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# Family Behaviors as Unchanging Obstacles in End-of-Life Care: 16-Year Comparative Data

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# Family Behaviors as Unchanging Obstacles in End-of-Life Care: 16-Year Comparative Data

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Master of Science

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# ABSTRACT

## Family Behaviors as Unchanging Obstacles in End-of-Life Care: 16-Year Comparative Data

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Background: Critical care nurses (CCNs) provide end-of-life (EOL) care for critically ill patients. CCNs face many obstacles while trying to provide quality EOL care. Some research has been published focusing on obstacles CCNs face while trying to provide quality EOL care; however, research focusing on family behavior obstacles is limited.

Objective: To determine if magnitude scores (obstacle item *size* x obstacle item *frequency of occurrence*) have changed since previous magnitude score data were first gathered in 1999.

Methods: A random geographically dispersed sample of 2,000 members of the American Association of Critical-Care Nurses (AACN) was surveyed. Responses from quantitative Likert-type items were statistically analyzed for mean and standard deviation for size of obstacle and how frequently each item occurred. Current data were then compared to similar data gathered in 1999.

Results: Six items' magnitude scores significantly increased over time. Four of the six items related to issues with families including families not accepting poor prognosis, interfamily fighting about continuing or stopping life-support, families requesting life-sustaining measures contrary to the patients' wishes and, families not understanding the term "life-saving" measures. Two other items included nurses knowing patients' poor prognosis before families knows and unit visiting hours that were too liberal.

Seven items significantly decreased in magnitude score over time, including two items specifically related to physician behavior such as physicians who would not let patients die from the disease process or physicians who avoid talking to family members. Other items which significantly decreased were poor design of units, visiting hours that were too restrictive, no available support personnel, and when the nurse's opinion regarding direction of care was not valued or considered.

Conclusions: EOL care obstacles emphasized in 1999 are still valid and pertinent. Based on magnitude scores, some EOL obstacles related to families increased significantly, whereas, obstacles related to ICU environment and physicians have significantly decreased. Based on this information, recommendations for areas of improvement include improved EOL education for families and nurses.



Keywords: obstacles, intensive care unit, end-of-life, critical care nurse, magnitude, families, physicians

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In 2014, over 2.6 million people died in the United States (Xu, Murphy, Kochanek & Arias, 2016), with 14.7% of those deaths occurring in intensive care units (ICUs) (The Dartmouth Institute, 2014). ICUs are staffed by critical care nurses who routinely provide end-of-life (EOL) care to dying patients. Unfortunately, critical care nurses are faced with obstacles that inhibit their ability to provide consistently high-quality EOL care (Beckstrand & Kirchhoff, 2005).

## Background

The SUPPORT (1995) study was the first published report regarding perceived obstacles at the EOL. Identified obstacles included insufficient communication between patients and physicians, the negative characteristics of hospital deaths, and overly aggressive treatments administered to dying patients. Since the SUPPORT study, researchers have investigated nurses' perceptions of EOL care obstacles in ICUs, emergency departments, oncology units, rural hospitals, and pediatric units (Beckstrand, Lamoreaux, Luthy, & Macintosh, 2017; Beckstrand, Smith, Heaston, & Bond, 2008; Beckstrand, Moore, Callister, & Bond, 2009; Beckstrand, Rohwer, Luthy, Macintosh & Rasmussen, 2017; & Beckstrand, Rawle, Calister & Mandleco, 2010).

In 1998 researchers gathered pilot study data using a small national random sample of critical care nurses. Critical care nurses' perceptions of obstacles that hindered their ability to provide patients with proper EOL care in an ICU were identified (Kirchhoff & Beckstrand, 2000). A year later, the same authors replicated the study with a larger (n = 1409), geographically distributed, national random sample (Beckstrand & Kirchhoff, 2005). Published data from that second study included magnitude scores (item size mean score x item frequency

of occurrence mean score) for both obstacle and supportive or helpful behavior items. The four obstacles with the largest magnitude scores included patients' families continually calling nurses for updates, patients and families not understanding the meaning and implications of the term, "life-saving measures," physicians differing opinions on how to provide care for a patient, and physicians trying to evade or avoid a patient's family (Beckstrand & Kirchhoff, 2005).

Although more studies have been conducted using critical care nurses to identify perceived EOL care obstacles, no research has been completed to follow up on the progress (or lack of progress) of magnitude scores for either obstacle or helpful behavior items that have occurred over a 16-year time period. Therefore, the purpose of this study was to derive magnitude scores (item size mean x item frequency mean) for currently perceived EOL obstacles and helpful behavior items then compare new data to magnitude scores gathered in 1999.

## Methods

EOL care obstacles exist in ICUs. Critical care nurses care for dying patients on a daily basis. Identifying and overcoming common obstacles can improve care at the EOL. What is unknown is if common obstacles (and their frequency of occurrence) have changed over the past 16 years. The goal of this study was to compare current magnitude scores of common EOL obstacles and helpful behavior items with similar data obtained in 1999.

### Sample

A geographically distributed sample of members of the American Association of Critical-Care Nurses (AACN) was surveyed. Of the 104,000 members at the time of data collection in 2014-2015, 2,000 subjects were randomly selected to receive the questionnaire. Eligible participants were registered nurses living in the United States, who could read English and had cared for at least 1 EOL care ICU patient.

**Design**

A cross-sectional mailed survey design was used. Comparison of current quantitative obstacle only data versus the pilot study obstacle only data (completed in 1998) along with the follow-up obstacle only data (completed in 1999) was previously published to determine how obstacles item size had changed over time (Beckstrand, Lamoreaux, et al., 2017). Qualitative data from this study have also been analyzed and published (Beckstrand, Hadley, Luthy, & Macintosh, 2017; Beckstrand, Mallory, Macintosh, & Luthy, 2018). Analysis of data for this paper covers the addition of *frequency of occurrence* quantitative data along with a comparison to the follow-up study data gathered in 1999.

**Instrument**

A pilot study questionnaire was developed in 1998 and minimally modified in 1999 for the original study (Beckstrand & Kirchhoff, 2005). Both obstacle and helpful behavior magnitude scores were analyzed and data were published (Beckstrand & Kirchhoff, 2005). In 2014, the National Survey of Critical-Care Nurses Regarding End-of-Life Care questionnaire was again minimally modified (an additional qualitative question was added) (Beckstrand, Lamoreaux, et al., 2017) and mailed to a national random sample of critical care nurses obtained from AACN. The questionnaire included 72 total items. There were 29 obstacles items (4 more than the original study due to nurses' suggestions of additional obstacles), 24 helpful behavior items, and 4 additional open-ended items requesting information about 1) any missed obstacles 2) general suggestions for EOL care improvement 3) EOL obstacle experiences and, 4) if the subject would be willing to be contacted for further information. Additionally, nurses were asked to answer 14 demographic questions.

**Data Analysis**

Return of current data occurred in late 2014 and early 2015. Current data were analyzed using SPSS software (SPSS, Inc. Chicago, Ill). Frequencies, measures of central tendency and dispersion were calculated for all current obstacle and helpful behavior items. Items were then ranked in size from highest mean to lowest mean and most frequently occurring to least frequently occurring.

To calculate Perceived Obstacle Magnitude Scores (POMS) or Perceived Helpful Behavior Magnitude Scores (PHBMS), each item's *size* mean was multiplied by the item's *frequency* mean. Magnitude scores for both obstacles and helpful behaviors were then ranked from highest to lowest score to identify which items were both large in size and frequently occurring (Beckstrand & Kirchhoff, 2005).

Independent-samples t-tests were conducted to compare item magnitude scores from 1999 and 2015. A two-tailed test with $\alpha = .05$ was used. Levene's Test for Equality of Variances was used to determine if the two conditions were variable between scores. Means reported in t-test calculations differed slightly from calculated item frequency means owing to some subjects being excluded from t-test analysis due to missing data (either not scoring an item's size or frequency).

**Procedure**

After obtaining Brigham Young University Institutional Review Board approval, a list of subject's home mailing addresses were purchased from AACN. Participants received a packet that included an explanatory cover letter, a 3-page questionnaire, and a pre-paid, pre-addressed return envelope. Subjects were to complete and return the questionnaire using the provided envelope. Three months later, a postcard reminder was sent to all non-respondents. Six weeks

after the post-card reminder, a duplicate questionnaire was sent to the remaining non-respondents. Consent to participate was implied upon the return of the questionnaire.

## Results

Of the 2000 potential subjects, 604 returned questionnaires, 95 questionnaires omitted due to subjects reporting that they were not eligible to participate ($n$ = 65) or because the questionnaire could not be delivered ($n$ = 30) (Beckstrand, Lamoreaux, et al., 2017). Useable responses were received from 509 subjects.

### Demographic Data

Analysis of sample demographic data was previously reported (Beckstrand, Lamoreaux, et al., 2017). As a summary, nurses in the most recent sample reported being RNs for an average of 18 years ($SD$ = 11.9) and having an average of 15.1 years of ICU experience ($SD$ = 10.7). Additionally, 65.4% of this sample reported having cared for more than 30 patients at EOL (see Table 1).

A table of comparative demographic characteristics between the original sample and the current data was previously published (Beckstrand, Lamoreaux, et al., 2017). In summary, subjects' age in years, ICU experience, current CCRN certification status, the percentage with master degrees, and hours worked per week was similar between groups. Differing data between groups included an increase in the percentage of male respondents and an increase in CCRN certification (Beckstrand, Lamoreaux, et al., 2017).

### Obstacles

Perceived Obstacle Magnitude Scores (POMS) for the 29 obstacle items were computed by multiplying the *item size* mean score which ranged from 0 (not an obstacle) to 5 (an extremely large obstacle) by the *item frequency of occurrence* mean score. Scores ranged from 0 (never

occurs) to 5 (always occurs) with a 25 being the possible highest magnitude score (5 x 5 = 25) (see Table 2).

**Obstacle items (POMS).** For current data, POMS (previously known as perceived intensity scores—[PIS]) for obstacle items ranged from a high of 14.26 to a low of 0.80. The obstacle receiving the highest magnitude score (#1) was when family members did not understand what the term "life-saving measures" really meant (POMS = 14.26) while the lowest magnitude score (#29) was "family visiting hours too restrictive" (POMS = 0.80).

***Top 10 items.*** Six of the top 10 items dealt with issues surrounding families: (#1) families' not understanding "life-saving measures" (POMS = 14.26); (#2) families continually calling the nurse for updates (POMS = 13.93); (#3) families not accepting poor prognosis (POMS = 12.13); (#6) families requesting to continue life-saving measures against patient's wishes (POMS = 10.78); (#7) families being angry (POMS = 10.74) or (#9) families being distraught (POMS = 10.37). Two top 10 times were related to nursing: (#5) nurse too busy to provide EOL care (POMS = 10.95) and, (#8) nurse not able to determine patient's EOL wishes (POMS = 10.49). The remaining two top 10 items related to physician behaviors: (#4) physicians differing in opinion about direction of care (POMS = 11.23) and (#10) physicians avoiding family members (POMS = 10.00).

***Bottom three items.*** In addition to visiting hours being too restrictive (#29), other lowest rated obstacles included (#28) continuing to provide advanced treatments for financial benefits to the hospital (POMS = 1.91) and, (#27) having no support help (social worker/chaplain) for families after a patient died (POMS = 3.05).

**Helpful Behaviors**

PHBMS (formally known as perceived supportive behavior score—[PSBS]) for the 24 helpful behavior items were computed by multiplying the *item size* mean score. Scores ranged

from 0 (not a help) to 5 (extremely large help) by the *item frequency of occurrence* mean score which ranged from 0 (never occurs) to 5 (always occurs) with a 25 being the possible highest magnitude score (5 x 5 = 25) (see Table 3).

**Helpful behavior items (PHBMS).** For current data, PHBMS for helpful behavior items ranged from a high of 17.76 to a low of 3.08. The helpful behavior receiving the highest magnitude score (#1) was when family members have adequate time to be alone with the patient after death (PHBMS = 17.76) while the lowest magnitude score (#24) was having an ethics committee member attend unit rounds and being involved from the beginning should an ethical situation later arise (PHBMS = 3.08).

***Top 10 items.*** Six of the top 10 helpful behavior items dealt with issues surrounding families. The family-related items were: (#1) family members having adequate time to be alone with patient after death (PHBMS = 17.76); (#2) families having a peaceful beside scene (PHBMS = 17.18); (#3) families being taught how to act around dying patient (PHBMS = 14.97); (#4) families having unlimited access to the dying patient (PHBMS = 13.47); (#7) families accepting the patient is dying (PHBMS = 11.98); and, (#8) families who designate one member as contact for information about the patient's status (PHBMS = 11.91). Three top 10 helpful behavior items placed the nurse as the focus: (#6) when nurses were shown gratitude for providing care (PHBMS = 12.89); (#9) nurses offering words of support to each other after a patient's death (PHBMS = 10.84); and, (#10) nurses having enough time to prepare the family for patient's death (PHBMS = 10.53). The remaining top 10 item (#5) related to physicians agreeing about the direction of patient care (PHBMS = 13.30).

***Bottom three items.*** In addition to the routine inclusion of an ethics committee member as the lowest rated helpful behavior (#24), the next two lowest rated items regarded nurses

having help from either (#23) unlicensed personnel (PHBMS = 5.41) or (#22) the family in caring for the dying patient (PHBMS = 6.24).

**Previous Magnitude Scores (PIS and PSBS)**

Originally reported intensity scores and rank for obstacle items are shown in Table 2. Previous reported supportive behavior scores and rank for helpful behavior items are shown in Table 3.

**Comparison of previous (PIS) and current (POMS) obstacle magnitude scores.** **I**ndependent-samples t-tests were conducted to compare magnitude scores for obstacle items rated in 1999 versus data gathered in 2015. Table 4 includes items that significantly increased or decreased in POMS. Other reported data are number of subjects, means, standard deviations, *p* values, and degrees of freedom (see Table 4).

***Significantly increased.*** Out of all 29 listed obstacle items, six items' magnitude scores significantly increased over time. Of the six increasing items, four related to issues with families including families not accepting poor prognosis (1999: *M*=11.2, *SD*=5.2) versus 2015 (*M*=12.6, *SD*=5.5); t (1351)=-4.87, *p* = .000; interfamily fighting about continuing or stopping life-support (1999: *M*=9.2, *SD*=5.0) versus 2015 (*M*=10.1, *SD*=5.2); t (1007)=-3.07, *p* = .002; families requesting life-sustaining measures contrary to patients' wishes (1999: *M*=10.6, *SD*=5.8) versus 2015 (*M*=11.5, *SD*=6.2); t (1347)=-2.77, *p* = .006; and, families not understanding the term "life-saving" measures (1999: *M*=13.6, *SD*=6.3) versus 2015 (*M*=14.8, *SD*=6.4); t (1341)=-3.26, *p* = .001. Two other items significantly increased in POMS from 1999 to 2015 including the nursing knowing the patient's poor prognosis before the family knows and unit visiting hours that are too liberal (see Table 4).

***Significantly decreased.*** Seven items significantly decreased in POMS from 1999 to 2015 including two items specifically related to physician behavior such as physicians who will

not let patients die from the disease process and physicians who avoid talking to family members. Other items which significantly decreased in POMS were poor design of units, visiting hours that were too restrictive, no available support personnel, and when the nurse's opinion regarding direction of care was not valued or considered (see Table 4).

**Comparison of Top 10 Obstacle Items over Time.** Looking at a comparison of the top 10 obstacle items from 1999 versus the current data, six obstacle items magnitude scores consistently ranked as top 10 items but did not significantly increase or decrease over time. These items were families continually calling the nurse for updates; physicians differing in opinion about patient care, nurses to busy offering life-sustaining measures to provide quality EOL care, nurses having to deal with angry family members, nurses not being able to communicate with the patient to learn the patient's wishes regarding care, and nurses having to deal with distraught family members (see Table 2).

**Comparison of previous (PSBS) and current helpful behavior scores (PHBMS).** Independent-samples t-tests were conducted to compare magnitude score means for helpful behavior items rated in 1999 and 2015. Table 5 data includes items that significantly increased or decreased in PHBMS. Other reported data are number of subjects, means, standard deviations, *p* values, and degrees of freedom (see Table 5).

***Significantly increased.*** Four helpful behavior items' magnitude scores significantly increased over time. Physicians agreeing about the direction of patient care (1999: $M$=12.5, $SD$=4.8) versus 2015 ($M$=13.8, $SD$=4.7); t (1344)=-2.76, $p$ = .006; families having unlimited access to dying patient (1999: $M$=12.8, $SD$=6.7) versus 2015 ($M$=14.1, $SD$=7.1); t (1342)=-3.38, $p$ = .001; the nurse having a support person outside of work (1999: $M$=8.7, $SD$=7.8) versus 2015 ($M$=9.6, $SD$=8.2); t (981)= -2.00, $p$ = .045, and the nurse having unlicensed personnel available

to help care for dying patients (1999: *M*=4.3, *SD*=4.9) versus 2015 (*M*=6.2, *SD*=6.3); t (841)=-5.94, *p* = .000.

***Significantly decreased.*** Three items significantly decreased in PHBMS from 1999 to 2015 including unit design which provides families places to grieve in private, the nurse relying on personal experiences with critical illness or death of a family member, and allowing either social workers or religious leaders to take primary care of the grieving family (see Table 5).

**Comparison of Top 10 Supportive Behavior Items over Time.** Looking at a comparison of the top 10 helpful behavior items from 1999 versus current data, eight obstacle magnitude scores consistently ranked as top 10 items but did not significantly increase or decrease over time. These items were family or nurse related. Family-related items were families having adequate time alone with the patient after death, having a dignified bedside scene after death, families being taught how to act around the dying patient, families showing gratitude to the nurse after the patient's death, families who accept that the patient is dying, and families who designate one member as the contact person for all information (see Table 3). Nurse related items that did not change over time were nurses offering words of support to each other after a patient's death and nurses having enough time to prepare for the family for the patient's death (see Table 3).

## Discussion

This study was conducted to determine if current EOL care obstacles and helpful behavior magnitude scores, compared to data gathered in 1999, had significantly changed. Using a national random sample, we received a large return adequate to achieve study purposes. Comparison of data from 1999 to current showed little had changed demographically other than increases in males and in certification; reflective of the general increases in both have been noted in nursing over time. While important information was determined about obstacle item *size* in the

current study (Beckstrand, Lamoreaux, et al., 2017), the addition of *frequency of occurrence* data was necessary to obtain the full breadth of magnitude sizes. Over time, nurses perceived greater issues with families as obstacles, increased belief that technology extends life, persistent problems with social and family communication, changes in visiting hours, better physician communication, increased clergy and social worker availability, increased availability of unlicensed personnel, and better EOL pain control.

**Obstacle and Helpful Behavior Data**

Magnitude scores verified that many of the same obstacles emphasized in 1999 were still valid and pertinent. The large number of obstacle items remaining in the top 10 without statistically increasing or decreasing over time demonstrated our obstacle list was not antiquated and remained consistent with currently identified EOL care obstacles.

**Families as Obstacles.** Previous research supports the perception families are major obstacles to providing quality EOL care regardless of the specialty (Beckstrand et al., 2008; Beckstrand, Collette, Callister & Luthy, 2012; Beckstrand et al., 2010**;** Losa Iglesias, M. E., Pascual, C., & Becerro de Bengoa Vallejo, R., 2013; Crump, Schaffer, & Schulte, 2010). ICU nurses deal with EOL care on a daily basis; however, frequent EOL care experiences are not the case for patient families. Thus, each potential EOL event is likely the first type of EOL experience for that family. Currently, there are few ways to educate families regarding EOL care until the event happens. Therefore, families' typical responses to EOL care such as anger, confusion, miscommunication, and unsupported hopefulness occur again with each new family in a similar situation (Beckstrand, Lamoreaux, et al., 2017).

**Technology extends Life.** Families wish to extend patients' lives. Healthcare is increasingly effective, and death is no longer a natural occurrence (Braithwaite, 2014). According to a study done by Jacobs, Burns, and Jacobs (2008), 57.4% of the public believe

divine intervention could save a patient even after physicians have determined treatment is futile. Obstacles related to families attempting to extend a patient's life coincides with the belief that modern medicine provides miracles and people can live forever.

**Social and family communication.** Nurse perceptions of patient families continually calling the nurse for patient updates remained high but did not significantly change in magnitude score over time. A drop in rank from 1999 to current data reflects increased social and family communication through advanced technologies such as smart phones, Facebook, and Instagram. For example, American smartphone users send and receive five times as many text messages compared to the number of calls made per day (Informate Mobile Intelligence, 2015). Still, this high ranking, consistently large item continues to illustrate nurses do not like being pulled away from bedside care as time spent communicating to family members on the phone distracts from EOL care.

**Change in visiting hours**. Over time, patient visitation has increased to nearly unlimited access to dying patients. Research shows families and patients cope better when ICU visiting hours are less restrictive (American Association of Critical Care Nurses, 2012). Interestingly, one of the obstacles that increased significantly was unit visiting hours that are too liberal. Understandably, if nurses see family members as consistent and large obstacles to providing EOL care, having open visiting hours, with even more family contact, would be perceived as problematic. While nurses might prefer more restrictive visiting hours, nurses also understand how helpful it is to patients to have family members at the bedside (Hart, Hardin, Townsend, Ramsey, & Mahrle-Henson, 2013).

**Better physician communication.** Physicians who avoid having conversations with family members is decreasing and physicians are doing a better job communicating with patients and families. Improved physician communication with families is likely related to better medical

school instruction with an increased focus on physician communication education (Choudhary & Gupta, 2015). Not only does increased physician communication help families feel more informed and part of the care team, but also eases nurse burden.

**Clergy and social worker support.** Decreasing scores for limited or no availability of social workers or clergy along with similar decreases in allowing both to take primary care of the family allude to more availability of support personnel at the EOL. Another possibility relates to the potential belief that clergy only introduces more false hope to patient family members (Bülow et al., 2012) thereby creating another obstacle in providing EOL care.

**Unlicensed personnel.** ICU culture has changed over time in that it was uncommon to have any unlicensed personnel working in an ICU in 1999. Currently, nursing assistive personnel are readily available to help nurses provide EOL care to patients.

**Pain Control.** Patients having pain that is difficult to control decreased significantly in magnitude reflecting a greater emphasis on comfortable EOL care and the addition of new pain control medication and pain medication delivery. Over time, it has become easier for nurses to control patients' pain as they near EOL (DeCato et al, 2013).

## Recommendations

Since an increasing number of EOL care obstacles are related to family behaviors, an increase in general public EOL care education needs to occur. Developing interventions that can attempt to overcome the acute crisis (to the family) of having a relative admitted to ICU would be difficult. Retention of information, given at the time of crisis, is extremely limited. Additionally, one of the largest barriers to preemptive education is the unpredictability of acute illness and possible death. Therefore, EOL care education would be best presented and retained before hospitalization. Nurses need to take the lead in becoming better communicators with the population at large. Writing and submitting weekly/monthly columns to local and regional

newspapers, social media outlets, or health care blogs could be a start. EOL/ICU topics could feature EOL experts who could provide information on terminology, normal course of care, and what families and future patients should know. Additional education materials could be placed in ICU waiting rooms or even in patient rooms. For example, having a poster/handout created defining common terminology would be an easy and informative read for family members.

In addition to family education, critical care nurses could also benefit from additional education concerning EOL care and how to communicate with families of those nearing EOL. The End-of-Life Nursing Education Consortium is a national program that provides 36 online EOL educational courses to both undergraduate nursing students and RNs. Increased EOL education could help RNs better educate patients and their family when faced with EOL, thereby improving the quality of EOL care.

## Limitations

While this study used a national random sample of highly experienced critical care nurses, there were some limitations including the decrease in response rate from 1999 to the current study. The decrease in response rates from the previous study to the current study could be explained by one less reminder for the current study and the phenomenon of *survey fatigue* over time. Additionally, critical care nurses who were not members of the AACN may have had differing views on EOL obstacles and helpful behaviors.

## Conclusion

Over time, obstacles related to families have increased in magnitude as perceived by CCNs. Obstacles related to families both increased significantly or, if not increased significantly, remained high in overall magnitude rankings. In contrast, magnitude scores of items concerning environment, nurses, and physicians decreased significantly. Magnitude scores of helpful

behaviors that the nurse controls remain ranked highest while having more unlicensed personnel and families having open access to dying patient significantly increased.

Many factors impact critical care nurse's ability to provide quality care at the EOL. The results of this study confirmed factors involving patient families remain the largest obstacle to critical care nurses providing EOL care in an ICU. More research needs to be conducted to provide a more effective way to educate patient families, so nurses are not faced with so many obstacles while providing patient care. When caring for patients at the EOL in an ICU, these elements should be considered so interventions can be made to ensure patients receive the highest quality of care.

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Table 1
*Critical Care Nurses' Demographic Characteristics (N = 509).*

| [a]Characteristics | | | | |
|---|---|---|---|---|
| | Number Responding | *Range* | *M* | *SD* |
| Age in years | *n* = 498 | 24 - 73 | 45.4 | 11.9 |
| Years working in ICU | *n* = 505 | 1 - 48 | 15.1 | 10.7 |
| Years as RN | *n* = 506 | 1.5 - 50 | 18 | 11.9 |
| Number of ICU beds | *n* = 502 | 4 - 56 | 19.4 | 8.7 |
| Hours worked per week | *n* = 500 | 8 - 76 | 36 | 8.4 |
| | | | | |
| Sex | | *Percent* | | |
| Male | *n* = 66 | 13.1 | | |
| Female | *n* = 438 | 86.9 | | |
| Practice area: | | | | |
| Direct care/bedside/staff nurse | *n* = 269 | 53.2 | | |
| Charge nurse/staff nurse | *n* = 210 | 41.5 | | |
| Educator, manager | *n* = 13 | 2.6 | | |
| Clinical Nurse Specialist | *n* = 4 | 0.8 | | |
| Other (rapid response team, documentation specialist, etc.) | *n* = 10 | 2.0 | | |
| Highest earned degree: | | | | |
| Bachelor | *n* = 343 | 68 | | |
| Master | *n* = 77 | 15.2 | | |
| Associate | *n* = 67 | 13.2 | | |
| Diploma | *n* = 15 | 3.0 | | |
| Doctorate | *n* = 3 | 0.6 | | |
| Dying patients cared for: | | | | |
| More than 30 | *n* = 329 | 65.4 | | |
| 21 – 30 | *n* = 64 | 12.7 | | |
| 11 – 20 | *n* = 69 | 13.7 | | |
| 5 – 10 | *n* = 33 | 6.6 | | |
| Less than 5 | *n* = 8 | 1.6 | | |

[a]Demographic data previously reported in Beckstrand, Lamoreaux, Luthy, & Macintosh. (2017). Critical care nurses' perceptions of end-of-life obstacles: Comparative 17-year data. *Dimensions of Critical Care, 36(2)94-105. doi: 1031097/DCC.0000000000000234*

Table 2

*Obstacle Item Size and Frequency Means, Standard Deviations, and Rank with Perceived Obstacle Magnitude Scores (POMS) and Previous Perceived Intensity Scores (PIS) and Former Rank*

| Obstacle Items | Size [a]*M* | Size *SD* | Size Rank | Freq. [b]*M* | Freq. *SD* | Freq. Rank | [c]**POM** (current) | [d]PIS (& rank) (1999) |
|---|---|---|---|---|---|---|---|---|
| 1. Family not understanding the term "life-saving measures" and what those measures mean if implemented | 4.05 | 0.97 | 1 | 3.52 | 1.01 | 2 | **14.26** | 12.94(2) |
| 2. Family continually calls the nurse for the update rather than designated contact person | 3.89 | 1.06 | 4 | 3.58 | 1.06 | 1 | **13.93** | 14.83(1) |
| 3. Families not accepting the poor prognosis | 3.85 | 0.96 | 5 | 3.15 | 0.89 | 5 | **12.13** | 10.70(6) |
| 4. Physicians differing in opinion about the patient's care | 3.94 | 1.13 | 2 | 2.85 | 1.13 | 8 | **11.23** | 11.77(3) |
| 5. Nurse too busy offering life-saving measures to provide quality EOL care | 3.59 | 1.08 | 9 | 3.05 | 1.14 | 6 | **10.95** | 10.99(5) |
| 6. Family requesting life-saving measures contrary to the patient's wishes | 3.92 | 1.23 | 3 | 2.75 | 1.12 | 12 | **10.78** | 9.98(11) |
| 7. Nurse having to deal with angry family members | 3.81 | 1.08 | 7 | 2.82 | 1.05 | 9 | **10.74** | 10.43(7) |
| 8. Nurse not being able to communicate with the patient and learn wishes regarding treatment | 3.58 | 1.18 | 10 | 2.93 | 1.11 | 7 | **10.49** | 10.31(9) |
| 9. Nurse having to deal with distraught family members while still caring for the patient | 3.23 | 1.15 | 15 | 3.21 | 1.05 | 4 | **10.37** | 10.40(8) |
| 10. Physicians who are evasive and avoid having conversations with family members | 3.83 | 1.13 | 6 | 2.61 | 1.13 | 14 | **10.00** | 11.60(4) |
| 11. Intra-family fighting about continuing or stopping life-support | 3.65 | 1.05 | 8 | 2.64 | 0.94 | 13 | **9.64** | 8.82(15) |
| 12. Physician overly optimistic about patient surviving | 3.38 | 1.21 | 13 | 2.77 | 0.97 | 10 | **9.36** | 9.84(12) |
| 13. The nurse called away from the patient and family to perform other duties | 3.20 | 1.22 | 16 | 2.75 | 1.22 | 11 | **8.80** | 9.19(13) |
| 14. Physicians who won't allow patients to die from the disease process | 3.50 | 1.36 | 11 | 2.51 | 1.18 | 15 | **8.79** | 10.19(10) |
| 15. Patient's treatments continue although painful or uncomfortable | 3.44 | 1.30 | 12 | 2.50 | 1.18 | 16 | **8.60** | 9.06(14) |
| 16. Nurse knows the patient's poor prognosis before the family | 2.46 | 1.62 | 22 | 3.48 | 1.19 | 3 | **8.56** | 7.76(17) |
| 17. Nurses opinion about the direction of patient care is not requested, valued, or considered | 3.23 | 1.40 | 14 | 2.28 | 1.25 | 18 | **7.36** | 8.38(16) |
| 18. Family legal action is a threat, | 3.13 | 1.49 | 17 | 2.13 | 1.23 | 21 | **6.67** | 7.16(19) |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| thus intensive care continues despite the poor patient prognosis | | | | | | | | |
| 19. Poor design of units which do not allow for privacy of dying patients or grieving family members | 2.54 | 1.62 | 21 | 2.31 | 1.51 | 17 | **5.87** | 7.44(18) |
| 20. Nurse not trained regarding family grieving and quality EOL care | 2.60 | 1.39 | 20 | 2.14 | 1.19 | 20 | **5.56** | 5.57(22) |
| 21. Patient having pain that is difficult to control or alleviate | 2.71 | 1.33 | 18 | 1.94 | 0.95 | 24 | **5.26** | 5.94(20) |
| 22. Family not with the patient when he or she is dying | 2.61 | 1.21 | 19 | 2.01 | 0.81 | 23 | **5.25** | 5.77(21) |
| 23. Unit visiting hours too liberal | 2.29 | 1.77 | 26 | 2.27 | 1.70 | 19 | **5.20** | 4.04(24) |
| 24. Family grieving in culturally diverse ways | 2.42 | 1.21 | 23 | 2.03 | 0.99 | 22 | **4.91** | 5.04(23) |
| 25. Unavailability of ethics board or committee to review difficult patient cases | 2.40 | 1.69 | 24 | 1.71 | 1.39 | 25 | **4.10** | 3.65(26) |
| 26. Family grieving time limited to accommodate new admission | 2.34 | 1.59 | 25 | 1.57 | 1.15 | 26 | **3.67** | 3.68(25) |
| 27. No available support person for family such as social worker or clergy | 1.98 | 1.44 | 27 | 1.54 | 1.07 | 27 | **3.05** | 3.55(27) |
| 28. Continuing to provide advanced treatments to dying patients because of financial benefits to hospital | 1.91 | 1.85 | 28 | 1.00 | 1.16 | 28 | **1.91** | 2.06 (29) |
| 29. Visiting hours too restrictive | 0.96 | 1.40 | 29 | 0.83 | 1.10 | 29 | **0.80** | 2.40 (28) |

[a]Obstacle item size response choices were: 0 = not an obstacle to 5 = extremely large obstacle.
[b]Frequency of occurrence for obstacle item choices were: 0 = never occurs to 5 = always occurs.
[c]POMS = Perceived Obstacle Magnitude Score (= obstacle item size mean multiplied by obstacle item frequency mean).
[d]PIS = Perceived Intensity Score was the previous name for POMS.

Table 3

*Helpful Behavior Size and Frequency Means, Standard Deviations, and Rank with Perceived Helpful Behavior Magnitude Score (PHBMS) and Previous Perceived Supportive Behavior Score (PSBS) and Former Rank*

| Helpful Behavior Items | Size [a]*M* | Size *SD* | Size Rank | Freq. [b]*M* | Freq. *SD* | Freq. Rank | [c]**PHBMS** (current) | [d]PSBS (& rank) (1999) |
|---|---|---|---|---|---|---|---|---|
| 1. Family members having adequate time to be alone with the patient after death | 4.44 | 0.73 | 5 | 4.00 | 1.00 | 1 | **17.76** | 17.58(1) |
| 2. Family having a peaceful and dignified bedside scene | 4.45 | 0.78 | 4 | 3.86 | 1.00 | 2 | **17.18** | 17.36(2) |
| 3. Families being taught how to act around dying patient | 4.17 | 0.81 | 9 | 3.59 | 1.00 | 4 | **14.97** | 15.33(3) |
| 4. Families having unlimited access to dying patient | 3.71 | 1.28 | 15 | 3.63 | 1.12 | 3 | **13.47** | 12.17(7) |
| 5. Physicians involved in patient care agree about the direction patient care should go | 4.57 | 0.70 | 2 | 2.91 | 0.93 | 7 | **13.30** | 12.53(5) |
| 6. Families show gratitude to nurse for care provided to a patient who has died | 4.34 | 0.89 | 6 | 2.97 | 1.06 | 6 | **12.89** | 13.05(4) |
| 7. Family members accept the patient is dying | 4.59 | 0.70 | 1 | 2.61 | .82 | 10 | **11.98** | 12.20(6) |
| 8. Family designates one member as the contact for the rest of the family | 4.53 | 0.77 | 3 | 2.63 | 1.02 | 9 | **11.91** | 11.36(9) |
| 9. Nurses offer words of support to each other after patient death | 3.65 | 1.42 | 17 | 2.97 | 1.23 | 5 | **10.84** | 10.96(10) |
| 10. Nurse having enough time to prepare the family for patient's death | 4.21 | 0.87 | 7 | 2.50 | 0.90 | 12 | **10.53** | [e]10.61(11) |
| 11. Nurse draws on previous experience with critical illness or death of a family member | 3.64 | 1.15 | 18 | 2.88 | 1.09 | 8 | **10.48** | 11.41(8) |
| 12. Nurses scheduled so that patient received continuity of care | 4.03 | 1.00 | 12 | 2.53 | 1.13 | 11 | **10.20** | [e]10.61(12) |
| 13. Unit designed so that the family has a place to grieve in private | 4.21 | 0.97 | 8 | 2.29 | 1.48 | 15 | **9.64** | 10.60(13) |
| 14. Staff compiles all paperwork to be signed by the family before they leave the unit | 4.07 | 1.12 | 11 | 2.23 | 1.50 | 16 | **9.08** | 9.62(14) |
| 15. Nurses offer supportive physical touch to each other after patient death | 3.46 | 1.47 | 22 | 2.49 | 1.34 | 13 | **8.62** | 8.48(15) |
| 16. Nurses having a supportive person outside of the work who will listen after death of patient | 3.66 | 1.41 | 16 | 2.33 | 1.68 | 14 | **8.53** | 7.71(17) |
| 17. Nurse talking with the patient about his/her feelings and thoughts about dying | 3.94 | 1.02 | 13 | 1.91 | 0.96 | 19 | **7.53** | 7.25(20) |

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| 18. Physicians meet in person with family after a patient's death | 4.11 | 1.02 | 10 | 1.81 | 1.28 | 22 | **7.44** | 7.87(16) |
| 19. Nurses take care of patients while affected nurse "gets away" for a moment after a patient's death | 3.72 | 1.37 | 14 | 1.94 | 1.47 | 18 | **7.22** | 7.20(21) |
| 20. Physicians putting hope in tangible terms for family | 3.47 | 1.48 | 21 | 2.04 | 0.98 | 17 | **7.08** | 7.54(18) |
| 21. Letting social worker or religious leader take primary care of the grieving family | 3.51 | 1.29 | 20 | 1.89 | 1.23 | 21 | **6.63** | 7.47(19) |
| 22. Family physically helping to care for dying patient | 3.30 | 1.18 | 24 | 1.89 | 0.99 | 20 | **6.24** | 6.14(22) |
| 23. Nurse having unlicensed personnel available to help care for dying patients | 3.40 | 1.51 | 23 | 1.59 | 1.38 | 23 | **5.41** | 3.50(23) |
| 24. Ethics committee member attends unit rounds so they are involved from the beginning should an ethical situation arise later | 3.58 | 1.39 | 19 | 0.86 | 1.23 | 24 | **3.08** | 2.63(24) |

[a]Helpful behavior item size response choices were: 0 = not a help to 5 = extremely large help.
[b]Frequency of occurrence for helpful behavior item choices were: 0 = never occurs to 5 = always occurs.
[c]PHBMS = Perceived Helpful Behavior Magnitude Score (= helpful behavior item size mean multiplied by helpful behavior item frequency mean).
[d]PSBS = Perceived Supportive Behavior Score was the previous name for PHBMS.
[e]Tie was due to rounding.

Table 4

*Statistically Significant Changes in Perceived Obstacle Magnitude Scores (POMS) over Time**

| Obstacle Item | | **1999** | | **2015** | | | |
|---|---|---|---|---|---|---|---|
| **Perceived Obstacle Magnitude Score (POMS) Increased Significantly from 1999 to 2015** | +/- | ***n*** | *M (SD)* | ***n*** | *M (SD)* | *p** | (df) |
| Families not accepting the poor prognosis | + | 854 | 11.2 (5.2) | 499 | 12.6 (5.5) | .000 | 1351 |
| Intra-family fighting about continuing or stopping life-support | + | 854 | 9.2 (5.0) | 499 | 10.1 (5.2) | .002 | 1007 |
| Family requesting life-saving measures contrary to the patient's wishes | + | 850 | 10.6 (5.8) | 499 | 11.5 (6.2) | .006 | 1347 |
| Family not understanding the term “life-saving measures” and what those measures mean if implemented | + | 846 | 13.6 (6.3) | 497 | 14.8 (6.4) | .001 | 1341 |
| Nurse knows the patient’s poor prognosis before the family | + | 853 | 7.9 (6.6) | 499 | 8.9 (7.3) | .012 | 1348 |
| Unit visiting hours that are too liberal | + | 845 | 6.1 (7.4) | 496 | 7.7 (8.2) | .000 | 1339 |
| | | | | | | | |
| **Perceived Obstacle Magnitude Score (POMS) Decreased Significantly from 1999 to 2015** | +/- | ***n*** | *M(SD)* | ***n*** | *M(SD)* | *p** | (df) |
| Poor design of units which do not allow for privacy of dying patients or grieving family members | - | 850 | 9.3 (8.0) | 500 | 7.8 (7.7) | .001 | 1348 |
| Visiting hours too restrictive | - | 850 | 4.1 (6.4) | 501 | 1.8 (7.7) | .000 | 1343 |
| Patient having pain that is difficult to control or alleviate | - | 854 | 6.6 (4.8) | 500 | 6.0 (4.8) | .042 | 1352 |
| No available support person for family such as social worker or clergy | - | 855 | 4.6 (5.2) | 500 | 4.1 (4.6) | .047 | 1138 |
| Physicians who won’t allow the patient to die from the disease process | - | 844 | 11.0 (6.1) | 496 | 9.8 (6.4) | .000 | 1338 |
| Physicians who are evasive and avoid having conversations with family members | - | 846 | 12.3 (6.3) | 499 | 10.6 (6.3) | .000 | 1343 |
| Nurses opinion about the direction of patient care is not requested, valued, or considered | - | 843 | 9.1 (6.2) | 500 | 8.3 (6.5) | .028 | 1341 |

*Statistical significance does not denote clinical significance.

Table 5

*Statistically Significant Changes in Perceived Helpful Behavior Magnitude Scores (PHBMS) over Time**

| Helpful Behavior Item | | **1999** | | **2015** | | | |
|---|---|---|---|---|---|---|---|
| **Perceived Helpful Behavior Magnitude Score (PHBMS) Increased Significantly from 1999 to 2015** | +/- | ***n*** | *M (SD)* | ***n*** | *M (SD)* | *p** | (df) |
| Physicians involved in patient care agree about the direction patient care should go | + | 844 | 12.5 (4.8) | 502 | 13.8 (4.7) | .006 | 1344 |
| Families having unlimited access to dying patient | + | 850 | 12.8 (6.7) | 494 | 14.1 (7.1) | .0021 | 1342 |
| Nurse having a support person outside of work who will listen after death of patient | + | 851 | 8.7 (7.8) | 494 | 9.6 (8.2) | .045 | 981 |
| Nurse having unlicensed personnel available to help care for dying patients | + | 840 | 4.3 (4.9) | 493 | 6.2 (6.3) | .000 | 841 |
| | | | | | | | |
| **Perceived Helpful Behavior Magnitude Score (PHBMS) Decreased Significantly from 1999 to 2015** | +/- | ***n*** | *M(SD)* | ***n*** | *M(SD)* | *p** | (df) |
| Unit designed so that the family has a place to grieve in private | - | 839 | 10.6 (6.9) | 501 | 9.8 (7.0) | .038 | 13438 |
| Nurse draws on previous experience with critical illness or death of a family member | - | 844 | 12.0 (6.1) | 492 | 11.2 (6.2) | .020 | 1334 |
| Letting the social worker or religious leader take primary care of the grieving family | - | 848 | 7.9 (5.6) | 493 | 7.2 (5.9) | .033 | 1339 |
| | | | | | | | |

*Statistical significance does not denote clinical significance.