



## Quality of End-of-Life Communication in Two High-Risk ICU Cohorts: A Retrospective Cohort Study

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Abstract:	<p><b>Background:</b> Identifying factors that influence the quality of end-of-life communication is relevant to improving end-of-life care; yet little is known of them. In this study, we assessed the quality of end-of-life communication and influencing factors in two intensive care unit (ICU) cohorts at high risk of death: nursing home (NH) patients, and those on extracorporeal membrane oxygenation (ECMO).</p> <p><b>Methods:</b> This retrospective cohort study used the clinical ICU database for Winnipeg, Manitoba, Canada, and manual chart review, including admissions 2000-2017 to four ICUs. There were 230 patients in the NH cohort, and 109 in the ECMO cohort. Quality of end-of-life communication was assessed using 18 previously described, binary quality indicators to calculate a weighted, scaled, composite score, ranging 0-100. We used median regression to identify factors associated with the composite score.</p> <p><b>Results:</b> The ECMO cohort was younger than the NH cohort, with longer hospital length of stay and higher disease severity. Composite scores for quality of end-of-life communication were extremely low; (mean±SD) 48.5±1.7 for the NH cohort, 49.1±2.5 for the ECMO cohort. Patient characteristics associated with higher composite scores were older age (5.0 per decade, 95% C.I. 2.1-7.8) and lower (worse) Glasgow Coma Scale score (1.8 per GCS point, 95% CI 0.5-3.2). The composite score also rose significantly over time (1.7 per year, 95% CI 0.5-2.8).</p> <p><b>Interpretation:</b> In addition to again demonstrating poor quality of end-of-life communication in ICUs, we have identified that factors associated with better prognosis are also associated with worse end-of-life communication.</p>

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STROBE Statement—Checklist of items that should be included in reports of *cohort studies*

	Item No	Recommendation	Page No
<b>Title and abstract</b>	1	(a) Indicate the study's design with a commonly used term in the title or the abstract	1
		(b) Provide in the abstract an informative and balanced summary of what was done and what was found	2
<b>Introduction</b>			
Background/rationale	2	Explain the scientific background and rationale for the investigation being reported	3
Objectives	3	State specific objectives, including any prespecified hypotheses	3
<b>Methods</b>			
Study design	4	Present key elements of study design early in the paper	
Setting	5	Describe the setting, locations, and relevant dates, including periods of recruitment, exposure, follow-up, and data collection	4
Participants	6	(a) Give the eligibility criteria, and the sources and methods of selection of participants. Describe methods of follow-up	4
		(b) For matched studies, give matching criteria and number of exposed and unexposed	n.a.
Variables	7	Clearly define all outcomes, exposures, predictors, potential confounders, and effect modifiers. Give diagnostic criteria, if applicable	5-6
Data sources/ measurement	8*	For each variable of interest, give sources of data and details of methods of assessment (measurement). Describe comparability of assessment methods if there is more than one group	4
Bias	9	Describe any efforts to address potential sources of bias	n.a.
Study size	10	Explain how the study size was arrived at	4
Quantitative variables	11	Explain how quantitative variables were handled in the analyses. If applicable, describe which groupings were chosen and why	5
Statistical methods	12	(a) Describe all statistical methods, including those used to control for confounding	6
		(b) Describe any methods used to examine subgroups and interactions	6
		(c) Explain how missing data were addressed	7
		(d) If applicable, explain how loss to follow-up was addressed	n.a.
		(e) Describe any sensitivity analyses	6
<b>Results</b>			
Participants	13*	(a) Report numbers of individuals at each stage of study—eg numbers potentially eligible, examined for eligibility, confirmed eligible, included in the study, completing follow-up, and analysed	7 Table 1
		(b) Give reasons for non-participation at each stage	7
		(c) Consider use of a flow diagram	n.a.
Descriptive data	14*	(a) Give characteristics of study participants (eg demographic, clinical, social) and information on exposures and potential confounders	Table 1
		(b) Indicate number of participants with missing data for each variable of interest	n.a.
		(c) Summarise follow-up time (eg, average and total amount)	n.a.
Outcome data	15*	Report numbers of outcome events or summary measures over time	

1	Main results	16	(a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates and their precision (eg, 95% confidence interval). Make clear which confounders were adjusted for and why they were included	7 Table2 Table3
2			(b) Report category boundaries when continuous variables were categorized	n.a.
3			(c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period	n.a.
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9	Other analyses	17	Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses	7 Table2 Table3
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12	<b>Discussion</b>			
13	Key results	18	Summarise key results with reference to study objectives	7-8
14	Limitations	19	Discuss limitations of the study, taking into account sources of potential bias or imprecision. Discuss both direction and magnitude of any potential bias	8
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17	Interpretation	20	Give a cautious overall interpretation of results considering objectives, limitations, multiplicity of analyses, results from similar studies, and other relevant evidence	7, 8
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20	Generalisability	21	Discuss the generalisability (external validity) of the study results	
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22	<b>Other information</b>			
23	Funding	22	Give the source of funding and the role of the funders for the present study and, if applicable, for the original study on which the present article is based	1
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\*Give information separately for exposed and unexposed groups.

**Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <http://www.plosmedicine.org/>, Annals of Internal Medicine at <http://www.annals.org/>, and Epidemiology at <http://www.epidem.com/>). Information on the STROBE Initiative is available at <http://www.strobe-statement.org>.

1 **Quality of End-of-Life Communication in Two High-Risk ICU Cohorts: A Retrospective Cohort**  
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3 **Study**  
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35 visualization of this manuscript. AG provided access to resources to conduct this study, and reviewed  
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## ABSTRACT

**Background:** Identifying factors that influence the quality of end-of-life communication is relevant to improving end-of-life care; yet little is known of them. In this study, we assessed the quality of end-of-life communication and influencing factors in two intensive care unit (ICU) cohorts at high risk of death: nursing home (NH) patients, and those on extracorporeal membrane oxygenation (ECMO).

**Methods:** This retrospective cohort study used the clinical ICU database for Winnipeg, Manitoba, Canada, and manual chart review, including admissions 2000-2017 to four ICUs. There were 230 patients in the NH cohort, and 109 in the ECMO cohort. Quality of end-of-life communication was assessed using 18 previously described, binary quality indicators to calculate a weighted, scaled, composite score, ranging 0-100. We used median regression to identify factors associated with the composite score.

**Results:** The ECMO cohort was younger than the NH cohort, with longer hospital length of stay and higher disease severity. Composite scores for quality of end-of-life communication were extremely low; (mean±SD) 48.5±1.7 for the NH cohort, 49.1±2.5 for the ECMO cohort. Patient characteristics associated with higher composite scores were older age (5.0 per decade, 95% C.I. 2.1-7.8) and lower (worse) Glasgow Coma Scale score (1.8 per GCS point, 95% CI 0.5-3.2). The composite score also rose significantly over time (1.7 per year, 95% CI 0.5-2.8).

**Interpretation:** In addition to again demonstrating poor quality of end-of-life communication in ICUs, we have identified that factors associated with better prognosis are also associated with worse end-of-life communication.

## INTRODUCTION

High quality end-of-life communication and decision-making should ensure that the medical care provided is concordant with patients' preferences and values.(1,2) However, problems in end-of-life communication persist for seriously ill adults admitted to Canadian hospitals, including in intensive care units (ICUs) where 19% of Canadians die.(3–6) Missing or inadequate advance care planning and goals of care communication often leads to more aggressive care than desired by patients.(7–12) Large variability in the quality of end-of-life care across ICUs suggests that organizational and other non-patient centered factors influence decisions about the aggressiveness of such care.(13) A majority of end-of-life discussions fail to include issues of importance to how patients make such decisions, such as long-term risks to their physical, cognitive, and social functioning.(14,15) Factors known to influence the decision for less aggressive care in ICU include older age, worse baseline functional status (especially neurological limitations), and female sex.(13,16) Knowing the factors that influence the quality of end-of-life communication and decision-making is also important to improve end-of-life care. Identification of gaps in end-of-life communication and decision-making are needed to inform interventions to improve patient-centered outcomes.(17)

We performed this retrospective cohort study to assess the quality of end-of-life communication in two groups of ICU patients: nursing home (NH) patients, and those placed on extracorporeal membrane oxygenation (ECMO). These cohorts were chosen for their high mortality rates. Across ICUs in Canada, elderly patients (>80 years old) consistently have poor post-ICU outcomes, with only one-quarter returning to physical functional baseline within one year.(18,19) Most nursing home patients admitted to ICUs die in hospital or soon after discharge.(18,19) Patients with severe cardiovascular and/or respiratory failure placed on ECMO face an invasive procedure requiring insertion of large vascular catheters, high risk of complications, high rates of hospital readmission, and mortality rates over 50%.(20,21)

## METHODS

### *Data sources:*

Data for this study were obtained from two sources. The Winnipeg ICU Database is a clinical database comprising all adult ICU admissions in the Winnipeg Health Region of the Canadian province of Manitoba since 1999.(22) The 2018 population of the Winnipeg region was 778,000 representing 57% of the provincial population,(23) but 93% of all high-intensity adult ICU admissions in Manitoba.(22) The Winnipeg ICU Database contains comorbid, admission and acquired diagnoses; severity of acute illness; invasive procedures performed, and disposition.(22) Of the 11 adult ICUs in six hospitals included in the Winnipeg ICU Database, for this study we included data from the four ICUs in the only two tertiary hospitals in the Winnipeg Health Region: two in the Winnipeg Health Sciences Centre (MICU, Medical Intensive Care Unit; SICU, Surgical Intensive Care Unit) and two in St. Boniface Hospital (MSU, Medical-Surgical Unit; CSU, Cardiac Surgical Unit). The second data source was manual review of hospital charts, performed by one author (TP).

### *Study cohorts:*

We identified two separate cohorts of patients admitted between January 1, 2000 and December 31, 2017 to any of the four study ICUs. The NH cohort comprised provincial residents  $\geq 50$  years old who resided in NHs prior to hospitalization. The ECMO cohort were  $\geq 18$  years old and received either arterio-venous or veno-venous ECMO at any point in their ICU stay. All ECMO done in Winnipeg is done in the MSU or CSU. For both cohorts, only the first eligible hospitalization was considered. Because of possibly of insufficient opportunity to fully explore end-of-life decision-making, ICU lengths of stay  $< 24$  hours were excluded.



**Data elements:**

Elements extracted for both cohorts were: age, sex, year of admission, ICU admission diagnosis, Acute Physiology and Chronic Health Evaluation (APACHE) II score including its Acute Physiology Score (APS), Glasgow Coma Scale score (GCS), hospital length of stay, hospital disposition, level of care, and the number of days between ICU admission and the first documentation in the chart of the level of care (“Elapsed ACP time”). Subtracting the neurologic subscore from the APS(24) gave the “APS-neuro score”. ICU admission diagnoses were categorized as: cardiac; endocrine; ear, nose and throat; gastrointestinal; genitourinary; hematologic; infectious; inflammatory; metabolic, musculoskeletal; neoplastic; neuropsychiatric; obstetrical; overdose and poisonings; renal; respiratory; trauma; vascular, and all others. In Manitoba there are, by provincial policy, three levels of care, in descending order of aggressiveness: (i) resuscitation, indicating that no types of medical interventions were to be withheld, (ii) medical, allowing application of all interventions except resuscitation, and (iii) comfort care only. As levels of care may change during a hospital stay, we recorded the least aggressive level assigned at any point in the ICU.

For the ECMO cohort we captured additional variables: (a) the type of ECMO used, (b) urban vs. rural residence, and (c) socioeconomic status. These latter two were not meaningfully available for the NH cohort, as they are derived from postal codes of residence, which in the NH cohort refer to the nursing homes in which they were living. Our measure of socioeconomic status was postal code-derived average family income (25) from the 2006 Canadian census, categorized into quintiles.

**Outcomes:**

We used a previously described and validated measure for the quality of end-of-life communication. Specifically, the presence/absence of 18 binary quality indicators: 13 goal of care communication items, and five documentation items described by Sinuff *et al.*(19,26) (Appendix 1) Obtained by manual chart review, our primary outcome – the composite weighted percent score – was calculated as the sum of these 18 items, weighted by the importance scores assigned in the creation of

1 this instrument (26) and rescaled to be 0-100 over the full span of the measure, with higher values  
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3 representing better quality of end-of-life communication. As secondary outcomes we report the  
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5 weighted percent scores from the goals of care communication, and documentation submeasures. The  
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7 scaled quality scores were classified as: extremely low quality <50%; low quality 50-74%; medium  
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9 quality 75-84%; and high quality 85-100%.

### 12 ***Statistical analysis:***

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15 We compared means with Student's t-test. The frequency of each of the 18 quality indicators  
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17 was assessed for the NH and ECMO cohorts, then compared using  $\chi^2$  tests with their frequency in a  
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19 previously reported (19) general ICU cohort.

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22 To identify factors associated with the quality of end-of-life communication, we used median  
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24 regression,(27) standard errors were estimated using bootstrapping with 100 replications. All variables  
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26 available were included, except for those expected to strongly confound end-of-life communication,  
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28 i.e. level of care, length of stay, and hospital mortality status. Because additional variables were  
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30 available for it, we performed an additional median regression including those variables for the ECMO  
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36 To assess the quality of chart review data extraction, we re-abstracted and recalculated the  
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38 weighted percent score of a 10% random sample of all abstracted charts. Test-retest reliability was  
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40 assessed as the Cohen's weighted kappa coefficient, where a value > 0.7 was considered satisfactory  
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42 agreement.(28–30) Stata 15 was used for statistical analysis (StataCorp, College Station, TX). P-  
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44 values less than 0.05 were considered significant. To account for the multiple comparisons inherent to  
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46 multivariable regression, for those analyses we used the two-stage step-up procedure of Benjamini *et*  
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48 *al.* for controlling the false discovery rate at <5%.(31)  
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### 50 ***Ethics***

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54 This study was approved by the Health Research Ethics Board of the University of Manitoba.  
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## RESULTS

For the NH cohort, a total of 230 charts were reviewed out of the 232 that met inclusion and exclusion criteria. For the ECMO cohort, a total of 109 charts were reviewed out of 110. The remaining two NH charts and one ECMO chart were not available in the medical records departments at the time these chart reviews were performed. The weighted Kappa's coefficient was 0.95 indicating very high agreement between first and second data extraction by the same data extractor.

Patient and illness characteristics are listed in Table 1. The ECMO cohort was younger than the NH cohort, with longer hospital length of stay, longer elapsed ACP time, and worse disease severity indices (APACHE II, GCS, APS, APS-neuro).

The composite score for quality of end-of-life communication (Table 2) was extremely low. For the composite score there was no significant difference between the two cohorts, but the ECMO cohort did have a significantly lower documentation subscore (Table 2).

Factors significantly associated with the median composite communication score (Table 3) were: year of admission, age and GCS. The composite score rose over time by 1.7 points yearly. It was higher by 5 points per decade of older age. Each one point lower (worse) for GCS was associated with 1.8 points higher in composite score. After adjustment for other covariates, the quality of end-of-life communication was similar for the NH and ECMO cohorts. The additional variables of socioeconomic status and urban/rural residence were not associated with the composite quality score in the ECMO cohort (Table E1 in Online Supplement).

Among the 18 individual binary quality items (Table E2 in Online Supplement), the frequency of them being present was substantially lower for the general Canadian ICU population cohort of Heyland *et al.* than for either of our two cohorts.(19)

## INTERPRETATION

In this study, each of two patient cohorts with high severity of illness and hospital mortality experienced extremely low quality of end-of-life communication. An additional, novel finding of our

1 study was systematically worse end-of-life communication in ICU patients with characteristics  
2 associated with better prognosis. In our data these characteristics were younger age and better  
3 neurologic function. This phenomenon is also supported by comparing our high-risk cohorts with the  
4 unselected, and lower risk, admissions from 12 Canadian ICUs reported by Heyland *et al.*(19) Those  
5 investigators, applying the same scoring system, reported an even lower average composite score of  
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14 That ICU clinicians perform worse in communicating about end-of-life care for patients who  
15 they perceive as less likely to die is problematic. Beyond the influence of age,(13) we are unaware of  
16 prior studies that have identified this phenomenon; thus, our study adds another to the spectrum of  
17 known problems in end-of-life care in ICUs.(10,11,15,32,33) Because the ability to prognosticate for  
18 individual ICU patients is poor (34) it means that critically ill patients with apparently better prognosis  
19 are exposed to worse end-of-life communication, which in turn puts them at higher risk for receiving  
20 care that fails to take account of their preferences and values,(1,35) and fails to be concordant with  
21 those wishes.(6,19)  
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33 There is a paucity of interventional studies attempting to improve end-of-life communication in  
34 ICUs. Wessman *et al.* conducted a before vs. after study of a multidisciplinary intervention in a single  
35 ICU in the U.S.; it included creation of a goals of care team, communication tools, pamphlets,  
36 standardized order sets and education.(36) Unfortunately, they did not evaluate actual end-of-life  
37 communication or care.  
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### 45 ***Limitations***

46 Although problems with end-of-life care and communication for ICU patients appear to be  
47 ubiquitous(6,11,13,37–43) the major limitations of our study are that it has a moderate sample size and  
48 derives from four ICUs in two hospitals in a single Canadian city. Other limitations are: (i) by using  
49 manual review of hospital charts, we could not include end-of-life conversations that occurred, but  
50 were not documented, and (ii) we did not test inter-rater reliability of the chart abstraction.  
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## ***Conclusion***

While it is encouraging that the composite quality measure increased substantially over time, high quality advance care planning, end-of-life communication and care should be provided to every critically ill patient, to help ensure that they receive care concordant with their preferences and values. More research needs to be done to uncover practical and sustainable interventions to accelerate this improvement, which should not be preferentially provided to only those perceived to be the most likely to die.

**Data Sharing Statement:** The source data for this study is not available for sharing, as the Data Custodian is the Winnipeg Regional Health Authority. Processed data generated in this study is available for use by other researchers by email upon request to author, Tammy Pham ([phamt347@myumanitoba.ca](mailto:phamt347@myumanitoba.ca)) at any time for educational and research purposes. Any publishing of data generated from this study should be properly referenced to this paper.

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**Table 1.** Patient and illness characteristics and outcomes. All values are # (%) unless indicated otherwise

	<i>Nursing home cohort</i>	<i>Extracorporeal membrane oxygenation cohort</i>
N	230	109
Age (years) mean $\pm$ SD, median (IQR)	72.0 $\pm$ 10.6, 73 (64,80)	51.8 $\pm$ 15.8, 56 (44,64)
Female sex	103 (44.8%)	45 (41.3%)
Year of admission		
2000-2004	5 (2.2%)	0
2005-2009	70 (30.4%)	8 (7.3%)
2010-2014	88 (38.3%)	60 (55.0%)
2015-2017	67 (29.1%)	41 (37.6%)
Urban status		
Urban		77 (70.6%)
Rural		26 (23.9%)
Out of province or nursing home resident		6 (5.5%)
Socioeconomic status quintile		
1st quintile (lowest income)		29 (28.2%)
2nd quintile		24 (23.3%)
3rd quintile		11 (10.7%)
4th quintile		17 (16.5%)
5th quintile (highest income)		22 (21.4%)
Primary admitting diagnosis category		
Cardiovascular	52 (21.7%)	59 (54.1%)
Infectious	78 (33.9%)	26 (23.9%)
Respiratory	47 (20.4%)	23 (21.1%)
All others	55 (23.9%)	1 (0.9%)
APACHE II score (points) mean $\pm$ SD, median (IQR)	22.4 $\pm$ 6.4, 22 (17,27)	28.5 $\pm$ 8.1, 27 (22,35)
GCS (points) mean $\pm$ SD, median (IQR)	12.0 $\pm$ 3.4, 13 (10,15)	8.3 $\pm$ 4.6, 7 (3,13)
APS (points) mean $\pm$ SD, median (IQR)	12.9 $\pm$ 4.8, 13 (9, 16)	18.7 $\pm$ 6.0, 18 (14, 23)
APS-neuro score (points) mean $\pm$ SD, median (IQR)	10.1 $\pm$ 5.4, 10 (6,14)	12.0 $\pm$ 7.1, 12 (7,17)
Elapsed ACP time (days) mean $\pm$ SD, median (IQR)	2.9 $\pm$ 6.2, 1.0 (1,2)	9.1 $\pm$ 16.3, 4.0 (1,13)
ECMO type		
veno-venous $\pm$ veno-arterial		16 (14.7%)
veno-arterial only		91 (83.5%)
Least aggressive Level of Care recorded		
Resuscitation	56 (24.3%)	44 (40.4%)
Medical	90 (39.1%)	6 (5.5%)
Comfort care	57 (24.8%)	45 (41.3%)
Missing	27 (11.8%)	14 (12.8%)
Hospital length of stay (days) mean $\pm$ SD, median (IQR)	20.1 $\pm$ 33.4, 11 (6,19)	33.8 $\pm$ 35.1, 20 (9,48)
Hospital mortality	69 (30.0%)	51 (46.8%)

SD, standard deviation; IQR, interquartile range; GCS, Glasgow coma scale; APS, acute physiology score; APS-neuro score, APS score with neurologic component removed; ECMO, extracorporeal membrane oxygenation; Elapsed ACP time, interval between ICU admission and first chart documentation of the level of care

**Table 2.** Quality of end-of-life communication

<i>Weighted percent scores</i>	<i>Nursing home cohort</i>	<i>Extracorporeal membrane oxygenation cohort</i>	<i>p-value*</i>
Composite measure	48.5±1.7	49.1±2.5	0.86
Goal of care discussion subscore	39.9±1.9	44.7±2.8	0.14
Documentation subscore	71.9±1.9	60.3±2.6	<0.01*

Values are mean±standard deviation; measures range 0-100; \*comparison via unpaired t-test

**Table 3.** Median regression results for composite of end-of-life communication

<i>Independent variable</i>	<i>Coefficient (95% C.I.)</i>	<i>unadjusted p-value</i>
ECMO cohort (vs. NH cohort reference)	-0.56 (-13.15, 12.02)	0.93
Age (per year)	0.50 (0.21, 0.78)	0.001*
Female sex (vs. male as reference)	-2.29 (-12.21, 7.63)	0.65
Year of admission (per year)	1.69 (0.54, 2.84)	0.004*
Glasgow Coma Scale score (per point)	-1.84 (-3.21, -0.47)	0.009*
APS-neuro score (per point)	0.72 (-0.18, 1.63)	0.12
Admitting diagnosis category		
Cardiovascular	Reference	
Infectious	0.93 (-9.02, 10.88)	0.85
Respiratory	-8.56 (-24.16, 7.05)	0.28
Other	-3.42 (-15.76, 8.92)	0.59

\*p-value significant after adjustment using the 0.05 false discovery rate threshold; C.I., confidence interval; APS-neuro, acute physiological score with neurological component removed; ECMO, extracorporeal membrane oxygenation; NH, nursing home.

**ONLINE SUPPLEMENTAL MATERIAL**Quality of End-of-Life Communication in Two High-Risk ICU Cohorts: A Retrospective Cohort Study  
Tammy L. Pham, MPAS, MSc; Allan Garland, MD, MA**Table E1.** Median regression results for composite end-of-life communication quality for the extracorporeal membrane oxygenation (ECMO) cohort, with additional variables.

<i>Independent variable</i>	<i>Coefficient (95% C.I.)</i>	<i>unadjusted p-value</i>
Age (year)	0.52 (-0.04, 1.07)	0.07
Female sex (vs. male as reference)	1.59 (-16.23, 19.45)	0.86
Year of admission (per year)	1.64 (-1.81, 5.09)	0.35
Glasgow Coma Scale score (per point)	-1.44 (-4.03, 1.14)	0.27
APS-neuro score (per point)	1.04 (-0.68, 2.76)	0.23
Admitting diagnosis category		
Cardiovascular	Reference	
Infectious	2.75 (-22.99, 28.50)	0.83
Respiratory	-7.94 (-36.77, 20.90)	0.59
Other	-5.40 (-41.15, 30.34)	0.77
Socioeconomic status		
1st quintile (lowest income)	Reference	
2nd quintile	0.89 (-23.38, 25.15)	0.94
3rd quintile	16.71 (-16.88, 50.30)	0.33
4th quintile	16.08 (-10.39, 42.54)	0.23
5th quintile (highest income)	-1.91 (-33.06, 29.25)	0.90
Urban residence (vs. rural as reference)	-1.18 (-20.58, 18.22)	0.90

APS-neuro, acute physiological score minus neurological component; C.I., confidence interval

**Table E2.** Frequency of individual quality indicators for three cohorts.

	Present NH cohort	Present ECMO cohort	External general ICU cohort*	p-value†
<b>Goals of care communication (GOCC) items</b>	<b>Yes</b>	<b>Yes</b>	<b>Yes</b>	
1. Since hospital admission, member of health care team has talked to patient and/or substitute decision maker about a poor prognosis or indicated in some way that the patient has a limited time left to live.	92 (40.0%)	76 (69.7%)	55 (13.9%)	<0.01
2. Since hospital admission, member of the health care team has talked to patient and/or substitute decision maker about artificial life support.	148 (64.5%)	80 (73.4%)	57 (14.4%)	<0.01
3. Since hospital admission, member of health care team has talked to patient and/or substitute decision maker about focusing on comfort care as the goal of the patient's treatment.	94 (40.9%)	51 (46.8%)	61 (15.4%)	<0.01
4. Since hospital admission, member of health care team has offered to arrange a time when patient/substitute decision maker/family can meet with the doctor to discuss treatment options and plans	147 (63.9%)	77 (70.6%)	58 (14.6%)	<0.01
5. Since hospital admission, member of health care team has asked if the patient or substitute decision maker had prior discussions or has written documents about the use of life-sustaining treatments.	114 (49.6%)	32 (29.4%)	109 (27.5%)	<0.01
6. Since hospital admission, member of health care team has asked patient or substitute decision maker what treatments the patient prefers to have or not have if they develop a life-threatening illness.	135 (58.7%)	53 (48.6%)	143 (36.0%)	<0.01
7. Since hospital admission, member of health care team has asked patient/substitute decision maker/family what is important to them as they consider health care decisions at this stage of the patient's life.	72 (31.3%)	42 (38.5%)	58 (14.6%)	<0.01
8. Since hospital admission, member of health care team has asked patient/family if they had any questions or needed things clarified regarding the patient's overall goals of care.	105 (45.7%)	44 (40.4%)	108 (27.2%)	0.02
9. Since hospital admission, member of health care team has given patient/substitute decision maker/family opportunity to express patient's fears or discuss what concerns the patient.	29 (12.6%)	24 (22.0%)	102 (25.7%)	0.65
10. Since hospital admission, patient/substitute decision maker has been informed that they may change their minds regarding their decisions around goals of care.	120 (52.2%)	59 (54.1%)	81 (20.4%)	<0.01
11. Since hospital admission, patient/substitute decision maker and family have been offered an opportunity to discuss with members of the health care team issues around capacity and consent with regard ACP; specifically, what actions would take place in the possible event of losing capacity to consent to care.	23 (10.0%)	10 (9.2%)	42 (10.6%)	0.89
12. Since hospital admission, patient & family have been offered support from the allied health care team (e.g., spiritual care, social work, and clinical nurse specialist) as needed.	88 (38.3%)	74 (67.9%)	80 (20.2%)	<0.01
13. Since hospital admission, member of health care team provided patient/family information about goals of care discussions to look at before conversations with the doctor.	0	0	30 (7.6%)	<0.01
<b>Documentation items</b>	<b>Yes</b>	<b>Yes</b>	<b>Yes</b>	
1. Documentation of a goals of care is present in medical record.	205 (89.1%)	95 (87.2%)	321 (80.9%)	0.24
2. Goals of Care present in the medical record is consistent with patient's stated preferences.	206 (89.6%)	94 (86.2%)	113 (28.5%)	<0.01
3. If the hospital uses a standardized folder or other strategy to locate ACP/Goals of Care documents in the medical record, these are present in the medical record.	138 (60.0%)	58 (53.2%)	228 (57.4%)	0.61
4. Documentation of ACP conversation is in patient's medical record.	151 (65.7%)	62 (56.9%)	363 (91.5%)	<0.01
5. Since admission, a member of the health care team has helped the patient and/or their family access legal documents to communicate the patient's ACPs	99 (43.0%)	5 (4.6%)	11 (2.8%)	<0.01

ACP, Advance Care Planning; †p-value from  $\chi^2$  test, comparing across all three cohorts; \*cohort from Heyland DK, Dodek P, You JJ, Sinuff T, *et al.* Validation of quality indicators for end-of-life communication: results of a multicentre survey. *CMAJ*. 2017;31(189):E980–9, with details supplied by Daren Heyland, personal communication.