------|----|-------|------------|-------------|--|
| the treatments cause the patient pain or discomfort. | | | | | | | | | | | | | |
| Family continually call the clinician wanting an update condition rather than calling the designated family member. | 3.65±1.01 | 4 | 3.69±1.35 | 3 | 13.46 | 3.12±1.29 | 21 | 3.42±1.31 | 6 | 10.67 | 2.45 (.10) | -1.23 (.85) | |
| 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 | 3.46±1.52 | 7 | 3.46±1.65 | 5 | 11.97 | 3.26±1.73 | 18 | 3.25±1.60 | 14 | 10.59 | .47 (.51) | -.50 (.77) | |
| Clinicians having to deal with angry family members. | 3.77±1.1 | 3 | 3.15±0.96 | 12 | 11.87 | 3.68±1.12 | 6 | 3.76±0.90 | 3 | 13.83 | .26 (.79) | 3.03 (.39) | |

RUNNING HEAD: END-OF-LIFE CARE IN CRITICAL CARE UNITS

| | | | | | | | | | | | | |
|---|-----------|----|-----------|----|-------|-----------|----|-----------|----|-------|-------------|------------|
| <p>Clinician not knowing the patient's wishes regarding continuing with treatments and tests due to the patient's inability to communicate.</p> | 3.42±1.23 | 9 | 3.31±1.12 | 8 | 11.32 | 3.49±1.24 | 11 | 3.37±1.19 | 9 | 11.76 | .04 (.98) | -.09 (.85) |
| <p>Being called away from the patient and family because of the need to deal with a new admission or consultation.</p> | 3.38±1.16 | 11 | 3.27±1.04 | 9 | 11.05 | 3.29±0.97 | 17 | 3.3±1.21 | 13 | 10.85 | .28 (.28) | .07 (.17) |
| <p>Lack of clinicians' education and training regarding family grieving and quality end-of-life care.</p> | 3.42±1.44 | 10 | 3.23±1.58 | 10 | 11.04 | 3.84±1.31 | 4 | 3.38±1.18 | 8 | 12.97 | -1.35 (.26) | .51 (.01) |

RUNNING HEAD: END-OF-LIFE CARE IN CRITICAL CARE UNITS

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|--|-----------|----|-----------|----|-------|-----------|----|-----------|----|-------|-------------|------------|
| The unavailability of an ethics board or committee to review difficult patient cases. | 3.5±1.10 | 6 | 3.12±1.39 | 13 | 10.92 | 3.57±1.31 | 9 | 3.11±1.67 | 16 | 11.10 | .02 (.17) | -.22 (.30) |
| Clinicians having to deal with distraught family members while still providing care for the patient. | 3.04±1.28 | 18 | 3.42±1.06 | 7 | 10.39 | 3.17±1.34 | 19 | 3.32±1.18 | 11 | 10.52 | -.47 (.70) | -.32 (.56) |
| No available support person for the family such as a social worker or religious leader. | 3.04±1.56 | 17 | 3.42±1.52 | 6 | 10.39 | 3.49±1.53 | 10 | 3.3±1.72 | 12 | 11.51 | -1.35 (.38) | -.25 (.33) |
| Families not accepting what the clinician is telling them | 3.35±1.44 | 12 | 2.96±1.21 | 15 | 9.91 | 3.59±1.45 | 7 | 3.5±1.12 | 5 | 12.56 | -.75 (1) | 2.05 (.60) |

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|--|-----------|----|-----------|----|------|-----------|----|-----------|----|-------|-------------|------------|--|
| about the patient's poor prognosis. | | | | | | | | | | | | | |
| Not enough time to provide quality end-of-life care because the clinicians focus is on activities that are trying to save the patient's life | 3.04±1.24 | 16 | 3.23±1.27 | 11 | 9.81 | 3.86±1.21 | 3 | 3.75±1.14 | 4 | 14.47 | -3.32 (.49) | 2.18 (.32) | |
| Clinicians who are evasive and avoid having conversations with family members. | 3.46±1.36 | 8 | 2.77±1.21 | 19 | 9.58 | 3.71±1.16 | 5 | 2.78±1.10 | 19 | 10.31 | -.98 (.45) | -.03 (.77) | |
| Unit visiting hours those are too liberal. | 3.27±1.58 | 13 | 2.85±1.71 | 16 | 9.31 | 3.43±1.33 | 14 | 3.14±1.53 | 15 | 10.77 | -.56 (.24) | .90 (.65) | |

RUNNING HEAD: END-OF-LIFE CARE IN CRITICAL CARE UNITS

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| The patient having pain that is difficult to control or alleviate. | 3.04±1.48 | 19 | 2.85±1.22 | 17 | 8.66 | 3.33±1.14 | 16 | 2.59±1.07 | 24 | 8.62 | -1.18 (.07) | -.89 (.58) |
| Pressure to limit family grieving after the patient's death to accommodate a new admission to that room. | 3.15±1.34 | 14 | 2.5±1.14 | 21 | 7.87 | 3.17±1.34 | 20 | 2.88±1.35 | 17 | 9.12 | .02 (.98) | 1.46 (.04) |
| Clinicians who are overly optimistic to the family about the patient surviving. | 3.08±1.16 | 15 | 2.46±1.20 | 22 | 7.57 | 2.91±1.51 | 26 | 2.54±1.03 | 25 | 7.39 | .46 (.09) | -.12 (.18) |
| The family, not being with the patient when he or she is dying. | 2.62±1.60 | 22 | 2.81±1.05 | 18 | 7.36 | 2.86±1.39 | 27 | 2.88±1.27 | 18 | 8.23 | -.94 (.15) | .39 (.12) |
| Multiple clinicians, involved with one patient, | 2.92±1.44 | 21 | 2.5±1.27 | 20 | 7.3 | 3.59±1.04 | 8 | 2.78±1.18 | 20 | 9.98 | -1.85 (.02) | .74 (.31) |

RUNNING HEAD: END-OF-LIFE CARE IN CRITICAL CARE UNITS

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|---|-----------|----|-----------|----|------|-----------|----|-----------|----|------|-------------|------------|--|
| who differ in opinion about the direction of care. | | | | | | | | | | | | | |
| Clinicians who won't allow the patient to die. | 3±0.98 | 20 | 2.38±1.23 | 24 | 7.14 | 2.99±1.48 | 23 | 2.37±1.38 | 28 | 7.08 | .19 (.01) | -.21 (.48) | |
| Dealing with the cultural differences that families employ in grieving for their dying family member. | 2.58±1.36 | 24 | 2.42±1.27 | 23 | 6.24 | 3.45±1.34 | 12 | 2.72±1.13 | 22 | 9.38 | -2.38 (.79) | .53 (.25) | |
| Intra-family fighting about whether to continue or stop life support. | 2.62±1.44 | 23 | 2.38±1.35 | 25 | 6.23 | 3.04±1.62 | 22 | 2.37±1.49 | 27 | 7.20 | -1.17 (.73) | -.19 (.40) | |
| Clinicians knowing about the patient's poor prognosis before the family is informed. | 1.85±1.56 | 29 | 3.08±1.38 | 14 | 5.69 | 2.21±1.66 | 29 | 3.38±1.38 | 7 | 7.46 | -.58 (.33) | .78 (.73) | |

RUNNING HEAD: END-OF-LIFE CARE IN CRITICAL CARE UNITS

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|---|-----------|----|-----------|----|------|-----------|----|-----------|----|------|-------------|------------|
| Unit visiting hours that is too restrictive. | 2.19±1.57 | 27 | 2.19±1.81 | 26 | 4.79 | 2.47±1.85 | 28 | 2.74±1.76 | 21 | 6.76 | -0.90 (.11) | 1.43 (.68) |
| Opinions of other critical care staff about the direction of patient care not being requested, valued, or considered. | 2.15±1.12 | 28 | 2.15±1.19 | 27 | 4.62 | 2.93±1.47 | 25 | 2.47±1.51 | 26 | 7.23 | -2.68 (.17) | 0.78 (.02) |
| Continuing to provide advanced treatments to dying patients because of financial benefits to the hospital. | 2.35±1.67 | 26 | 1.69±1.61 | 28 | 3.97 | 3.36±1.32 | 15 | 2.61±1.70 | 23 | 8.76 | -2.92 (.07) | 2.51 (.38) |

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|--|-----------|----|-----------|----|------|----------|----|-----------|----|------|--------------|------------|
| Employing life sustaining measures at the families' request even though the patient had signed advanced directives requesting no such care. | 2.58±1.39 | 25 | 1.23±1.07 | 29 | 3.17 | 2.93±1.1 | 24 | 1.78±1.33 | 29 | 5.21 | -1.57 (0.02) | .202 (.20) |
|--|-----------|----|-----------|----|------|----------|----|-----------|----|------|--------------|------------|

Table 3: Intensity, frequency, and perceived facilitator scores (PFSs) for facilitators items (N=76).

| Facilitator | Intensity | | Frequency | | PFSs |
|---|-----------|------|-----------|------|-------|
| | Mean± | Rank | Mean± | Rank | |
| Having family members accept that the patient is dying. | 4.12±1.01 | 1 | 2.82±0.93 | 2 | 11.61 |
| Allowing family members adequate time to be alone with the patient after he or she has died. | 3.83±0.94 | 3 | 3.03±1.31 | 1 | 11.60 |
| Having the physicians involved in the patient's care agree about the direction care should go. | 3.59±0.95 | 8 | 2.71±1.05 | 4 | 9.72 |
| Having family members thank you or in some other way show appreciation for your care of the patient who has died. | 3.75±1.12 | 5 | 2.54±1.08 | 5 | 9.52 |
| Having enough time to prepare the family for the expected death of the patient. | 3.91±1.16 | 2 | 2.36±1.00 | 9 | 9.22 |
| The nurse drawing on his/her own previous experience with the critical illness or death of a family member. | 3.28±1.02 | 14 | 2.78±1.21 | 3 | 9.11 |

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|---|-----------|----|-----------|----|------|
| Providing a peaceful, dignified bedside scene for family members once the patient has died. | 3.53±1.21 | 9 | 2.49±1.38 | 6 | 8.78 |
| Having a fellow nurse tell you that, "you did all you could for the patients," or some other word of support. | 3.63±1.10 | 7 | 2.41±1.38 | 7 | 8.74 |
| Having the physician meet in person with the family after the patient's death to offer support and validate that all possible care was done. | 3.75±1.20 | 4 | 2.24±1.33 | 11 | 8.40 |
| Having one family member be the designated contact person for all other family members regarding patient information. | 3.67±1.38 | 6 | 2.11±1.20 | 15 | 7.74 |
| After the patient's death, having support staff compile all the necessary paper work for you which must be signed by the family before they leave the unit. | 3.12±1.26 | 18 | 2.38±1.44 | 8 | 7.42 |
| Having fellow nurses take care of your other patient(s) while you get away | 3.47±1.34 | 11 | 2.11±1.66 | 14 | 7.32 |

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|---|-----------|----|-----------|----|------|
| from the unit for a few moments after the death of your patient. | | | | | |
| Teaching families how to act around the dying patient such as saying to them, “She can still hear...it is OK to talk to her.” | 3.17±1.15 | 16 | 2.22±1.55 | 12 | 7.03 |
| Physicians who put hope in real tangible terms by saying to the family that, for example, only 1 out of 100 patients in this patient’s condition will completely recover. | 2.91±1.63 | 21 | 2.17±1.25 | 13 | 6.31 |
| Having a support person outside of the work setting who will listen to you after the death of your patient. | 3.16±1.57 | 17 | 1.82±1.58 | 17 | 5.75 |
| Allowing families unlimited access to the dying patient even if it conflicts with nursing care at times. | 2.47±1.45 | 24 | 2.32±1.39 | 10 | 5.73 |
| Having the family physically help care for the dying patient. | 2.8±1.27 | 22 | 1.95±1.22 | 16 | 5.46 |

| | | | | | |
|---|-----------|----|-----------|----|------|
| Having a fellow nurse put his or her arm around you, hugs you, pat you on the back or give some other kind of brief physical support after the death of your patient. | 3.18±1.46 | 15 | 1.67±1.47 | 18 | 5.31 |
| A unit designed so that the family has a place to go to grieve in private. | 3.51±1.38 | 10 | 1.33±1.31 | 21 | 4.66 |
| Talking with the patient about his or her feelings and thoughts about dying. | 3.01±1.69 | 19 | 1.47±1.25 | 19 | 4.42 |
| Having a unit schedule that allows for continuity of care for the dying patient by the same nurses. | 3.01±1.37 | 20 | 1.41±1.34 | 20 | 4.24 |
| Letting the social worker or religious leader take primary care of the grieving family. | 3.46±1.36 | 12 | 1.12±1.33 | 22 | 3.87 |
| Having an ethics committee member routinely attend unit rounds so they are involved from the beginning should an ethical situation with a patient arise later | 3.36±1.29 | 13 | 1.08±1.33 | 23 | 3.62 |

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|--|----------|----|--------|----|-----|
| Having un-licensed personnel available | 2.5±1.48 | 23 | 1±1.33 | 24 | 2.5 |
|--|----------|----|--------|----|-----|

to help care for dying patients.