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Critical Care Nurses' Perceptions of End-of-Life

Care: Comparative 17-Year Data

Nicole Lamoreaux

A thesis submitted to the faculty of
Brigham Young University
in partial fulfillment of the requirements for the degree of
Master of Science

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ABSTRACT

Critical Care Nurses' Perceptions of End-of-Life Care: Comparative 17-Year Data

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BACKGROUND: Nurses working in intensive care units (ICUs) frequently care for patients and their families at the end-of-life (EOL). Providing high quality EOL care is important for both patients and families, yet ICU nurses face many obstacles that hinder EOL care. Researchers have identified various ICU nurse-perceived obstacles, but no studies have been found addressing the progress that has been made over the last 17 years.

OBJECTIVE: To determine the most common and current obstacles in EOL care as perceived by ICU nurses and then to evaluate whether or not meaningful changes have occurred since data were first gathered in 1998.

METHODS: A quantitative-qualitative mixed methods design was used. A random, geographically dispersed sample of 2,000 members of the American Association of Critical-Care Nurses was surveyed.

RESULTS: Five obstacle items increased in mean score and rank as compared to 1999 data including: (1) family not understanding what the phrase "life-saving measures" really means; (2) providing life-saving measures at families' requests despite patient's advance directive listing no such care; (3) family not accepting patient's poor prognosis; (4) family members fighting about use of life support; and, (5) not enough time to provide EOL care because the nurse is consumed with life-saving measures attempting to save the patient's life. Five obstacle items decreased in mean score and rank compared to 1999 data including (1) physicians differing in opinion about care of the patient; (2) family and friends who continually call the nurse rather than calling the designated family member; (3) physicians who are evasive and avoid families; (4) nurses having to deal with angry families; and, (5) nurses not knowing their patient's wishes regarding continuing with tests and treatments.

CONCLUSIONS: Obstacles in EOL care, as perceived by critical care nurses, still exist. Family-related obstacles have increased over time and may not be easily overcome as each family, dealing with a dying family member in an ICU, likely has never experienced a similar situation. Based on the current top five obstacles, recommendations for possible areas of focus may include (1) improved nursing assessment regarding the health literacy of families followed with directed, appropriate, and specific EOL information, (2) improved care coordination between physicians and other health care providers to facilitate sharing care plans, (3) advanced directives that are followed as written by patients, (4) designated family contact communicating with family and friends regarding patient information, and, finally, (5) earlier, transparent discussions of patient prognoses as disease processes advance and patient conditions deteriorate.

Keywords: obstacles, intensive care units, end-of-life care, critical-care nurse

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Critical Care Nurses' Perceptions of Families as Obstacles
to End-of-Life Care: Comparative 17 year Data

Critical care nurses care for dying patients on a daily basis. In the United States, annual deaths for 2011 surpassed 2.4 million.¹ Nearly 540,000 deaths² occur in ICUs each year due to more complex patients presenting with multiple diagnoses and poorer prognoses.³ Therefore, providing high quality end-of-life (EOL) care to ICU patients and families is essential.⁴ ICU nurses face many obstacles in providing quality EOL care.

Background

A search of the literature identified the most common obstacles, as perceived by critical care nurses, since publication of the SUPPORT study in 1995.⁵

Obstacles

Several studies have identified common obstacles in EOL care as perceived by critical-care nurses. In 1998, a pilot study was completed surveying a national random sample of 300 ICU nurses regarding obstacles to providing quality EOL care to dying patients.⁶ Researchers concluded that nurses' perceptions of EOL obstacles primarily dealt with patients' families and with physician behaviors.⁶ In a follow-up study with data gathered in 1999, the same researchers⁷ surveyed a larger national random sample of 1500 ICU nurses. Findings from the larger study supported pilot data results in that the most commonly perceived obstacles were (1) physicians differing in opinion about patient care, (2) family continually calling the nurse for updates, (3) physicians' evasive behaviors and avoidance of family, and (4) families not understanding the term "life-saving measures" and with the associated implications.⁷

In 2006, a nationally representative sample of nurse and physician directors of 600 ICUs was surveyed.⁸ These researchers found the largest perceived EOL obstacles were those

primarily relating to families, patients, or physicians.⁸ For families and patients, noted obstacles were *unrealistic expectations* or *inability [of patients] to participate in discussions*. For those obstacles related to physicians were *insufficient training in communication regarding EOL issues* and *inadequate communications between the ICU [physician] and patients/families about appropriate goals*. Obstacles related to institutional factors included poor environment and poor staffing.

In 2008, investigators conducted a literature review comprised of 13 quantitative and 9 qualitative research studies.⁹ Identified obstacles in providing high-quality EOL nursing care were inadequate patient pain relief, poor coping mechanisms of nursing staff, lack of EOL education and/or experience among physicians and nurses, heavy patient loads, and unrealistic expectations of families.⁹

In 2010, a replication of an earlier study⁷ surveyed 180 nurses working in critical care units in a Midwestern urban trauma center.¹⁰ Similar to earlier published results, these researchers found a lack of direct and consistent information to families, issues with physicians, inadequate EOL education for nurses, and unclear advanced directives as commonly perceived obstacles.¹⁰

In another report of a multidisciplinary sample, including ICU nurses, obstacle items were coded into four domains including patient and family factors, institutional factors, clinician factors, and education/training factors.¹¹ The most consistently reported obstacles perceived by ICU nurses were language barriers between nurses and families, patients' inability to participate in making EOL decisions, lack of designated palliative care service, poor continuity of care for physicians and nurses, inadequate time to complete all nursing duties, apprehension of

withdrawing care due to potential legal liability, and inadequate physician training and communication skills.¹¹

In summary, over the last 17 years, researchers have determined that EOL care obstacles, as identified by critical-care nurses, exist in ICUs and impede delivery of quality care to dying patients. What is unknown is if mean obstacles scores have changed over time.

Objectives

Although studies have been conducted to identify perceived obstacles by ICU nurses providing EOL care, no studies were found addressing the progress that has been made over the last 17 years. The purposes of this study were to determine the most common current obstacles in EOL care, as perceived by ICU nurses, and then to evaluate whether or not meaningful changes have occurred since data were first gathered in 1998.

Research Questions

1. Which listed items do ICU nurses perceive as being the largest obstacles in providing EOL care to dying patients?
2. Have critical care nurses' perceptions of EOL obstacles changed over the last 17 years?

Methods

Sample

A geographically-dispersed sample of 2,000 members of the American Association of Critical-Care Nurses (AACN) was surveyed. Subjects were randomly selected from the 104,000 members of AACN. To be eligible for participation, subjects needed to live in the U.S., read English, and have cared for at least one ICU patient at the EOL.

Design

A quantitative-qualitative mixed methods design was used for this study. Analysis presented here covers quantitative obstacle data only. Published data from two previous studies were used for comparison.⁶⁻⁷

Instrument

The questionnaire, entitled the “*National Survey of Critical Care Nurses' Perceptions of End-of-life Care*” was first developed in 1998 and then minimally adapted in 2014. The final questionnaire consisted of 72 items including 29 obstacle items (four more than the pilot due to suggestions from nurses), 25 supportive behavior items, and 1 open-ended item for nurses to add any additional obstacle item that the survey did not cover. Three other open-ended items were also included. In addition, nurses were asked to complete 14 demographic items.

Cronbach α for the 29 obstacle size items was 0.89 suggesting that scale score was internally consistent. This is the same Cronbach α score for obstacle size items as was obtained in the obstacle size data gathered in 1999⁷ confirming that the instrument, for obstacle items, was consistent over time. Matching reliability scores were expected given that the instruments, for the list of obstacle items, were identical in both studies (collected in 1999⁷ and 2015).

Procedure

Institutional review board approval was obtained. A mailing list for subjects was purchased from AACN. Subjects received a packet including a cover letter explaining the study, a three-page questionnaire, and a pre-addressed postage-paid return envelope. Subjects were asked to self-administer and return the questionnaire upon completion. For the first mailing, packets were sent to the subjects' home addresses, with a reminder postcard sent three months later to non-responders. An additional second complete packet was sent to non-responders six

weeks after mailing of the postcard reminder. Consent to participate was implied upon return of the questionnaire.

Data Analysis

All 509 responses were entered into an SPSS® version 23 database (SPSS® Inc., 2015).¹² The accuracy of the entered data was checked by two people. Data were examined for missing values and univariate outliers using appropriate descriptive statistics and figures before further analyses were performed. Missing data were found to be minimal (less than two percent) for most variables. Descriptive statistics were calculated. Independent t-tests were conducted to assess differences in means between 1999 data⁷ and current means for obstacle size. Frequencies, measures of central tendency and dispersion, and reliability statistics were calculated for all obstacle items. Obstacle items were then ranked on the basis of their mean scores to determine which items were perceived to be the largest obstacles (see Table 1).

Results

Current Demographic Data

Of the 2,000 potential respondents, 604 questionnaires were returned with 95 of those eliminated from the study sample because either the questionnaire could not be delivered ($n = 30$) or because subjects reported they were ineligible to participate ($n = 65$). Usable responses were received from 509 of the 1905 eligible respondents for a response rate of 26.7%.¹³

Mean age of nurses was 45.4 years ($SD = 11.9$). Nurses reported a mean of 18 years ($SD = 11.8$) working as an RN and a mean of 15.1 years ($SD = 10.7$) working in an ICU setting. More than 65% of these nurses reported having provided care for 30 or more ICU patients at the EOL with only 1.6% reporting caring for less than 5 dying ICU patients. Additional demographic data is represented in Table 2.

Current Obstacle Size Ratings

Nurses rated a provided list of 29 obstacle items on a scale of 0 (not an obstacle) to 5 (extremely large obstacle). Mean size scores for obstacle items ranged from a high of 4.05 to a low of 0.96. The obstacle items receiving the highest mean scores for size (perceived largest obstacle) were, *family members not understanding what “life-saving measures” really means* ($M = 4.05, SD 0.97$), *multiple physicians, for one patient, who differ in opinion regarding direction of care* ($M = 3.94, SD = 1.13$), and *employing life sustaining measures, at the families' request, even though the patient signed advanced directives requesting no such treatments* ($M = 3.92, SD = 1.23$) (see Table 1). These top three items were noted to currently be large obstacles in providing EOL care to dying ICU patients.

Four other top 10 obstacle items related to issues with patient's families including, *family and friends continually calling the nurse for updates* ($M = 3.89, SD 1.06$), *families not accepting the patient's prognosis* ($M = 3.85, SD = 0.96$), *nurses having to deal with angry family members* ($M = 3.81, SD = 1.08$) and, *intra-family fighting regarding whether or not to continue or stop life support* ($M = 3.65, SD = 1.08$).

The lowest scoring obstacles (perceived smallest obstacles) were related to *unit visiting hours that are too restrictive* ($M = 0.96, SD = 1.40$) and *continuing to provide advanced treatments to dying patients because of [perceived] financial benefit to the hospital* ($M = 1.91, SD = 1.85$).

Comparison Data

Overall, 19 of the 29 obstacles rankedrlb5, at some time, in the top 15 items over the three data collection periods: 1998,⁶ 1999,⁷ and 2015 (see Table 3). Four top-ranking obstacle items were new to the 1999 questionnaire and remained part of the 2015 questionnaire. Because

the 1998 and 1999 data were collected relatively closely together in time and because four items were added to the 1999 questionnaire due to nurses' suggestions from the 1998 study, the following major comparisons will primarily be made between 1999 and currently gathered data.

Comparison of demographic data over time. For 1999 and 2015 data respectively, mean age in years of subjects was similar ($M = 45.1$ vs. 45.4), as was mean years' experience in ICU ($M = 15.4$ years vs. 15.1 years) and, whether the nurse was currently CCRN certified ($M = 87.6\%$ vs. 88.7%) (see Table 4). Differing demographic data from 1999 to 2015 included the number of subjects who stated they were male increasing from 6.7% to 13.1% and whether the nurse were ever certified as a CCRN (73.5% vs. 79.1%). Differences in education between times were also noted where the percentage of diploma nurses decreased from 1999 levels to 2015 levels respectively (13.9% down to 3%) and percentage of associate degrees decreased from 19.2% down to 13% . Percentage of critical-care nurses with bachelor degrees increased over time respectively (51.3% up to 67.5%) as did those with master degrees (14.1% up to 14.7%).

Individuals working in staff and charge nurse positions remained relatively stable between 1999 and current data while the percentage of clinical nurse specialists decreased somewhat over time. Nurses participating at both time points reported working similar numbers of hours. Facility characteristics described by both samples are reported in Table 5.

Comparison of obstacles mean scores and ranking over time. Five items in the current obstacle top-10 list increased in mean score as compared to 1999 data. Items that increased, over time, in mean score and rank (denoted by rank #) included the current #1 highest ranked item, *family not understanding what the phrase "life-saving measures" really means* (in 1999 was #4); current #3 item, *providing life-saving measures at families' request despite patient AD requesting no such care* (in 1999 was #6); current #5 item, *family not accepting patient's poor*

prognosis (in 1999 was #8); current #8 item, *family members fighting about use of life support* (in 1999 was #12); and current #9 item, *not enough time to provide EOL care because nurse is consumed with life-saving measures* (in 1999 was #11).

Five items in the current obstacle top-10 list decreased in mean score as compared to 1999 data. Those items that decreased in mean score from 1999 to 2015 data collection included current #2 item, *physicians differing in opinion about care of the patient* (in 1999 was #1); current #4 item, *family and friends who continually call the nurse rather than calling the designated family member* (in 1999 was #3); current #6 item, *physicians who are evasive and avoid families* (in 1999 was #3); current #7 item, *nurse having to deal with angry family* (in 1999 was #5); and current #10 item, *nurse not knowing patient's wishes regarding continuing with tests and treatments* (in 1999 was #9).

Comparison of statistical mean scores over time. Data were analyzed to compare mean scores between 1999 and current data. Twelve obstacle items were statistically and significantly different between data acquisition times. Three obstacle item mean scores increased significantly from 1999 to 2015 (see Table 6). Nine obstacle item mean scores decreased significantly from 1999 to 2015. It is important to note that statistical significance does not necessary denote clinical significance.

Discussion

Demographics

Changes in demographic data over time reflect the national trend of increases of males into nursing¹⁴ and the focus on nursing degrees beyond diploma and associate. A relative steady state was noted in the mean age of bedside nurses and the average number of years working as RNs.

The mean score ranges for items in the current obstacle size section were similar to those observed at 1999, suggesting that serious deficiencies in EOL care continue to exist in ICUs across the nation. That most of this sample of nurses reported having cared for 30 or more dying patients shows that these nurses were highly experience in EOL care. A high level of experience is important to note as the highest ranked item was perceived only to be *large* compared to the highest possibility (*extremely large*) suggesting that these experienced nurses may have found ways to work around common EOL obstacles. Another possibility could be that this sample of nurses considered these obstacles so common in occurrence that the obstacles were considered a routine part of EOL care with dying patients and thus were not rated as extremely large.

While some obstacle item means differed significantly over time, true judgment of clinical significance is subjective at best. Does it really matter, at the bedside, if a particular obstacle item increased significantly by mean score? What is probably more important is the type of obstacle item that significantly increased and the comparative ranking of top obstacle items. For example, two of the three statistically increasing obstacle means scores related to issue with families.

Families as Obstacles

Interestingly, issues with families seem to have increased over the last 17 years in that six of the top ten currently rated obstacles identified issues with families as obstacles—an increase from data gathered 17 years ago. It is possible that as other obstacles, not related to families, are addressed and improved upon, family issues will continue to increase over time. Increases in obstacle items related to families may be due to the nature of death and dying. For critical care nurses, dying patient events happen every day; however, for families, that dying patient may be their first ICU death experience therefore, typical responses to that death event (anger, confusion,

miscommunication, and unsupported hopefulness) occur with each family placed in a similar position.

Top Five Obstacles

The current top five reported obstacles have consistently been reported in the top eight obstacles over the past 17 years indicating that little has been done to reduce top obstacles in EOL care. Discussion of the top five obstacles follows.

The current top obstacle, where families misunderstand medical terminology, is an example of deficient health literacy. The Institute of Medicine report on health literacy defined health literacy as, “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions.”¹⁵ Older adults are vulnerable for health literacy issues even as these adults develop more chronic illnesses using more medical services than other population ages.¹⁵ Critical care nurses need to assess the health literacy levels of their patients’ families and assure that information regarding EOL issues is clearly matched to the families’ literacy level. As nurses definitively explain that endotracheal tubes, ventilators, small bowel feeding tubes, and vasoactive medications may all be forms of “lifesaving measures,” families may more clearly understand the amount of actual support being given to their family member to sustain life. Nursing education of families regarding each care being provided is essential in high quality care.¹⁶

The second top obstacle, physician disagreement about the direction of patient care, may be directly impacted by the training and experience of each physician.¹⁷ It is imperative that physicians reach a consensus on patients’ prognoses to provide the best information for the families and care for patients.¹⁶

Advanced directives play an important role in fulfilling patient wishes regarding EOL care. Unfortunately, when patients are unable to speak or explain their completed advance directives, families, nurses, or physicians may misinterpret the patient's wishes and an advanced directive may not be followed.¹⁸ As the third highest obstacle, measures need to be implemented where advanced directives are followed, as specified by individual patients, so that EOL decisions are not changed by family members when critical illness ensues.

Nurses need time to provide high-quality EOL care. When nurses are called away from the patient multiple times throughout the shift to talk to various family members and friends of the patient, the quality of provided care suffers (#4 obstacle). By identifying a designated family spokesperson, who can get updates from the nurse and disseminate that information to friends and family, more of nurses' time can be spent caring for patients.¹⁹

Families not accepting a patient's poor prognosis until the time of death can be a frustrating obstacle, yet families often do not have the needed information to understand, let alone accept poor prognoses (#5 top obstacle). Physicians often wait to discuss the prognosis with family until a disease process is so advanced or a patient's condition so deteriorated that families do not have time to consider or make difficult decisions for the patient.²⁰ Earlier communication regarding all possible eventualities may lead to earlier decisions for comfort care over prolonged futile treatments.

Limitations

Only members of AACN were sampled. Critical care nurses who are not members of AACN may have rated obstacle items differently than this sample of nurses. In addition, non-responders may have also scored obstacles differently.

While it has been noted that surveys of health care professionals have generally low response rates, the low response rates have continued to decrease over time.²¹ Response rate for this study was well below the response rates of 1999 data acquisition (61%) and the 1998 pilot study (69%). While low, our response rate was almost identical to another national survey of registered nurses.²² In a U.S. Department of Health and Human Services survey of registered nurses using a multimodal approach, overall response rate for paper returns was 27% (additional online returns were 24% while phone completion was 10%).²² The lower response rate could reflect the absence of a monetary incentive given in 1999 (a \$2 bill) but not provided at 2015 data collection, the lack of three complete follow-up mailings, or could reflect the feeling of “survey fatigue.” Survey fatigue is common when a potential research subject is inundated with invitations to complete surveys leading to an adverse effect on response rates.²³

Recommendations

Improving EOL care for dying ICU patients remains a high priority in nursing. Optimal EOL care may not be possible for all patients and families,²⁴ but identifying current nurse-perceived obstacles is essential in providing quality EOL care for as many patients and families as possible. As obstacles are identified, focused effort can be aimed at developing meaningful interventions to improve EOL care. Based on the current top five obstacles, recommendations for possible areas of focus may include (1) improved nursing assessment regarding the health literacy of families followed with directed, appropriate, and specific EOL information, (2) improved care coordination between physicians and other health care providers to facilitate sharing care plans, (3) advanced directives that are followed as written by patients, (4) designated family contact communicating with family and friends regarding patient information,

and, finally, (5) earlier, transparent discussions of patient prognoses as disease processes advance and patient conditions deteriorate.

Conclusion

Obstacles, as perceived by critical-care nurses, continue to exist and impede quality delivery of EOL care. Obstacles related to issues with families seem to have increased slightly over time. These family issues may be inherent with the situation of dying in ICUs and may not be easily overcome as each EOL event is new to that family but familiar to ICU nurses. In general, implementing strategies which support clearer communication, guide all care toward one goal, and allow nurses to be at the bedside caring for dying patients are ultimately the best ways to improve care for dying critically ill patients.

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Table 1**Obstacle Item Size by Mean as Reported by Critical-Care Nurses in Regard to End-of-Life Care**

Obstacle	<i>M</i>	<i>SD</i>	<i>n</i>^a
1. Family members not understanding what "life-saving measures" really means.	4.05	0.97	502
2. Multiple physicians, involved with one patient, who differ in opinion about the direction care should go.	3.94	1.13	506
3. Employing life sustaining measures at the families' request even though the patient had signed advanced directives requesting no such treatment.	3.92	1.23	507
4. Family and friends who continually call the nurse wanting updates on the patient's condition rather than calling the designated family member.	3.89	1.06	504
5. Families not accepting what the physician is telling them about the patient's prognosis.	3.85	0.96	506
6. Physicians who are evasive and avoid having conversations with Family members.	3.83	1.13	505
7. The nurse having to deal with angry family members.	3.81	1.08	502
8. Intra-family fighting about whether to continue or stop life support.	3.65	1.08	502
9. Not enough time to provide quality end-of-life care because the nurse is consumed with activities that are trying to save the patient's life.	3.59	1.08	505
10. Nurse not knowing the patient's wishes regarding continuing with treatments and tests because of the inability to communicate.	3.58	1.18	502
11. Physicians who won't allow the patient to die from the disease Process.	3.50	1.36	502
12. Continuing treatments for a dying patient even though the treatments cause the patient pain or discomfort.	3.44	1.30	503
13. Physicians who are overly optimistic to the family about the patient surviving.	3.38	1.21	504
14. When the nurses' opinion about the direction patient care should go is not requested, not valued, or not considered.	3.23	1.40	506

Table 1 Continued**Obstacle Item Size by Mean**

Obstacle	<i>M</i>	<i>SD</i>	<i>n^a</i>
15. The nurse having to deal with distraught family members while still providing care for the patient.	3.23	1.15	505
16. Being called away from the patient and family because of the need to help with a new admit or help another nurse care for his/her cases.	3.20	1.22	501
17. 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.	3.13	1.49	505
18. The patient having pain that is difficult to control or alleviate.	2.71	1.33	505
19. The family, for whatever reason, is not with the patient when he or she is dying.	2.61	1.21	506
20. Lack of nursing education and training regarding family grieving and quality end-of-life care.	2.60	1.39	504
21. Poor design of units which do not allow for privacy of dying patients or grieving family members.	2.54	1.62	508
22. The nurse knowing about the patient's poor prognosis before the family is to the prognosis.	2.46	1.62	504
23. Dealing with the cultural differences that families employ in grieving for their dying family member.	2.42	1.21	507
24. The unavailability of an ethics board or committee to review difficult patient cases.	2.40	1.69	500
25. Pressure to limit family grieving after the patient's death to accommodate a new admit to that room.	2.64	1.59	506
26. Unit visiting hours that are too liberal.	2.29	1.77	502
27. No available support person for the family such as a social worker or religious leader.	1.98	1.44	507
28. Continuing to provide advanced treatments to dying patients because of financial benefits to the hospital.	1.91	1.85	497
29. Unit visiting hours that are too restrictive.	0.96	1.40	506

^an = number of nurses rating this item.

Table 2**Demographics of Nurses (N = 509).**

Characteristics			
Sex	<u>n</u> %		
Female	438 (86.9)		
Male	66 (13.1)		
	<u>M</u>	<u>SD</u>	<u>Range</u>
Age	45.4	11.9	24 - 73
Years as RN	18	11.8	1.5 - 50
Years in ICU	15.1	10.7	1 - 48
Hours worked/week	36	8.4	8 - 76
Number of beds in ICU	19.4	8.7	4 - 56
Dying patients cared for:	<u>%</u>		
>30	65.4		
21 - 30	12.7		
11 - 20	13.7		
5 - 10	6.6		
<5	1.6		
Highest degree:	<u>%</u>		
Diploma	3		
Associate	13.2		
Bachelor	68		
Master	15.2		
Doctoral	0.6		
Ever certified as CCRN	<u>n</u> %		
Yes	400 (79.1)		
No	106 (20.9)		
Currently CCRN	<u>n</u> %		
Yes	307 (88.7)		
No	39 (11.3)		
Years as CCRN	8.9	8.3	0.5 - 36
Practice area:	<u>%</u>		
Direct Care/Bedside Nurse	53.2		
Staff/Charge Nurse	41.5		
Clinical Nurse Specialist	0.8		
Other (Manager, Educator, etc.)	4.5		

Table 3
Comparative data of obstacle size mean and rank over 3 time periods

1998 [*]		1999 ^{**}		2015	
Obstacles	Mean	Obstacles	Mean	Obstacles	Mean
1 Family and friends who continually call the nurse rather than calling designated family member [#]	3.76	1 Physicians differing in opinion about care of the patient [^]	4.03	1 Family not understanding what the phrase "life-saving measures" really means	4.05
2 Family not understanding what the phrase "life-saving measures" really means	3.66	2 Family and friends who continually call the nurse rather than calling designated family member	4.02	2 Physicians differing in opinion about care of the patient	3.94
3 Family not accepting patient's poor prognosis	3.51	3 Physicians who are evasive and avoid families [^]	4.00	3 Providing life-saving measures at families' request despite patient AD requesting no such care	3.92
4 Providing life-saving measures at families' request despite patient AD requesting no such care	3.51	4 Family not understanding what the phrase "life-saving measures" really means	3.91	4 Family and friends who continually call the nurse rather than calling designated family member	3.89
5 Physicians who are overly optimistic about patient surviving	3.50	5 Nurse having to deal with angry family	3.85	5 Family not accepting patient's poor prognosis	3.85
6 Nurse having to deal with angry family	3.36	6 Providing life-saving measures at families' request despite patient AD requesting no such care	3.81	6 Physicians who are evasive and avoid families	3.83
7 Family members fighting about use of life support	3.33	7 Physicians won't allow patient to die from disease process	3.72	7 Nurse having to deal with angry family	3.81
8 Giving painful treatments to a dying patient	3.26	8 Family not accepting patient's poor prognosis	3.64	8 Family members fighting about use of life support	3.65
9 Nurse not knowing patient wishes regarding continuing with tests and treatments	3.26	9 Nurse not knowing patient wishes regarding continuing with tests and treatments	3.63	9 Not enough time to provide EOL care because nurse consumed with life-saving activities	3.59
10 Not enough time to provide EOL care because nurse consumed with life-saving activities	3.25	10 Patient's treatments continue although painful or uncomfortable	3.58	10 Nurse not knowing patient wishes regarding continuing with tests and treatments	3.58
11 Continuing care because of threat of legal action	3.12	11 Not enough time to provide EOL care because nurse consumed with life-saving activities	3.58	11 Physicians won't allow patient to die from disease process	3.50
12 Nurse dealing with distraught family members	2.79	12 Family members fighting about use of life support	3.57	12 Patient's treatments continue although painful or uncomfortable	3.44
13 Poor unit design which limits privacy	2.62	13 Physicians who are overly optimistic about patient surviving	3.50	13 Physicians who are overly optimistic about patient surviving	3.38
14 Nurse being called away from patient to help others	2.51	14 Nurse's opinion about patient's care not valued	3.45	14 Nurse's opinion about patient's care not valued	3.23
15 Patient having pain that is difficult to control	2.40	15 Nurse being called away from patient to help others	3.27	15 Nurse dealing with distraught family members	3.23

Response choices were 0, not an obstacle; 1, extremely small obstacle; 2, small obstacle; 3, medium obstacle; 4, large obstacle; and 5, extremely large obstacle.

^{*}Column years denote data gathering period; Kirchhoff & Beckstrand, 2000

^{**}Beckstrand & Kirchhoff, 2005

[^]These items were added to the 1999 version

Table 4 Comparative Demographic Characteristics

Characteristic	1999 ⁷ (SD)	2015 (SD)
Age mean in years	45.1	45.4
Gender		
Female	799 (92.5%)	438 (86.2%)
Male	57 (6.6%)	65 (12.8%)
Highest Degree		
Diploma	120 (13.9%)	15 (3.0%)
Associate	166 (19.2%)	64 (13%)
Bachelors	443 (51.3%)	343 (67.5%)
Masters	121 (14%)	75 (14.7%)
Doctoral	7 (.8%)	3 (.6%)
Other		2 (.4%)
Years as RN Mean (SD)	19.0 (8.2)	18.0 (11.9)
Years in ICU Mean (SD)	15.4 (7.0)	15.1 (10.7)
Position		
Staff Nurse	450 (52.1%)	268 (52.8%)
Charge Nurse	323 (37.4%)	210 (41.3%)
Clinical Nurse Specialist	39 (4.5%)	4 (.8%)
Educator/Manager		13 (2.6%)
Other	48 (5.6%)	10 (2.0%)
Ever Certified CCRN		
Yes	630 (72.9%)	400 (78.7%)
No	228 (26.4%)	105 (20.7%)
Missing	6 (.7%)	3 (.6%)
Currently Certified CCRN		
Yes	591 (68.4%)	307 (60.4%)
No	83 (9.6%)	39 (7.7%)
Missing	190 (22.0%)	162 (31.9%)
Years CCRN	9.1 (4.8)	8.9 (8.3)
Hours Worked per Week	36.1 (9.8)	36.0 (8.4)
Number of Patient Deaths		
< 5	7 (.8%)	8 (1.6%)
5 - 10	27 (3.1%)	33 (6.5%)
11 - 20	74 (8.6%)	69 (13.6%)
21 - 30	85 (9.8%)	64 (12.6%)
> 30	586 (67.8%)	328 (64.6%)
Other	77 (8.9%)	

Table 5
Facility Characteristics

Characteristic	1999	2015
Type of Facility		
Community Hosp. non-profit	512 (59.3%)	290 (57.1%)
Community Hosp. for-profit	126 (14.6%)	71 (14.0%)
University Medical Center	133 (15.4%)	104 (20.5%)
Federal Hospital	29 (3.4%)	14 (2.8%)
State Hospital	6 (.7%)	5 (1.0%)
County Hospital	22 (2.5%)	15 (3.0%)
Military Hospital	12 (1.4%)	5 (1.0%)
Other	19 (2.2%)	2 (.4%)
Type of ICU		
ICU	102 (11.8%)	98 (19.3%)
CCU	75 (8.7%)	28 (5.5%)
Combined ICU/CCU	345 (39.9%)	109 (21.5%)
MICU	41 (4.7%)	74 (14.6%)
SICU	56 (6.5%)	37 (7.3%)
Resp. ICU	1 (.1%)	1 (.2%)
Neuro ICU	20 (2.3%)	25 (4.9%)
Shock/Trauma Unit	25 (2.9%)	40 (7.9%)
Cardio/Surgical ICU	126 (14.6%)	82 (16.1%)
Other		11 (2.2%)
Unit Beds Mean (<i>SD</i>)	15.4 (8.1)	19.5 (8.8)

Table 6**Statistically Significant Changes in Obstacle Mean Scores over Time***

Obstacle Item

		1999	2015		
Obstacle Item Mean Score Increased Significantly	+/-	Mean (SD)	Mean (SD)	p	d
Family not accepting what physician tells them about prognosis.	+	3.6 (1.0)	3.9 (1.0)	0.000*	0.233
Visiting hours that are too liberal	+	2.1 (1.7)	2.3 (1.8)	0.019*	0.128
Family not understanding what "life-saving" measures mean	+	3.9 (1.0)	4.0 (1.0)	0.024*	0.123
Obstacle Item Mean Score Decreased Significantly	+/-	Mean (SD)	Mean (SD)	p	d
Poor design of units which no not allow for privacy	-	2.9 (1.6)	2.5 (1.6)	0.000*	0.190
Visiting hours too restrictive	-	1.6 (1.7)	1.0 (1.4)	0.000*	0.443
Patient having pain that is difficulty to control	-	3.0 (1.3)	2.7 (1.3)	0.001*	0.184
No Social Work or Religious	-	2.2 (1.5)	2.0 (1.4)	0.016*	0.130
Continued treatments for dying patient even though treatments cause pain or discomfort	-	3.6 (1.2)	3.4 (1.3)	0.042*	0.111
Family and friends who continually call the nurse for updates	-	4.0 (1.0)	3.9 (1.1)	0.026*	0.142
Physicians who won't allow the patient to die from the disease process	-	3.7 (1.2)	3.5 (1.4)	0.002*	0.201
Physicians who avoid family members	-	4.0 (1.1)	3.8 (1.1)	0.006*	0.171
Nurse opinion is not valued	-	3.5 (1.3)	3.2 (1.4)	0.003*	0.159

*Statistical significance does not denote clinical significance.