

Evaluation of a standardized order form for the withdrawal of life support in the intensive care unit*

Patsy D. Treece, RN, MN; Ruth A. Engelberg, PhD; Lauren Crowley, BA; Jeannie D. Chan, PharmD, MPH; Gordon D. Rubinfeld, MD, MSc; Kenneth P. Steinberg, MD; J. Randall Curtis, MD MPH

Objective: The intensive care unit remains a setting where death is common, and a large proportion of these deaths are preceded by withdrawal of life support. We describe a quality improvement project implementing and evaluating a "withdrawal of life support order form" to improve quality of end-of-life care in the intensive care unit.

Design: Before-after evaluation.

Setting: County-owned, university-operated, tertiary, level I trauma center.

Subjects: Subjects were 143 nurses and 61 physicians.

Interventions: We conducted a before-after evaluation of the order form's implementation. The order form has sections on preparations, sedation/analgesia, withdrawal of mechanical ventilation, and the principles of life support withdrawal. To evaluate the form, we surveyed intensive care unit clinicians regarding satisfaction with the form, measured nurse-assessed quality of dying and death with a 14-item survey (scored 0 for worst possible death to 100 for best possible), and performed chart review to assess narcotic and benzodiazepine use and time from ventilator withdrawal to death.

Measurements and Main Results: We surveyed 143 nurses and 61 physicians about satisfaction with the form. Among nurses reporting that the form was used ($n = 73$), most (84%) reported that the order form was helpful and they were most satisfied with the sedation and mechanical ventilation sections. Almost all phy-

sicians found the form helpful (95%), and >70% of physicians found three of the four sections helpful (sedation, mechanical ventilation, and preparations). We obtained quality of dying and death scores for 41 patient deaths before and 76 deaths after the intervention. These scores did not significantly change (mean preintervention score, 78.3; mean postintervention score, 74.2; $p = .54$) before and after the intervention. Total doses of narcotics and benzodiazepines increased after implementation of the order form in the hour before ventilator withdrawal, the hour after ventilator withdrawal, and the hour before death ($p \leq .03$). There was no change in the median time from ventilator withdrawal to death (preintervention 37 mins, postintervention 39 mins; $p = .49$).

Conclusions: Nurses and physicians found the withdrawal of life support order form helpful. The order form did not improve nurses' assessment of patients' dying experience. Medications for sedation increased during the postorder form period without evidence of significantly hastening death. Although the order form was helpful to clinicians and changed medication delivery, demonstrating clear improvements in quality of dying may require larger sample sizes, more sensitive measures, or more effective interventions. (Crit Care Med 2004; 32:1141-1148)

KEY WORDS: intensive care; critical care; withdrawing life support; end-of-life care; dying; death; palliative care

Approximately half of patients with chronic illness who die in the hospital are cared for in an intensive care unit (ICU) within 3 days of their death (1), and a recent study of five states in the United States suggests that almost 20% of all deaths occur in the ICU (2). Throughout

North America and Europe, the majority of deaths in ICU are preceded by withholding or withdrawing life-sustaining therapies (3-12). Therefore, the ICU is a setting where death is common and where withdrawal of life-sustaining treatments is an important component of overall quality of care. However, some studies suggest that the quality of end-of-life care is suboptimal in the ICU, especially concerning management of symptoms (1, 13, 14) and communication with patients and families (15). There are also indirect indicators that the quality of end-of-life care in the ICU is not uniformly good (16). Critical care nurses express frustration with the end-of-life care provided by physicians (17, 18) and demonstrate much higher levels of dissatisfaction than physicians with the end-of-

life care in the ICU (19). Finally, family members report a number of physician and nursing behaviors that made families feel excluded or increased their burden after a loved one died in the ICU (20). These data provide some evidence that end-of-life care in the ICU is an important target for quality improvement efforts. Despite these data, there are relatively few studies demonstrating ways to improve this care.

The SUPPORT study attempted to improve end-of-life care for seriously ill patients and their families (1). This randomized trial showed no benefit associated with using trained study nurses to provide prognostic data to patients, families, and physicians, identifying patient preferences for end-of-life care, providing this information to phy-

*See also p. 1230.

From the Division of Pulmonary and Critical Care, Department of Medicine (PDT, RAE, LC, GDR, KPS, JRC), and the Department of Pharmacy (JDC), Harborview Medical Center, University of Washington, Seattle, WA.

Supported, in part, by a grant from the Greenwall Foundation and by grant R01NR05226 from the National Institute of Nursing Research.

Copyright © 2004 by the Society of Critical Care Medicine and Lippincott Williams & Wilkins

DOI: 10.1097/01.CCM.0000125509.34805.0C

sicians, and facilitating communication between patients, families, and clinicians. Although there have been a number of suggestions as to why the SUPPORT study did not show a benefit of the intervention, a leading hypothesis is that the intervention did not influence the systems of care at the target institutions (21, 22). Systems of care that focus on high-quality patient- and family-centered end-of-life care are important to patients and their families (23). Interventions to improve systems of care at institutions are not easily amenable to randomized controlled trials, since the unit of randomization and target of the intervention must often be the institution. Therefore, quality improvement projects at single institutions may provide some insight into ways to improve end-of-life care in the ICU and serve as a precursor to randomized trials (24–26).

We conducted a quality improvement project at our institution to implement and evaluate a standardized order form regarding withholding and withdrawing life support. Our hypotheses were that the order form, if successful, would achieve high levels of satisfaction from physicians and nurses, would be associated with increased quality of dying and death, and would result in increased use of narcotics and benzodiazepines without a decrease in the time from withdrawal of the ventilator to death.

METHODS

We conducted a before-after study of an intervention designed to improve the quality of end-of-life care in the ICU setting. The setting was a county-owned, university-operated, tertiary, level I trauma center in Seattle, WA. The hospital has 353 total beds and 65 ICU beds located in six physically distinct ICUs. The intervention was the development and implementation of a standardized order form for the withdrawal of life support in the circumstance where the patient was expected to die. The order form was evaluated in three ways. First, we assessed physician and nurse satisfaction with the order form after implementation. Second, we assessed the nursing perspective on the “quality of dying and death” before and after the intervention using an adaptation of the previously validated “quality of dying and death” questionnaire (27, 28). Finally, we conducted a chart review of patients before and after the intervention to assess the dose of narcotics and benzodiazepines used during the 1 hr before and after withdrawal of mechanical ventilation and 1 hr before death and also to measure the time between with-

drawal of mechanical ventilation and death. The Institutional Review Board reviewed this project and determined it to be exempt from requirements for written consent because it represented a quality improvement project and data were collected in a way such that patients and clinicians could not be identified after completion of data collection.

Development and Implementation of the Withdrawal of Life Support Order Form

We formed a task force of critical care nurses, physicians, social workers, and pharmacists to design a standardized order form that provided guidance for withdrawing life support. The orders were based on principles and recommendations from a textbook on the topic (29). The task force developed a two-page order form document (see Appendix 1; also available at <http://depts.washington.edu/eolcare>). The first page contains three sections and the first section includes “preparations” (items such as discontinue all previous orders including medications and routine tests; remove all devices not aimed at increasing patient comfort such as cardiac monitors, blood pressure cuffs, and sequential compression devices; complete do-not-resuscitate orders; and document discussions with family). The second section contains guidelines for the administration of narcotics and benzodiazepines. The guidelines provide for titration of medications as needed for comfort with orders for continuous infusion and boluses as needed and with no maximum dose. The third section provides guidelines for rapid removal of the ventilator while titrating sedation and analgesia to maintain patient comfort. The second page contains the principles that support the orders on the front page.

The order form was presented at several forums within the hospital for feedback from a multidisciplinary group. Suggestions were incorporated in the order form, and the Ethics Committee and the Critical Care Advisory Committee reviewed and approved the final form. Once the order form was approved, a staff nurse was trained by the investigators to educate the ICU nurses about the withdrawal of life support orders and conducted in-service training regarding the use of the orders in all units on all shifts to reach as many staff nurses as possible. The training consisted of reviewing the order form and the rationale for each of the sections.

Evaluation of the Order Form

Pre- and Postintervention Patient Sample. Based on sample size calculations described subsequently, we anticipated needing approx-

imately 50–60 patients in both the pre- and postintervention periods. All patients ($n = 178$) who died in the ICUs of Harborview Medical Center during the preorder form implementation period of June to August 2000 and the postorder form implementation period of July to November 2001 were screened for eligibility. To ensure comparability between both pre- and postintervention periods, we excluded patients who were not likely to have had the opportunity to receive the order form. This included patients who were brain dead (preintervention, $n = 10$; postintervention, $n = 19$), patients who were not on ventilators (preintervention, $n = 4$; postintervention, $n = 6$), and patients who died while receiving cardiopulmonary resuscitation (preintervention, $n = 11$; postintervention, $n = 11$). A total of 41 patients were included for the preintervention period, and 76 patients were included in the postintervention period.

Clinician Satisfaction. To assess the opinions of physicians and nurses, we conducted a survey of satisfaction with the order form. After implementation of the order form, we attached a five-item survey to the order form asking for overall satisfaction with the order form as well as satisfaction with each of the four sections of the form. The survey was accompanied by a letter from investigators asking all physicians who used the order form to complete the survey. This survey was developed specifically to assess satisfaction with the order form (questions available from authors). To assess the nursing perspective, we surveyed a consecutive sample of nurses caring for patients who died in the ICU after implementation of the form. If the withdrawal of life support order form was used for a patient, the nurse caring for the patient at the time of the patient’s death was asked to complete the same five-item survey assessing overall satisfaction with the form as well as its four components.

Nurse Assessment of the Quality of Dying and Death. A 31-item Quality of Death and Dying (QODD) questionnaire was developed for assessing the quality of the dying experience from the perspective of family members and clinicians (27). The family-assessed QODD has been validated in a study of 204 deaths in Missoula County and was shown to have good internal consistency (Cronbach’s alpha .86) and construct validity, correlating significantly with measures of symptom burden, patient-clinician communication about treatment preferences, and several measures of quality of care (28). Similarly, the QODD was shown to correlate with other markers of quality of care in a study of 100 patients in hospice (30). We conducted a focus group of six ICU nurses to adapt the instrument for use by nurses in the ICU. The ICU nurses believed that a number of items were not applicable to nurse-assessment in the ICU setting. The 18 items ICU nurses felt unable to rate were removed from the survey. An example of one of the eliminated items was, “How important was

it to your patient that he/she spent time with his/her pet?" Based on this focus group, we also added an item about the patient's experience with sedation in the ICU. This version of the QODD, like the full 31-item version, has a total score from 0 to 100 where 0 represents the worst death possible and 100 represents the best death possible. In this current study, we did not administer the QODD to physicians. An adaptation of the QODD specifically for use with patients dying in the ICU is available from the authors (<http://depts.washington.edu/eolcare>) and contains all 14 items used in this study.

Chart Abstraction and Assessment of Narcotic and Benzodiazepine Use. Chart abstraction was conducted using a standardized chart abstraction form. Basic demographic characteristics (age, gender, race) and clinical information (ICU diagnoses, Glasgow Coma Scale score, ICU length of stay, and intravenous narcotic and sedative drugs used 24 hrs before death) were collected by a trained chart abstractor. Based on a study that compiled a relative potency scale for benzodiazepines and opiates (31), opiate doses (fentanyl and morphine) were compared according to a dose-equivalent conversion factor of 15 µg of fentanyl to 1 mg of morphine. Lorazepam and midazolam were compared based on a dose-equivalent conversion factor of 2.5 mg of midazolam to 1 mg of lorazepam. Cumulative amounts of benzodiazepines and narcotics were calculated during three time periods: the hour before ventilator withdrawal, the hour after ventilator withdrawal, and the hour before death. If the patient survived <1 hr after ventilator withdrawal, cumulative medication use during the time the patient survived was expressed. We chose the time periods surrounding mechanical ventilation to minimize the potential confounding that might occur if patients who >1 hr after withdrawal of mechanical ventilation require increasing doses of narcotics or benzodiazepines due to drug tolerance.

Statistical Analyses

Satisfaction with the order form was expressed as the proportion of clinicians reporting that the form was helpful with 95% confidence intervals. For all other analyses, we compared data from the preorder form period to the data from the postorder form period and set statistical significance at a two-tailed $p \leq .05$. Comparisons of the QODD total score during the pre and post periods were conducted using the Student's *t*-test without equal variance assumption. Not all patients in the postorder period had orders completed, but we analyzed all patients to avoid selection bias introduced by examining only patients in the postorder period for whom orders were used. Comparisons of time from ventilator withdrawal to death were analyzed using Mann-Whitney test to account for the non-

parametric distribution. Comparisons between hourly medication dosages at different stages of life support withdrawal were analyzed using linear regression with robust variance estimates to account for the nonparametric drug dose data but also to allow controlling for potential confounding variables including ICU service and proportion of patients unresponsive before death.

Power Calculations

The power was calculated based on a previous study using the QODD (28). Although the minimally important difference has not been defined for this instrument, we used a difference of 7 points that is based on the difference seen between patients who died in their place of choice compared with those who died in locations other than their place of choice (28). Based on the SD seen in prior studies (28) and using a two-tailed alpha of .05 and a beta of .2, we estimated that we would need 50–60 patients in each group.

RESULTS

A multidisciplinary team developed the order form between May 2000 and May 2001. The implementation occurred during a 5-month period from July 2001 to November 2001. The preorder form assessment period was between June 2000 and August 2000, and the postorder form evaluation period was between July 2001 and November 2001. The evaluation of the order form was based on 41 deaths in the preorder form period and 76 deaths in the postorder form period. The demographic characteristics of these groups are shown in Table 1. There were no significant differences in patient demographics between the pre and post groups. The patients were predominantly Caucasian. The majority of patients in both groups were unresponsive at the time of death, although a slightly higher proportion were unresponsive in the preorder form group. The ICU length of stay was not significantly different between the groups. Of the 76 patients in the postorder form period, 54 patients (71%) had the withdrawal of life support order form used.

Clinician Satisfaction

Sixty-one physicians and 73 nurses returned questionnaires assessing satisfaction with orders. All respondents reported high levels of satisfaction with the order form. Overall, 60 of 61 (98%) physicians using the form and returning the

attached survey reported that the order form was helpful. Among the nurses caring for a patient when the withdrawal of life support order form was used, 61 of 73 (84%) reported that the order form was helpful. As shown in Table 2, the majority of physicians found three of the four sections of the order form helpful, whereas the majority of nurses found only the sedation and analgesia section helpful.

Quality of Dying and Death

Neither the total score nor individual items on the 14-item QODD were significantly different between the pre- and postorders period for either the full sample or the subsample with completed orders. During the preorder period, the mean total score of the 14-item QODD was 78.3 (SD = 16.7). During the postorder period, the mean total score was 74.2 (SD = 21.7) for the full sample and 78.9 (SD = 18.7) for the subsample with order form used ($p = .54$ comparing preorders and full sample postorders). We conducted multivariate analyses to determine whether differences in the characteristics in Table 1 (ICU service or proportion of patients unresponsive before death) might confound a relationship between pre- or postorder period, but there remained no difference in the 14-item QODD scores between the pre- and postorder form periods (analyses not shown). *Post hoc* power calculations suggest we had an 80% power to detect a 10-point difference in the 14-item QODD total score, a greater difference than the targeted 7-point difference.

Narcotic and Benzodiazepine Use

The mean doses of narcotics and benzodiazepines during the hour before death increased significantly after implementation of the order form ($p \leq .01$, Table 3). The use of narcotics and benzodiazepines was significantly higher after implementation of the order form for both the 1 hr before and the 1 hr after withdrawal of mechanical ventilation ($p < .03$, Table 3). There was no statistically or clinically significant difference in the median time from withdrawal of mechanical ventilation to death between the time period before implementation of the order form and the time period after implementation ($p = .49$). There was also no change in these associations after we controlled for differences in characteristics in Table 1.

Table 1. Demographic characteristics of patients during the periods before and after implementation of the withdrawal of life support order form

	Preorders (n = 41)	Postorders (n = 76)	p Value
Average age, mean (SD) ^a	57.1 (19.4)	59.3 (19.2)	.56
Male, % (n) ^b	61.0 (25)	56.6 (43)	.70
Race, % (n) ^b			
White	75.6 (31)	81.6 (62)	.45
African-American	7.3 (3)	7.9 (6)	.92
Hispanic	4.9 (2)	2.6 (2)	.52
Asian, Pacific Islander	2.4 (1)	1.3 (1)	.65
Native American	4.9 (2)	3.9 (3)	.80
Service, % (n) ^b			.17
MICU	17.1 (7)	35.5 (27)	
CCU	2.4 (1)	6.6 (5)	
Neurology	7.3 (3)	6.6 (5)	
Neurosurgery	53.7 (22)	31.6 (24)	
General surgery/trauma	9.8 (4)	13.2 (10)	
Burns/plastics	4.9 (2)	3.9 (3)	
Unresponsive just before death, % (n) ^b	95.1 (39)	85.5 (65)	.09
ICU diagnosis, % (n) ^a			
Intracranial hemorrhage	36.6 (15)	32.9 (25)	.69
Trauma	31.7 (13)	27.6 (21)	.64
Acute renal failure	22.0 (9)	27.6 (21)	.50
Sepsis/septic shock	17.1 (7)	9.2 (7)	.21
Myocardial infarction	12.2 (5)	13.2 (10)	.88
Congestive heart failure	9.8 (4)	7.9 (6)	.73
Stroke	9.8 (4)	5.3 (4)	.36
Pneumonia	7.3 (3)	18.4 (14)	.10
ARDS	7.3 (3)	11.8 (9)	.44
Hepatic failure	7.3 (3)	9.2 (7)	.73
Perforation/rupture	7.3 (3)	5.3 (4)	.66
Post cardiac arrest	7.3 (3)	5.3 (4)	.66
Gastrointestinal bleed	4.9 (2)	7.9 (6)	.54
Burn	4.9 (2)	3.9 (3)	.81
Cardiogenic shock	2.4 (1)	5.3 (4)	.47
COPD	2.4 (1)	1.3 (1)	.66
Anoxic brain injury	2.4 (1)	6.6 (5)	.33
Other	2.4 (1)	3.9 (3)	.67
Hospital length of stay, median (IQR) ^a	3.0 (1.5–9.5)	5.0 (1.0–14.5)	.32
Unit length of stay, median (IQR) ^a	2.0 (1.0–6.0)	4.0 (1.0–10.0)	.10

MICU, medical intensive care unit; CCU, critical care unit; ICU, intensive care unit; ARDS, acute respiratory distress syndrome; COPD, chronic obstructive pulmonary disease; IQR, interquartile range.

^aFrom medical records data; diagnoses sum to >100% and *p* values reported for each diagnosis because patients could have more than one diagnosis; ^bfrom nurse survey data.

Table 2. Proportion of clinicians reporting that the withdrawal of life support order form was helpful and which sections were helpful

	Physicians (n = 61)	Nurses (n = 73)
Overall, were the orders helpful?	98 (95–100)	84 (76–92)
Which sections were helpful?		
Preparations	71 (60–82)	36 (25–47)
Sedation and analgesia	93 (87–99)	70 (59–81)
Termination of mechanical ventilation	79 (69–89)	44 (33–55)
Principles of withdrawing life support	46 (33–59)	6 (1–11)

Values are percent (95% confidence interval).

DISCUSSION

This quality improvement project suggests that the implementation of a withdrawal of life support order form in our

institution was associated with high levels of clinician satisfaction with the order form and an increase in the use of narcotics and benzodiazepines without a significant decrease in the time from with-

Implementation of a withdrawal of life support order form in our institution was associated with high levels of physician and nurse satisfaction with the form overall and increased use of narcotics and benzodiazepines during withdrawal of life support without a decrease in the time from withdrawal of mechanical ventilation to death.

drawal of mechanical ventilation to death. There has been increasing interest in identifying system-level changes that can improve the quality of end-of-life care in the ICU setting as evidenced by recent requests for proposals (32) and editorial comments (33). Two recent studies have suggested that implementation of policies for routine ICU family conferences or routine palliative care consultation in the ICU can improve end-of-life care in the ICU and thereby reduce ICU length of stay for those patients who will ultimately die (24–26). Although ICU length of stay is a relatively crude measure of quality end-of-life care, these two before-after studies have highlighted potential ways to improve care in the ICU and have provided direction for future research. In this report, we describe a quality improvement project implementing a standardized order form for withdrawing life support that also identifies a potential way to improve care in the ICU and provides direction for future research.

The evaluation of this system-level intervention was conducted in several ways. Clinician satisfaction with the order form overall was high, although there is no way to accurately compare these satisfaction ratings with other interventions since the questions were specific to this intervention. Since the primary purpose of this project was to implement a pro-

Table 3. Mean narcotic and benzodiazepine dose in the 1 hr before death in all patients and the 1 hr before and after withdrawal of mechanical ventilation for patients undergoing mechanical ventilation at the time of withdrawal of life support

	Preorders	Postorders	<i>p</i> Value
All patients	n = 41	n = 76	
Narcotic dose 1 hr before death, mean mg (SD) [range]	8.6 (12.51) [0,60]	18.5 (27.58) [0,142]	.001
Benzodiazepine dose 1 hr before death, mean mg (SD) [range]	0.6 (1.74) [0,8]	4.9 (9.30) [0,39]	.0002
Patients undergoing mechanical ventilation at time of withdrawal of life support	n = 28	n = 58	
Narcotic dose 1 hr before ventilator withdrawal, mean mg (SD) [range]	3.3 (4.34) [0,17]	7.6 (12.99) [0,54]	.03
Narcotic dose 1 hr after ventilator withdrawal, mean mg (SD) [range]	5.2 (7.70) [0,34]	12.3 (21.29) [0,108]	.03
Benzodiazepine dose 1 hr before ventilator withdrawal, mean mg (SD) [range]	0.1 (0.45) [0,2]	1.5 (3.88) [0,20]	.02
Benzodiazepine dose 1 hr after ventilator withdrawal, mean mg (SD) [range]	0.4 (1.34) [0,6]	3.2 (8.60) [0,20]	.02
Median time to death after ventilator withdrawal, mins (IQR)	37 (19–70)	39 (13–190)	.49

IQR, interquartile range.

cess of quality improvement regarding withdrawal of life support in the ICU, this study suggests that implementation and evaluation of an order form concerning withdrawal of life support are feasible and are found helpful by most ICU clinicians. However, we were unable to demonstrate that this order form was associated with improved nurse-assessment of quality of the dying experience as assessed by this adapted 14-item QODD instrument. We cannot determine, based on this study, whether the intervention was ineffective or whether the outcome instrument was not sensitive enough to detect an effect. Future studies are needed to differentiate these possibilities.

We also examined narcotic and benzodiazepine usage and found a significant increase in the use of both narcotics and benzodiazepines after implementation of the order form. These differences in drug use were not associated with a significant difference in the time from withdrawal of mechanical ventilation to death. These findings suggest that patients received increased use of sedatives to achieve comfort, but this increased sedative use was not associated with significantly hastened death. However, since we did not assess patient comfort, we cannot show that increased narcotic or benzodiazepine use was associated with increased comfort. Although the principle of double effect might be used to rationalize a decrease in time to death for an individual patient (34), we believe that the absence of a reduction in time to death provides some assurance that these orders were not used in a systematic way to hasten death. The medication dosages and ranges we document are similar to findings from earlier

studies regarding analgesic and sedative use during withdrawal of life support suggesting that practice in our institution is similar to that in other institutions, although there is tremendous variability in the range of these medications (8, 31, 35). It is interesting to note that the variation of medication use seems to increase after order implementation, as evidence by the SD and the range. Although protocols often decrease variability, this may be a circumstance where the protocol facilitates use of the doses necessary to control symptoms for individual patients resulting in an increase in variability because individual patients' needs are highly variable.

There are a number of important limitations of this study. First, a before-after design is subject to a number of potential biases and confounding factors such as temporal changes. For example, if educational efforts occurring independently of the order form resulted in increased awareness of the importance of treating pain and anxiety during withdrawal of life support, it is possible the increased doses of narcotics or benzodiazepines may have been due to this education rather than the order form and education associated with it. Although integrating palliative care into the critical care unit has become a focus at our institution, systematic educational efforts in this regard started after the data collection for this quality improvement project was completed. Nonetheless, this limitation regarding temporal trends cannot be adequately addressed in a single-center quality improvement project. A randomized, controlled trial of such an order form would require many institutions. This before-after design also does not allow us to differenti-

ate the effect of the order form, the implementation of the order form, and the evaluation of the order form. A second limitation is the relatively small sample size. We had intended to power this study to find a difference of 7 in the QODD score; however, implementation of the order form occurred before obtaining our target QODD questionnaires and as a result we were actually powered to find a 10-point difference in the QODD score. The absolute difference between the pre and post group was 4.1, and therefore the study was underpowered to determine whether this difference was significant. A third limitation of this study was that we used clinician satisfaction with the order form and clinician assessment of the quality of dying and death. Improvements in clinician satisfaction may not be associated with improvements in family satisfaction or patient experience as outcome measures. Future studies are needed to assess the association between clinician assessments of quality of care or quality of dying and death and assessments of patients or families. A fourth limitation of conducting this quality improvement project at a single site is that this approach limits the generalizability of the findings. This project was conducted as a quality improvement effort and is reported not to suggest that the findings are generalizable to other institutions but rather to provide a model for how such a quality improvement project might be conducted at other institutions. Finally, if the baseline quality of end-of-life care in our institution were unusually high, we might be limited in our ability to demonstrate an effective intervention because of a ceiling effect. Although this is an important theoretical concern, we believe there is room to

improve the quality of end-of-life care in all institutions.

CONCLUSION

Implementation of a withdrawal of life support order form in our institution was associated with high levels of physician and nurse satisfaction with the form overall and increased use of narcotics and benzodiazepines during withdrawal of life support without a decrease in the time from withdrawal of mechanical ventilation to death. Despite these effects, we found no change in the nurse-assessed quality of dying and death. Demonstration of improved quality of dying and death may require more effective interventions or more sensitive outcome measures. Nonetheless, the clinician satisfaction and drug use data suggest that system-level changes such as the implementation of a withdrawal of life support order form offer an opportunity to improve the quality of end-of-life care provided in the ICU.

REFERENCES

1. The SUPPORT Principal Investigators. A controlled trial to improve care for seriously ill hospitalized patients: The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). *JAMA* 1996; 274:1591–1598
2. Angus DC, Barnato AE, Linde-Zwirble W, et al: Use of intensive care at the end of life in the United States: An epidemiologic study. *Crit Care Med* 2004; 32:638–643
3. Prendergast TJ, Luce JM: Increasing incidence of withholding and withdrawal of life support from the critically ill. *Am J Respir Crit Care Med* 1997; 155:15–20
4. Faber-Langendoen K: A multi-institutional study of care given to patients dying in hospitals. Ethical practices and implications. *Arch Intern Med* 1996; 156:2130–2136
5. Smedira NG, Evans BH, Grais LS, et al: Withholding and withdrawal of life support from the critically ill. *New Engl J Med* 1990; 322:309–315
6. Vincent JL, Parquier JN, Preiser JC, et al: Terminal events in the intensive care unit: Review of 258 fatal cases in one year. *Crit Care Med* 1989; 17:530–533
7. Eidelman LA, Jakobson DJ, Pizov R, et al: Foregoing life-sustaining treatment in an Israeli ICU. *Intensive Care Med* 1998; 24:162–166
8. Keenan SP, Busche KD, Chen LM, et al: A retrospective review of a large cohort of patients undergoing the process of withholding or withdrawal of life support. *Crit Care Med* 1997; 22:1020–1025
9. Koch K: Changing patterns of terminal care management in an intensive care unit. *Crit Care Med* 1994; 22:233–243
10. Vernon DD, Dean JM, Timmons OD, et al: Modes of death in the pediatric intensive care unit: Withdrawal and limitation of supportive care. *Crit Care Med* 1993; 21:1798–1802
11. Youngner SJ, Lewandowski W, McClish DK, et al: Do not resuscitate orders: Incidence and implications in a medical intensive care unit. *JAMA* 1985; 253:54–57
12. Bedell SE, Pelle D, Maher PL, et al: Do not resuscitate orders for critically ill patients in the hospital: How are they used and what is their impact? *JAMA* 1986; 256:233–237
13. Desbiens NA, Wu AW: Pain and suffering in seriously ill hospitalized patients. *J Am Geriatr Soc* 2000; 48:S183–S186
14. Nelson JE, Meier D, Oei EJ, et al: Self-reported symptom experience of critically ill cancer patients receiving intensive care. *Crit Care Med* 2001; 29:277–282
15. Hofmann JC, Wenger NS, Davis RB, et al: Patients' preferences for communication with physicians about end-of-life decisions. *Ann Int Med* 1997; 127:1–12
16. Christakis NA, Asch DA: Biases in how physicians choose to withdraw life support. *Lancet* 1993; 342:642–646
17. Asch DA, DeKay ML: Euthanasia among US critical care nurses: Practices, attitudes, and social and professional correlates. *Med Care* 1997; 35:890–900
18. Asch DA, Shea JA, Jedrzejewski MK, et al: The limits of suffering: Critical care nurses' views of hospital care at the end of life. *Soc Sci Med* 1997; 45:1661–1668
19. Ferrand E, Lemaire F, Regnier B, et al: Discrepancies between perceptions by physicians and nursing staff of intensive care unit end-of-life decisions. *Am J Respir Crit Care Med* 2003; 167:1310–1315
20. Tilden VP, Tolle SW, Garland MJ, et al: Decisions about life-sustaining treatment: Impact of physicians' behaviors on the family. *Arch Intern Med* 1995; 155:633–638
21. Lynn J, Arkes HR, Stevens M, et al: Rethinking fundamental assumptions: SUPPORT's implications for future reform. *J Am Geriatr Soc* 2000; 48:S214–S221
22. Lo B: Improving care near the end of life: Why is it so hard? *JAMA* 1995; 274:1634–1636
23. Carline JD, Curtis JR, Wenrich MD, et al: Physicians' interactions with health care teams and systems in the care of dying patients: Perspectives of dying patients, family members, and health care providers. *J Pain Symptom Manage* 2002, In Press
24. Campbell ML, Guzman JA: Impact of a proactive approach to improve end-of-life care in a medical ICU. *Chest* 2003; 123:266–271
25. Lilly CM, De Meo DL, Sonna LA, et al: An intensive communication intervention for the critically ill. *Am J Med* 2000; 109:469–475
26. Lilly CM, Sonna LA, Haley KJ, et al: Intensive communication: Four-year follow-up from a clinical practice study. *Crit Care Med* 2003; 31:S394–S399
27. Patrick DL, Engelberg RA, Curtis JR: Evaluating the quality of dying and death. *J Pain Symptom Manage* 2001; 22:717–726
28. Curtis JR, Patrick DL, Engelberg RA, et al: A measure of the quality of dying and death: Initial validation using after-death interviews with family members. *J Pain Symptom Manage* 2002; 24:17–31
29. Rubenfeld GD, Crawford S. Principles and practice of withdrawing life-sustaining treatments in the ICU. In: *Managing Death in the Intensive Care Unit: The Transition From Cure to Comfort*. Curtis JR, Rubenfeld GD (Eds). New York, Oxford University Press, 2001, pp 127–148
30. Patrick DL, Curtis JR, Engelberg RA, et al: Measuring and improving the quality of dying and death. *Ann Intern Med* 2003; 139:410–415
31. Wilson WC, Smedira NG, Fink C, et al: Ordering and administration of sedatives and analgesics during the withholding and withdrawal of life support from critically ill patients. *JAMA* 1992; 267:949–953
32. Robert Wood Johnson Foundation. Available at: <http://www.promotoingexcellence.com>. Accessed 2003
33. Morris AH: Perceptions, confessions: A systems response is needed. *Am J Respir Crit Care Med* 2003; 167:1302–1303
34. Sulmasy DP, Pellegrino ED: The rule of double effect: Clearing up the double talk. *Arch Int Med* 1999; 159:545–550
35. Hall RI, Rocker GM: End-of-life care in the ICU: Treatments provided when life support was or was not withdrawn. *Chest* 2000; 118:1424–1430

APPENDIX 1.

DATE	TIME	ADMITTING SERVICE/ATTENDING
------	------	-----------------------------

Complete the following:

- Do Not Attempt Resuscitation (DNAR) order written
- Note written in chart that documents rationale for comfort care, discussions with attending and discussions with family (or attempts to contact family)
- 1) Discontinue all previous orders including routine vital signs, medication, enteral feeding, intravenous drips, radiographs, laboratory tests. See below for new orders.
- 2) Remove devices not necessary for comfort including monitors, blood pressure cuffs, and leg compression sleeves. See below for orders related to the ventilator.
- 3) Remove all devices (cardiac output computer, transfusers, defibrillator, intra-aortic balloon pump, ventricular assist device, temporary pacemaker) from ICU room.
- 4) Liberalize visitation.

SEDATION AND ANALGESIA:

- 5) Select one:
 - Morphine drip at current rate (assuming patient comfortable at that dose) or 10 mg/hr or _____ mg/hr
For signs of discomfort, up to Q 15 min, give additional morphine equal to current hourly drip rate and increase drip by 25%
 - Fentanyl drip at current rate (assuming patient comfortable at that dose) or 100 ug/hr or _____ ug/hr
For signs of discomfort, up to Q 15 min, give additional fentanyl equal to current hourly drip rate and increase drip by 25%
 - Other narcotic: _____
- 6) Select one:
 - Lorazepam drip at current rate (assuming patient comfortable at that dose) or 5 mg/hr or _____ mg/hr
For signs of discomfort, up to Q 15 min, give additional lorazepam equal to current hourly drip rate and increase drip by 25%
 - Midazolam drip at current rate (assuming patient comfortable at that dose) or 10 mg/hr or _____ mg/hr
For signs of discomfort, up to Q 15 min, give additional midazolam equal to current hourly drip rate and increase drip by 25%
 - Other benzodiazepine, barbiturate, or propofol: _____

VENTILATOR:

- 7) Initial ventilator setting: IMV rate _____, PS level _____, (Choose IMV or PS not a combination), F_iO₂ _____, PEEP _____.
- 8) Reduce apnea, heater, and other ventilator alarms to minimum setting.
- 9) Reduce F_iO₂ to room air and PEEP to zero over about 5 minutes and titrate sedation as indicated for discomfort.
- 10) As indicated by level of discomfort, wean IMV to 4 or PS to 5 over 5 to 20 minutes and titrate sedation as indicated for discomfort.
- 11) When patient is comfortable on IMV rate 4 or PS of 5, select one:
 - Extubate patient to air
 - T-piece with air (not CPAP on ventilator)

PHYSICIAN SIGNATURE	DATE:	TIME:	RN's SIGNATURE	DATE	TIME
M.D.			R.N.		

PT.NO.

NAME

D.O.B

UNIVERSITY OF WASHINGTON MEDICAL CENTERS
HARBORVIEW MEDICAL CENTER – UW MEDICAL CENTER
SEATTLE, WASHINGTON

COMFORT CARE ORDERS FOR THE WITHDRAWAL OF LIFE SUPPORT IN ADULTS IN THE ICU

DATE	TIME	
------	------	--

PRINCIPLES FOR WITHHOLDING AND WITHDRAWING LIFE SUSTAINING TREATMENT

- 1) Death occurs as a complication of the underlying disease. The goal of the comfort care outlined on the reverse is to relieve suffering in a dying patient not to hasten death.
- 2) Withdrawal of life sustaining treatment is a medical procedure that requires the same degree of physician participation and quality as other procedures.
- 3) Actions solely intended to hasten death (for example, high doses of potassium or paralytic drugs) are morally unacceptable, however, any dose of pain relieving medication can be used when required to provide comfort even if these doses may hasten death.
- 4) Withholding treatments is morally and legally equivalent to withdrawing them.
- 5) When one life sustaining treatment is withheld, strong consideration should be given to withdrawing other current life sustaining treatments and changing the goals of care to comfort.
- 6) Any treatment can be withdrawn including nutrition, fluids, antibiotics, and blood.
- 7) Assessing pain and discomfort in intubated, critically ill, patients can be difficult. The following should be assessed and documented in the medical record when increasing sedation: tachypnea, tachycardia, diaphoresis, grimacing, accessory muscle use, nasal flaring, and restlessness.
- 8) Concerns about hastening death by over-sedating patients are understandable. However, clinicians should be extremely sensitive to the difficulties of assessing discomfort in critically ill patients and should know that many patients develop tolerance to sedative medication. Therefore, clinicians should be wary of under-treating discomfort during the withdrawal of life sustaining treatments in the ICU.
- 9) Brain dead patients do not need sedation during the withdrawal of life sustaining treatment.
- 10) Patients should not have life support withdrawn while receiving paralytic drugs as these will mask signs of discomfort. Life support can be withdrawn from patients after paralytic drugs have been stopped as long as clinicians feel that the patient has sufficient motor activity to demonstrate discomfort.

PHYSICIAN SIGNATURE	DATE	TIME	RN'S SIGNATURE	DATE	TIME
M.D.			R.N.		

PT. NO.

NAME

D.O.B

UNIVERSITY OF WASHINGTON MEDICAL CENTERS
HARBORVIEW MEDICAL CENTER – UW MEDICAL CENTER
SEATTLE, WASHINGTON

COMFORT CARE ORDERS FOR THE WITHDRAWAL OF LIFE SUPPORT IN ADULTS IN THE ICU