FAMILY BEHAVIORS AS UNCHANGING OBSTACLES IN END-OF-LIFE CARE: 16-YEAR COMPARATIVE DATA

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Background Critical care nurses routinely care for dying patients. Research on obstacles in providing end-of-life care has been conducted for more than 20 years, but change in such obstacles over time has not been examined.

Objective To determine whether the magnitude scores of obstacles and helpful behaviors regarding end-of-life care have changed over time.

Methods In this cross-sectional survey study, questionnaires were sent to 2000 randomly selected members of the American Association of Critical-Care Nurses. Obstacle and helpful behavior items were analyzed using mean magnitude scores. Current data were compared with data gathered in 1999.

Results Of the 2000 questionnaires mailed, 509 usable responses were received. Six obstacle magnitude scores increased significantly over time, of which 4 were related to family issues (not accepting the poor prognosis, intrafamily fighting, overriding the patient's end-of-life wishes, and not understanding the meaning of the term *lifesaving measures*). Two were related to nurse issues. Seven obstacles decreased in magnitude, including poor design of units, overly restrictive visiting hours, and physicians avoiding conversations with families. Four helpful behavior magnitude scores increased significantly over time, including physician agreement on patient care and family access to the patient. Three helpful behavior items decreased in magnitude, including intensive care unit design.

Conclusions The same end-of-life care obstacles that were reported in 1999 are still present. Obstacles related to family behaviors increased significantly, whereas obstacles related to intensive care unit environment or physician behaviors decreased significantly. These results indicate a need for better end-of-life education for families and health care providers. (*American Journal of Critical Care.* 2020;29:e81-e91)

I n 2014, more than 2.6 million people died in the United States,[1] with 14.7% of those deaths occurring in intensive care units (ICUs).[2] Intensive care units are staffed by critical care nurses who routinely provide end-of-life (EOL) care to dying patients. Often, critical care nurses are faced with obstacles that inhibit their ability to provide consistently high-quality EOL care.[3]

The SUPPORT study (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments)[4] was the first published report regarding perceived obstacles to EOL care. 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.[5-9]

In 1998, researchers gathered pilot study data using a small national random sample of critical care nurses. In their study, they identified critical care nurses' perceptions of obstacles that hindered their ability to provide patients with proper EOL care in an ICU.[10] A year later, the same authors replicated the study with a larger (N = 1409), geographically distributed, national random sample.[3] Published data from that second study included magnitude scores (mean item size multiplied by mean item frequency) for both obstacle and helpful behavior items. The 4 obstacles with the largest magnitude scores were the patient's family continually calling the nurse for updates, the patient and family not understanding the meaning and implications of the term *lifesaving measures*, physicians differing in opinion about how to provide care for a patient, and physicians being evasive and avoiding the patient's family.[3] Higher-scoring helpful behavior items were mostly in the control of the nurse.[3]

> Critical care nurses often face obstacles that inhibit their ability to provide end-of-life care to dying patients.

Although more studies have been conducted on critical care nurses' perceived obstacles to EOL care, no research has been performed to follow up on the progress (or lack of progress) of magnitude scores for either obstacle or helpful behavior items from 1999 to the present. Therefore, this study was conducted to determine magnitude scores for currently perceived obstacle and helpful behavior items and compare them with magnitude scores gathered in 1999.

Methods
Sample
This study involved a random sample of 2000 members of the American Association of Critical-Care Nurses (AACN). Eligible participants were registered nurses living in the United States who could read English and had provided EOL care to at least 1 ICU patient.

Design
This study used a cross-sectional mailed survey design. The current quantitative obstacle and helpful behavior data, along with frequency of occurrence data, were compared with the 1999 data. The original pilot study and follow-up study data on obstacle size change over time were published previously.[5] Qualitative data obtained from this study were also analyzed and published.[11,12]

Instrument
The pilot study questionnaire was developed in 1998 and minimally modified in 1999 for the original larger study.[3] Both obstacle and helpful behavior magnitude scores were analyzed and data were published.[3] In 2014 to 2015, the National Survey of Critical-Care Nurses Regarding End-of-Life Care questionnaire was again minimally modified (an additional qualitative question was added) and mailed to a national random sample of critical care nurses who were members of AACN.[5] We used the modified version for this study. The questionnaire included a total of 72 items. There were 29 obstacle items (4 more than the original study owing to nurses' suggestions of additional obstacles), 24

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helpful behavior items, and 4 additional open-ended items requesting information about (1) any missed obstacles, (2) general suggestions for improvement of EOL care, (3) experiences with EOL care obstacles, and (4) whether the participant was willing to be contacted for further information. Additionally, nurses were asked to answer 15 demographic questions.

Data Analysis

Data were analyzed using IBM SPSS Statistics. Frequencies, measures of central tendency, and dispersion were calculated for all current obstacle and helpful behavior items. Items were then ranked from highest to lowest in terms of mean size and mean frequency of occurrence.

To calculate the 29 obstacle magnitude scores (OMS) or 24 helpful behavior magnitude scores (HBMS), each item's mean size (range, 0-5) was multiplied by the item's mean frequency (range, 0-5). Magnitude scores for both obstacles and helpful behaviors were then ranked from highest to lowest to identify items that were both large in size and frequently occurring.[3]

Independent-samples *t* tests were performed to compare item magnitude scores from 1999 and 2015. A 2-tailed test at α equal to .05 was used. The Levene test for equality of variances was used to determine if the 2 conditions were variable between scores. Item means reported in *t* test calculations differed slightly from the previously reported[5] calculated item size and frequency means owing to some participants' data being excluded from *t* test analysis because of missing information (not scoring either an item's size or its frequency).

Procedure

After approval of the study was obtained from the Brigham Young University institutional review board, a list of potential participants and their home mailing addresses was purchased from AACN. Each potential participant received a packet that included an explanatory cover letter, a 3-page questionnaire, and a prepaid, preaddressed return envelope. The recipient was instructed to complete and return the questionnaire using the provided envelope. Three months later, a postcard reminder was sent to all nonrespondents. Six weeks after the postcard reminder was sent, a duplicate questionnaire was sent to the remaining nonrespondents. Consent to participate was implied by the return of the questionnaire.

Results

Of the 2000 questionnaires that were mailed out, 604 were returned. Of the 604 returned questionnaires,

95 were excluded from analysis because respondents reported that they were not eligible to participate (n = 65) or because the questionnaire could not be delivered (n = 30).[5] Usable responses were thus received from 509 individuals.

Demographic Data

Analysis of participants' demographic data was previously reported.[5] In summary, participants reported working as a registered nurse for a mean (SD) of 18 (11.9) years and having a mean (SD) of 15.1 (10.7) years of ICU experience, and 65.4% of the participants reported having provided EOL care to more than 30 patients. Participants' age, ICU experience, current CCRN certification status, educational level (percentage with master's degrees), and hours worked per week were similar between the respondents from 1999 and the current respondents. Data that differed between those 2 groups included the percentage of respondents who were male and CCRN certification status, both of which increased over time.[5]

> We used a cross-sectional mailed survey design where current quantitative obstacle and helpful behavior items were compared with similar data obtained in 1999.

Obstacle Magnitude Scores

Obstacle magnitude scores for the 29 obstacle items were computed by multiplying the mean item size by the mean item frequency of occurrence. The highest possible OMS was 25 (5 × 5). For current data, OMS for obstacle items ranged from a high of 14.26 to a low of 0.80 (Table 1).

Top 10 Items. Six of the top 10 items dealt with issues surrounding families: family not understanding the term *lifesaving measures* (No. 1; OMS = 14.26), family continually calling the nurse for updates (No. 2; OMS = 13.93), family not accepting the poor prognosis (No. 3; OMS = 12.13), family requesting to continue lifesaving measures against the patient's wishes (No. 6; OMS = 10.78), family being angry (No. 7; OMS = 10.74), and family being distraught (No. 9; OMS = 10.37). Two of the top 10 items were related to nursing issues: nurse too busy to provide quality EOL care (No. 5; OMS = 10.95) and nurse not able to determine patient's EOL wishes (No. 8; OMS = 10.49). The remaining 2 of the top 10 items related to physician issues: physicians differing in opinion about the patient's care (No. 4; OMS = 11.23) and physicians avoiding conversations with family members (No. 10; OMS = 10.00).

Table 1
Obstacle item size and frequency with perceived obstacle magnitude scores (OMS), both current and former, and former ranking

Obstacle	Size			Frequency			Current OMS[c,d]	Former OMS[d,e] (ranking)
	Mean[a]	SD	Ranking	Mean[b]	SD	Ranking		
1. Family not understanding the term *lifesaving 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 calling the nurse for the update rather than the designated contact person	3.89	1.06	4	3.58	1.06	1	13.93	14.83 (1)
3. Family 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 lifesaving measures to provide quality end-of-life care	3.59	1.08	9	3.05	1.14	6	10.95	10.99 (5)
6. Family requesting lifesaving 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 being evasive and avoiding having conversations with family members	3.83	1.13	6	2.61	1.13	14	10.00	11.60 (4)
11. Intrafamily 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. 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 not allowing 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 knowing the patient's poor prognosis before the family does	2.46	1.62	22	3.48	1.19	3	8.56	7.76 (17)
17. Nurse's 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; thus intensive care continues despite the patient's poor prognosis	3.13	1.49	17	2.13	1.23	21	6.67	7.16 (19)
19. Poor design of units that does 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 end-of-life 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)

Continued

Table 1
Continued

Obstacle	Size			Frequency			Current OMS[c,d]	Former OMS[d,e] (ranking)
	Mean[a]	SD	Ranking	Mean[b]	SD	Ranking		
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. 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] Response choices for obstacle item size were from 0 = not an obstacle to 5 = extremely large obstacle.
[b] Response choices for obstacle item frequency of occurrence were from 0 = never occurs to 5 = always occurs.
[c] The current OMS equals the mean obstacle item size multiplied by the mean obstacle item frequency.
[d] The OMS are products of the mean and include all available data.
[e] Data from 1999, when the OMS was called the perceived intensity score (PIS).

Bottom 3 Items. In addition to visiting hours being too restrictive (No. 29; OMS = 0.80), other lowest-ranked obstacles included continuing to provide advanced treatments because of financial benefits to the hospital (No. 28; OMS = 1.91) and having no support person (eg, social worker or clergy) for families after a patient died (No. 27; OMS = 3.05).

Helpful Behavior Magnitude Scores

Helpful behavior magnitude scores for the 24 helpful behavior items were computed by multiplying the mean item size by the mean item frequency of occurrence. The highest possible HBMS was 25 (5 × 5). For current data, HBMS for helpful behavior items ranged from a high of 17.76 to a low of 3.08 (Table 2).

Top 10 Items. Six of the top 10 helpful behavior items dealt with issues surrounding families. The family-related items were as follows: family members having adequate time to be alone with the patient after death (No. 1; HBMS = 17.76), family having a peaceful bedside scene (No. 2; HBMS = 17.18), families being taught how to act around the dying patient (No. 3; HBMS = 14.97), family having unlimited access to the dying patient (No. 4; HBMS = 13.47), family members accepting that the patient is dying (No. 7; HBMS = 11.98), and family designating 1 member as the contact for information about the patient's status (No. 8; HBMS = 11.91). Three of the

top 10 helpful behavior items placed the nurse as the focus: the nurse being shown gratitude for providing care (No. 6; HBMS = 12.89), nurses offering words of support to each other after a patient's death (No. 9; HBMS = 10.84), and the nurse having enough time to prepare the family for the patient's death (No. 10; HBMS = 10.53). The remaining top 10 item related to physicians agreeing about the direction of patient care (No. 5; HBMS = 13.30).

Bottom 3 Items. In addition to the routine inclusion of an ethics committee member as the lowest-ranked helpful behavior (No. 24; HBMS = 3.08), the next 2 lowest-ranked items related to nurses having help from either unlicensed personnel (No. 23; HBMS = 5.41) or the family in caring for the dying patient (No. 22; HBMS = 6.24).

> Obstacles related to family issues increased significantly over time.

Comparison of Former OMS and Current OMS

Previously reported magnitude (intensity) scores and rank for obstacle items are shown in Table 1. Independent-samples *t* tests were performed to compare mean magnitude scores for obstacle items rated in 1999 and in 2015 (Table 3).

Significantly Increased. Of the 29 listed obstacle items, 6 magnitude scores increased significantly from 1999 to 2015. Of these 6 items, 4 related to

Table 2
Helpful behavior size and frequency with helpful behavior magnitude scores (HBMS), both current and former, and former ranking

Helpful behavior	Size			Frequency			Current HBMS[c,d]	Former HBMS[d,e] (ranking)
	Mean[a]	SD	Ranking	Mean[b]	SD	Ranking		
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. Family 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. Family shows 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	0.82	10	**11.98**	12.20 (6)
8. Family designates 1 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**	10.61 (11)[f]
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**	10.61 (12)[f]
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. Nurse having a supportive person outside of 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)

Continued

Table 2
Continued

Helpful behavior	Size			Frequency			Current HBMS[c,d]	Former HBMS[d,e] (ranking)
	Mean[a]	SD	Ranking	Mean[b]	SD	Ranking		
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] Response choices for helpful behavior item size were from 0=not a help to 5=extremely large help.
[b] Response choices for helpful behavior item frequency of occurrence were from 0=never occurs to 5=always occurs.
[c] The current HBMS equals the mean helpful behavior item size multiplied by the mean helpful behavior item frequency.
[d] HBMS are products of the means including all available data.
[e] Data from 1999, when HBMS were called perceived supportive behavior scores (SBS).
[f] Tie was due to rounding.

Table 3
Statistically significant changes in perceived obstacle magnitude scores with time

Obstacle	1999		2015		P[b]
	No.	Mean[a] (SD)	No.	Mean[a] (SD)	
Obstacle magnitude score increased significantly from 1999 to 2015					
Family not accepting the poor prognosis	854	11.2 (5.2)	499	12.6 (5.5)	<.001
Intrafamily fighting about continuing or stopping life support	854	9.2 (5.0)	499	10.1 (5.2)	.002
Family requesting lifesaving measures contrary to the patient's wishes	850	10.6 (5.8)	499	11.5 (6.2)	.006
Family not understanding the term *lifesaving measures* and what those measures mean if implemented	846	13.6 (6.3)	497	14.8 (6.4)	.001
Nurse knowing the patient's poor prognosis before the family does	853	7.9 (6.6)	499	8.9 (7.3)	.012
Visiting hours too liberal	845	6.1 (7.4)	496	7.7 (8.2)	<.001
Obstacle magnitude score decreased significantly from 1999 to 2015					
Poor design of units that does not allow for privacy of dying patients or grieving family members	850	9.3 (8.0)	500	7.8 (7.7)	.001
Visiting hours too restrictive	850	4.1 (6.4)	501	1.8 (7.7)	<.001
Patient having pain that is difficult to control or alleviate	854	6.6 (4.8)	500	6.0 (4.8)	.04
No available support person for family such as social worker or clergy	855	4.6 (5.2)	500	4.1 (4.6)	.047
Physicians not allowing patients to die from the disease process	844	11.0 (6.1)	496	9.8 (6.4)	<.001
Physicians being evasive and avoiding having conversations with family members	846	12.3 (6.3)	499	10.6 (6.3)	<.001
Nurse's opinion about the direction of patient care is not requested, valued, or considered	843	9.1 (6.2)	500	8.3 (6.5)	.03

[a] Means of the cross product with missing cases excluded.
[b] Statistical significance does not denote clinical significance.

issues with families: family not accepting the poor prognosis (mean [SD] = 11.2 [5.2] vs 12.6 [5.5]; $t_{1351} = -4.87$; $P < .001$), intrafamily fighting about continuing or stopping life support (9.2 [5.0] vs 10.1 [5.2]; $t_{1007} = -3.07$; $P = .002$), family requesting lifesaving measures contrary to the patient's wishes (10.6 [5.8] vs 11.5 [6.2]; $t_{1347} = -2.77$; $P = .006$), and family not understanding the term *lifesaving measures* (13.6 [6.3] vs 14.8 [6.4]; $t_{1341} = -3.26$; $P = .001$).

Two other items increased significantly in magnitude score from 1999 to 2015: the nurse knowing the patient's poor prognosis before the family does (7.9 [6.6] vs 8.9 [7.3]; $t_{960} = -2.508$; $P = .01$) and unit visiting hours that are too liberal (6.1 [7.4] vs 7.7 [8.2]; $t_{949} = -3.70$; $P < .001$ (Table 3).

Significantly Decreased. Seven items decreased significantly in magnitude score from 1999 to 2015, including 2 items specifically related to physician

Table 4
Statistically significant changes in perceived helpful behavior magnitude scores with time

Helpful behavior	1999		2015		P^b
	No.	Mean^a (SD)	No.	Mean^a (SD)	
Helpful behavior magnitude score <u>increased</u> significantly from 1999 to 2015					
Physicians involved in patient care agree about the direction patient care should go	844	12.5 (4.8)	502	13.8 (4.7)	.006
Family having unlimited access to dying patient	850	12.8 (6.7)	494	14.1 (7.1)	.001
Nurse having a supportive person outside of work who will listen after death of patient	851	8.7 (7.8)	494	9.6 (8.2)	.04
Nurse having unlicensed personnel available to help care for dying patients	840	4.3 (4.9)	493	6.2 (6.3)	<.001
Helpful behavior magnitude score <u>decreased</u> significantly from 1999 to 2015					
Unit designed so that the family has a place to grieve in private	839	10.6 (6.9)	501	9.8 (7.0)	.04
Nurse draws on previous experience with critical illness or death of a family member	844	12.0 (6.1)	492	11.2 (6.2)	.02
Letting social worker or religious leader take primary care of the grieving family	848	7.9 (5.6)	493	7.2 (5.9)	.03

^{a} Means of the cross product with missing cases excluded.
^{b} Statistical significance does not denote clinical significance.

behavior: physicians not allowing patients to die from the disease process (mean [SD] = 11.0 [6.1] vs 9.8 [6.4]; t_{1338} = 3.51; P < .001) and physicians being evasive and avoiding having conversations with family members (12.3 [6.3] vs 10.6 [6.3]; t_{1343} = 4.70; P < .001). Other items that significantly decreased in magnitude score were poor design of units (9.3 [8.0] vs 7.8 [7.7]; t_{1348} = 3.30; P = .001), visiting hours that were too restrictive (4.1 [6.4] vs 1.8 [7.7]; t_{1343} = 8.39; P < .001); patient having pain that is difficult to control or alleviate (6.6 [4.8] vs 6.0 [4.8]; t_{1352} = 2.04; P = .04); no available support personnel (4.6 [5.2] vs 4.1 [4.6]; t_{1138} = 1.99; P = .047), and the nurse's opinion about the direction of care not being valued or considered (9.1 [6.2] vs 8.3 [6.5]; t_{1341} = 2.20; P = .03) (Table 3).

Comparison of Top 10 Obstacles Over Time. In comparing the top 10 obstacle items in 1999 versus the current data, 6 items consistently ranked in the top 10 but had magnitude scores that did not significantly increase or decrease over time. These were the family continually calling the nurse for updates, physicians differing in opinion about the patient's care, the nurse being too busy offering lifesaving measures to provide quality EOL care, the nurse having to deal with angry family members, the nurse not being able to communicate with the patient to learn his or her wishes regarding care, and the nurse having to deal with distraught family members (Table 1).

Comparison of Former and Current HBMS

Previously reported supportive behavior scores and rank for helpful behavior items are shown in Table 2. Independent-samples *t* tests were performed to compare mean magnitude scores for helpful behavior items rated in 1999 and 2015 (Table 4).

Significantly Increased. Of the 24 listed helpful behavior items, 4 magnitude scores significantly increased from 1999 to 2015: physicians agreeing about the direction of patient care (mean [SD] = 12.5 [4.8] vs 13.8 [4.7]; t_{1344} = −2.76; P = .006), family having unlimited access to the dying patient (12.8 [6.7] vs 14.1 [7.1]; t_{1342} = −3.38; P = .001) nurse having a supportive person outside of work (8.7 [7.8] vs 9.6 [8.2]; t_{981} = −2.00; P = .04), and nurse having unlicensed personnel available to help care for dying patients (4.3 [4.9] vs 6.2 [6.3]; t_{841} = −5.94; P < .001).

Significantly Decreased. Three items significantly decreased in magnitude score from 1999 to 2015: unit design that provides the family a place to grieve in private (mean [SD] = 10.6 [6.9]) vs 9.8 [7.0]; t_{1338} = 2.08; P = .04); nurse drawing on previous experience with critical illness or death of a family member (12.0 [6.1] vs 11.2 [6.2]; t_{1341} = 2.33; P = .02), and letting a social worker or religious leader take primary care of the grieving family (7.9 [5.6] vs 7.2 [5.9]; t_{1339} = 2.13; P = .03) (Table 4).

Comparison of Top 10 Supportive Behaviors Over Time. In comparing the top 10 helpful behaviors from 1999 versus current data, 8 items consistently ranked in the top 10 but had magnitude scores that did not significantly increase or decrease over time. These items were family or nurse related. Family-related items were family members having adequate time to be alone with the patient after death, family having a peaceful and dignified bedside scene after death, families being taught how to act around the

dying patient, family showing gratitude to the nurse after the patient's death, family members accepting that the patient is dying, and family designating 1 member as the contact for all information. Nurse-related items that did not change over time were nurses offering words of support to each other after a patient's death and the nurse having enough time to prepare the family for the patient's death (Table 2).

Discussion

This study was conducted to determine whether the magnitude of obstacles and helpful behaviors related to EOL care changed from 1999 to 2015. Using a national random sample that was geographically dispersed (more participants were randomly chosen from areas containing more AACN members), we received a large return adequate to achieve study purposes. Comparison of current data with previous data showed that little had changed demographically other than increases in the proportion of male nurses and in certification status, reflecting the general increases in both that have occurred in nursing over time. Although the current study yielded important information about obstacle item size,[5] the addition of frequency of occurrence data was necessary to obtain a fuller picture. 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, improved 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 confirmed that many of the same obstacles highlighted in 1999 were still present and pertinent. The large number of obstacle items remaining in the top 10 without statistically significantly increasing or decreasing over time demonstrated that our obstacle list was not antiquated and remained consistent with currently identified EOL care obstacles. We found that nurses still perceive families to be obstacles to high-quality EOL care.

Families as Obstacles. Previous research supports the perception that families are major obstacles to providing high-quality EOL care regardless of specialty.[6,10,12-15] Intensive care unit nurses frequently provide EOL care for patients; however, EOL care experiences are rare for patients' families. The current ICU admission may be the first time a family has experienced the death of a loved one. In addition,

providing EOL education to families before their family member is at the end of his or her life is challenging. Currently, there are few ways to educate families about 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.[5]

Technology Extending Life. Another factor in nurses' considering families as obstacles to EOL care is that families often have unrealistic expectations of what technology can do. Families generally want to extend patients' lives. Health care technology is increasingly effective, and death is no longer an immediate natural occurrence.[16] Additionally, according to one study,[17] 57.4% of the public believe that divine intervention can save a patient even after physicians have determined that treatment is futile. Obstacles related to families attempting to extend a patient's life coincide with a belief that modern medicine can always provide miracle cures.

Social and Family Communication. Nurse perceptions of patients' 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 2015 reflects increased social and family communication through advanced technologies such as smartphones, Facebook, and Instagram. For example, US smartphone users send and receive 5 times as many text messages compared with the number of calls made per day.[18] Still, this high-ranking, consistently large item continues to illustrate that nurses do not like being pulled away from bedside care, as time spent communicating with family members detracts from EOL care.

Change in Visiting Hours. Over time, patient visitation has increased to nearly unlimited access to dying patients. Research shows that families and patients cope better when ICU visiting hours are less restrictive.[19] Interestingly, one of the obstacles that increased significantly was unit visiting hours that are too liberal. It is understandable that if nurses see family members as consistent and large obstacles to providing EOL care, having open visiting hours resulting in even more family contact would be perceived as problematic. Although nurses might prefer more restrictive visiting hours, they also understand how

> **Obstacles related to unit design, restrictive visiting hours, pain control, physician behaviors and nurses' opinions showed significant decreases in magnitude scores.**

helpful it is to patients to have family members at the bedside.[20]

Better Physician Communication. The number of physicians avoiding having conversations with family members has decreased over time, and physicians are now doing a better job communicating with patients and families. Improved physician communication with families is most likely related to better medical school instruction with an increased focus on physician communication education.[21] Not only does increased physician communication help families feel more informed and part of the care team, but it 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 scores for letting these professionals take primary care of the family, suggest the increasing availability of support personnel. Another possibility for decreasing scores for this item is the belief that clergy convey false hope to the patient's family members,[22] thereby creating another obstacle to the provision of EOL care.

Unlicensed Personnel. Intensive care unit culture has changed over time with regard to the presence of unlicensed personnel. In 1999, it was uncommon to have staff members who were not licensed registered nurses working in the ICU. Currently, many ICUs have nursing assistive personnel such as certified nursing assistants available to help provide EOL care to patients.

> Many of the same obstacles to high-quality end-of-life care, including family behaviors, were still present 16 years later.

Pain Control. Patients having pain that is difficult to control decreased significantly in magnitude, reflecting a greater emphasis on patient comfort and the availability of new pain control medications and delivery methods. Over time, it has become easier for nurses to control patients' pain as they near the end of life.[23]

Recommendations

The increasing number of EOL care obstacles related to family behaviors indicates the need for enhanced education of the general public about EOL care. Developing interventions designed to counter the acute family crisis of having a relative admitted to the ICU would be difficult. When information is given at a time of crisis, retention 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 must take the lead in becoming better communicators with the population at large. Writing and submitting weekly or monthly columns to local and regional newspapers, social media outlets, or health care blogs could be a start. Experts in ICU and EOL care could provide information on terminology, the normal course of care, and what families and future patients should know. Additional educational materials could be placed in ICU waiting rooms or even in patient rooms. For example, a poster or handout that defines common terminology might be easily understood and informative 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 patients nearing the end of life. The End-of-Life Nursing Education Consortium is a national program that provides 36 online EOL educational courses to both undergraduate nursing students and registered nurses. Increased EOL education could help nurses better educate patients and their families, thereby improving the quality of EOL care.

Limitations

Although this study involved a national random sample of highly experienced critical care nurses, it had some limitations, including the decrease in response rate from the previous to the current study. This decrease could be explained by the current study's using 1 fewer reminder and the phenomenon of "survey fatigue" over time. Also, nurses who did not respond may have different perceptions of EOL care than those who did respond. Additionally, critical care nurses who were AACN members may have had views on obstacles and helpful behaviors regarding EOL care that differed from those of nonmembers.

Conclusion

Over time, obstacles to EOL care related to families have increased in magnitude as perceived by critical care nurses, with such obstacles either increasing significantly or remaining high in overall magnitude rankings. In contrast, magnitude scores of items concerning environment, nurses, and physicians have decreased significantly. Helpful behaviors that the nurse controls remain ranked highest in magnitude, with the availability of unlicensed personnel and the family having unlimited access to the dying patient significantly increasing in magnitude.

Many factors affect critical care nurses' ability to provide high-quality care at the end of a patient's

life. The results of this study confirm that factors involving patients' families remain the largest obstacles to the provision of EOL care in an ICU. More research is needed to identify effective ways to educate patients' families and to provide direct EOL care to families and patients concurrently.

> **SEE ALSO**
> For more about families in the intensive care unit at the end of life, visit the *Critical Care Nurse* website, **www.ccnonline.org**, and read the article by DeKeyser Ganz, "Improving Family Intensive Care Unit Experiences at the End of Life: Barriers and Facilitators" (June 2019).

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