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Research

Quality of end-of-life communication in 2 high-risk ICU cohorts: a retrospective cohort study

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Abstract

Background: Factors influencing the quality of end-of-life communication are relevant to improving end-of-life care. We assessed the quality of end-of-life communication and influencing factors in 2 intensive care unit (ICU) cohorts at high risk of death: patients living in nursing homes and those on extracorporeal membrane oxygenation (ECMO).

Methods: This retrospective cohort study included admissions to 4 ICUs in Winnipeg, Manitoba, from 2000 to 2017. We identified cohorts and influencing factors from the Winnipeg ICU database and by manual chart review. We assessed quality of end-of-life communication using 18 validated, binary quality indicators to calculate a weighted, scaled, composite score (range 0–100). We used median regression to identify factors associated with the composite score.

Results: The ECMO cohort (n = 109) was younger than the nursing home cohort (n = 230), with longer hospital stays and higher disease severity. Mean composite scores of end-of-life communication were extremely low in both cohorts (mean 48.5 [standard error of the mean (SEM) 1.7] for the nursing home cohort, 49.1 [SEM 2.5] for the ECMO cohort). Patient characteristics associated with higher median composite scores were older age (5.0 per decade, 95% confidence interval [CI] 2.1–7.8) and lower (worse) Glasgow Coma Scale (GCS) scores (1.8 per GCS point, 95% CI 0.5–3.2). The median composite score rose significantly over time (1.7 per year, 95% CI 0.5–2.8).

Interpretation: The quality of end-of-life communication in ICUs is poor, and factors associated with better prognosis are also associated with worse communication. Direct and early communication should occur with all patients in the ICU and their surrogates, not just those who are believed most likely to die.

Timely receipt of honest, comprehensible information about prognosis and care options has been identified as a priority by critically ill patients and their families but is not always provided.[1,2] End-of-life communication occurs between a care team and an individual with a foreseeably limited life expectancy and those who speak for that individual. As defined by Sinuff and colleagues, end-of-life communication strives to create "a shared understanding about a person's values and care preferences that will lead to a plan of care that is congruent with these values and preferences."[3]

However, problems in end-of-life communication persist for seriously ill, hospitalized adults, including in intensive care units (ICUs), where 19% of Canadians die.[4–7] Missing or inadequate communication on advance care planning and goals of care often leads to more aggressive care than desired by patients.[8–13] Most discussions fail to include issues of importance to patients that help them make end-of-life decisions, such as long-term risks to their physical, cognitive and social functioning.[14,15]

Few hospitals routinely collect information about the quality of communication regarding palliative and end-of-life care.[16] Widespread and large variation in end-of-life decision-making and practice in ICUs[12,14,17,18] suggest that factors outside of patient-centred care influence them, providing strong, indirect evidence of variation in end-of-life communication. Indeed, poor communication with the ICU team has been found to be the most common complaint among families of people who die in ICUs.[1,2] Knowing the factors that influence the quality of end-of-life communication is important to improve end-of-life care. Identification of gaps in end-of-life communication is needed to inform interventions to improve patient-centred outcomes.[19] However, relatively few studies have directly assessed end-of-life communication.

Across ICUs in Canada, older patients from nursing homes consistently have poor ICU outcomes, with most dying in hospital or soon after discharge.[20,21] Patients with severe cardiovascular or respiratory failure placed on extracorporeal

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membrane oxygenation (ECMO) face an invasive procedure requiring insertion of large vascular catheters, with high rates of complications and death.[22,23] Thus, these specific cohorts reasonably mandate a high level of attention to end-of-life communication, and they represent different population subgroups in terms of patient characteristics such as age and burden of comorbidity.[20,24] In this study, we aimed to assess the quality of, and factors associated with, end-of-life communication among these 2 groups of ICU patients.

Methods

Study design and population

We conducted a retrospective cohort study in the Winnipeg Health Region of Manitoba, Canada. Its population was 778 000 in 2018, representing 57% of the provincial population.[25] We hypothesized that, given the poor ICU outcomes of patients from nursing homes, end-of-life communication would be better for them than for patients on ECMO.

Of the 11 adult ICUs across 6 hospitals in the health region, we included data from the 2 tertiary hospitals capable of performing ECMO. These hospitals contain 4 ICUs: the Medical Intensive Care Unit and the Surgical Intensive Care Unit at the Winnipeg Health Sciences Centre, and the Medical Surgical Unit and the Cardiac Surgical Unit at St. Boniface Hospital.

We identified 2 separate cohorts of patients admitted between Jan. 1, 2000, and Dec. 31, 2017, to any of the 4 ICUs. The nursing home cohort comprised all provincial residents aged 50 years and older identified as having resided in nursing homes before hospitalization. The ECMO cohort comprised all provincial residents aged 18 years and older identified as having received either arteriovenous or venovenous ECMO at any point in their ICU stay. For both cohorts, we considered only the first eligible hospitalization. Because of the potential for insufficient opportunity to explore end-of-life decision-making fully, we excluded patients with ICU lengths of stay less than 24 hours.

Data sources

We used 2 data sources. The Winnipeg ICU Database is a clinical database that captures all adult ICU admissions in the Winnipeg Health Region since 1999, encompassing 93% of all high-intensity adult ICU admissions in Manitoba.[26] It contains data on diagnoses (including those at admission, acquired diagnoses and comorbidities), severity of acute illness, invasive procedures performed and disposition.[26] These data, which have been used extensively for 30 years, are directly abstracted from ICU medical records by dedicated data collectors, and are subjected to numerous checks of internal consistency.[26]

One author (T.P.) also performed manual review of hospital charts using a data abstraction tool created in Microsoft Access. To assess the quality of chart review data extraction, we reabstracted and recalculated the unweighted score of a 10% random sample of all abstracted charts. We also assessed test–retest (intrarater) reliability using the Cohen κ coefficient, where a value greater than 0.7 was considered satisfactory agreement.[27]

Variables and outcomes

We extracted the following elements for both cohorts from the ICU database: age, sex, year of admission, prehospital domicile type, ICU admission diagnosis, hospital length of stay, hospital disposition, the Glasgow Coma Scale (GCS) score[28] and the Acute Physiology and Chronic Health Evaluation (APACHE) II score, including its Acute Physiology Score (APS).[29] The GCS is a measure of the extent of impaired consciousness, and the APACHE II score and the APS are measures of acute illness severity. The APS is the sum of elements, including GCS. We explicitly included the GCS in our models and, to avoid collinearity, removed it from the APS to generate the APS-neuro score, which has been previously used.[30]

In the ICU database, ICU admission diagnoses were categorized as cardiac, endocrine, gastrointestinal, genitourinary, hematologic, infectious, inflammatory, metabolic, musculoskeletal, neoplastic, neuropsychiatric, obstetrical, otolaryngological, renal, respiratory or vascular. Diagnoses could also be categorized as an overdose or poisoning, trauma or "other." We identified patients who resided in a nursing home from detailed data supplied by the provincial department of health (for patients from 2006 onward) or from less detailed data supplied by the regional health authority (for patients before 2006).

For the ECMO cohort, we also captured the type of ECMO used, urban or rural residence and socioeconomic status. We derived residence and socioeconomic status from residential postal codes; we measured socioeconomic status as the average family income quintile from the 2006 Canadian census.[31] This information was not meaningfully available for patients in the nursing home cohort, as their postal codes refer to the nursing homes in which they were living.

One team member (T.P.) conducted manual chart review, from which we obtained the elements of a previously described and validated measure for the quality of end-of-life communication. This measure is a composite score of the presence or absence of 18 quality indicators, including 13 items on the goal of care communication and 5 documentation items, described by Sinuff and colleagues[3,21] (Appendix 1, Supplementary Table 2, available at www.cmajopen.ca/content/9/2/E570/suppl/DC1). We calculated the composite weighted percent score, our primary outcome, as the sum of these 18 items, weighted by the importance scores assigned in the creation of this instrument[3] and rescaled it to a range of 0–100, with higher values representing better quality of end-of-life communication. As secondary outcomes, we calculated the weighted scores from the goals of care communication and documentation submeasures. We classified the quality of scaled scores as extremely low (< 50), low (50–74), medium (75–84) or high (85–100).

We also used chart review to establish the number of days between ICU admission and the first documentation in the chart of the level of care (elapsed time to advance care planning), and level of care. In Manitoba, provincial policy defines 3 levels of care, in descending order of aggressiveness: resuscitation (i.e., no types of medical interventions were to be withheld), medical (i.e., allowing application of all interventions except resuscitation) and comfort care only.[32] As levels of care may change during a hospital stay, we recorded the least aggressive level assigned at any point in the ICU.

Statistical analysis

For the composite and subscale measure scores, we compared the unadjusted means and medians of the nursing home and ECMO cohorts with the Student *t* test and the Mann–Whitney test, respectively. We compared the frequency of each of the 18 quality indicators for the nursing home and ECMO cohorts using Fisher exact tests.

We used multivariable regression to identify factors associated with the quality of end-of-life communication. As our data violated the linear regression requirements of normality and homoscedasticity of the residuals,[33] we used median regression[34] with standard errors via bootstrapping with 100 replications. We included all available variables, except for those expected to strongly confound end-of-life communication (i.e., level of care, length of stay and hospital death). We also performed median regression for the ECMO cohort, including the additional variables of ECMO type, socioeconomic status and urban or rural residence.

We performed 2 sensitivity analyses. First, as the weightings of the 18 items were derived from expert opinions, we reran the median regression with equal weighting of all items. Second, as identification of patients from nursing homes was less reliable before 2006 and clearly missed many such transfers, we reran the median regression, excluding the years 2000–2005.

We used Stata 15 for statistical analysis (StataCorp) and considered *p* values less than 0.05 as significant. To account for the multiple comparisons inherent to multivariable regression, we used the step-up procedure of Simes for controlling the false discovery rate at less than 5%.[35]

Ethics approval

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

Results

For the nursing home cohort, we reviewed 230 charts of the 232 that met inclusion and exclusion criteria. For the ECMO cohort, we reviewed 109 of 110 charts. The remaining 2 nursing home charts and 1 ECMO chart were not available in the medical records departments at the time of chart review. The weighted κ coefficient was 0.95, showing 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 nursing home cohort, with longer hospital stays, longer elapsed time to advance care planning and worse disease severity indices (APACHE II, GCS, APS, APS-neuro).

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

Year of admission, age and GCS score were significantly associated with the median composite communication score (Table 3). The composite score rose over time, by 1.7 points yearly. Composite scores increased significantly with age (5 points per decade) and with lower GCS scores (1.8 points for each GCS point lower, representing more severe presentations). After adjustment for covariates, the quality of end-of-life communication was similar for the nursing home and ECMO cohorts. The additional variables of socioeconomic status and location of residence were not associated with the composite quality score in the ECMO cohort (Appendix 1, Supplementary Table 1).

Among the 18 individual binary quality items (Appendix 1, Supplemental Table 2), only 4 items differed in frequency between our 2 cohorts, with 2 in each direction. In sensitivity analyses, equal weighting of the 18 items, and excluding the years 2000–2005 gave similar findings (Appendix 1, Supplementary Tables 3 and 4).

Interpretation

Two cohorts of ICU patients both experienced extremely low quality of end-of-life communication. These 2 cohorts both had high disease severity and rates of hospital death, but were otherwise disparate in characteristics such as age and the burden of comorbid illness.[20,24] However, end-of-life communication did improve over time. Patients in the ICU with characteristics associated with better prognosis, specifically younger age and better neurologic function, experienced systematically worse end-of-life communication. The magnitude of variation of median score by these factors is about 10% for a 5-point difference in GCS scores or a 20-year difference in age. This phenomenon could explain the even lower average composite score observed among less acutely ill patients by Heyland and colleagues[21] in their study of 12 Canadian hospitals.

The observation that ICU clinicians perform worse in communicating about end-of-life care for patients who they perceive as less likely to die is problematic. Beyond the influence of age,[14] we are unaware of other studies that have identified this phenomenon; thus, our study adds more insight into the problems of end-of-life care in ICUs.[11,12,36–38] Because it is difficult to determine prognoses for ICU patients[39] it means that critically ill patients with apparently better prognoses are exposed to worse end-of-life communication, which in turn puts them at higher risk of receiving care that fails to take their preferences and values into account,[40,41] and fails to be concordant with those wishes.[7,21]

There is a paucity of interventional studies attempting to improve end-of-life communication in ICUs. Wessman and colleagues conducted a before-and-after study of a multidisciplinary intervention in a single ICU in the United States, including creation of a goals of care team, communication tools, pamphlets, standardized order sets and education.[42]

Table 1: Patient and illness characteristics among 2 ICU cohorts, 2000–2017

Variable	No. (%) of cohort*	
	Nursing home *n* = 230	ECMO *n* = 109
Age, yr		
Mean ± SD	72.0 ± 10.6	51.8 ± 15.8
Median (IQR)	73 (64–80)	56 (44–64)
Sex, female	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)
Location of residence		
Urban		77 (70.6)
Rural		26 (23.9)
Out-of-province or nursing home resident		6 (5.5)
Socioeconomic status quintile		
1 (lowest income)		29 (28.2)
2		24 (23.3)
3		11 (10.7)
4		17 (16.5)
5 (highest income)		22 (21.4)
Category of primary diagnosis at admission		
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)
Disease severity		
APACHE II score, mean ± SD	22.4 ± 6.4	28.5 ± 8.1
APACHE II score, median (IQR)	22 (17–27)	27 (22–35)
GCS, mean ± SD	12.0 ± 3.4	8.3 ± 4.6
GCS, median (IQR)	13 (10–15)	7 (3–13)
APS, mean ± SD	12.9 ± 4.8	18.7 ± 6.0
APS, median (IQR)	13 (9–16)	18 (14–23)
APS-neuro score, mean ± SD	10.1 ± 5.4	12.0 ± 7.1
APS-neuro score, median (IQR)	10 (6–14)	12 (7–17)
Elapsed ACP time, d		
Mean ± SD,	2.9 ± 6.2	9.1 ± 16.3
Median (IQR)	1.0 (1–2)	4.0 (1–13)
ECMO type		
Venovenous with or without arteriovenous		16 (14.7)
Arteriovenous only		91 (83.5)
Level of care†		
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, d		
Mean ± SD	20.1 ± 33.4	33.8 ± 35.1
Median (IQR)	11 (6–19)	20 (9–48)
Hospital death	69 (30.0)	51 (46.8)

Note: APACHE = acute physiology and chronic health evaluation, APS = acute physiology score, APS-neuro score = APS score with neurologic component removed, ECMO = extracorporeal membrane oxygenation, elapsed ACP time = elapsed advance care planning time (i.e., interval between ICU admission and first chart documentation of the level of care), GCS = Glasgow Coma Scale, ICU = intensive care unit, IQR = interquartile range, SD = standard deviation.
*Unless indicated otherwise.
†Least aggressive level of care recorded.

Table 2: Quality of end-of-life communication among 2 ICU cohorts, 2000–2017, unadjusted values*

Weighted scores*	Nursing home cohort	ECMO cohort	*p* value†
Composite measure of EOL communication*			
Mean ± SD	48.5 ± 25.8	49.1 ± 25.9	0.67
Median (IQR)	56.2 (28.4–73.8)	52.2 (27.5–68.9)	0.86
Goals of care communication subscore			
Mean ± SD	39.9 ± 28.5	44.7 ± 29.1	0.17
Median (IQR)	43.4 (8.2–63.5)	50.0 (15.2–70.5)	0.14
Documentation subscore			
Mean ± SD	70.9 ± 28.2	60.3 ± 27.1	0.001
Median (IQR)	80.3 (62.6–83.5)	63.8 (42.9–83.5)	0.001

Note: ECMO = extracorporeal membrane oxygenation, EOL = end-of-life, IQR = interquartile range, SD = standard deviation.
*Measures range 0–100.
†Mean comparison via unpaired Student *t* test. Median comparison via Mann–Whitney test.

Table 3: Median regression results for composite measure of end-of-life communication among 2 ICU cohorts, 2000–2017

Variable	Coefficient (95% CI)
Cohort	
Nursing home cohort	Reference
ECMO cohort	–0.56 (–13.15 to 12.02)
Age (per year)	0.50 (0.21 to 0.78)*
Sex	
Male	Reference
Female	–2.29 (–12.21 to 7.63)
Year of admission (per year)	1.69 (0.54 to 2.84)*
Glasgow Coma Scale score (per point)	–1.84 (–3.21 to -0.47)*
APS-neuro score (per point)	0.72 (–0.18 to 1.63)
Category of primary diagnosis at admission	
Cardiovascular	Reference
Infectious	0.93 (–9.02 to 10.88)
Respiratory	–8.56 (–24.16 to 7.05)
Other	–3.42 (–15.76 to 8.92)

Note: APS-neuro score = acute physiologic score with neurologic component removed, CI = confidence interval, ECMO = extracorporeal membrane oxygenation
**p* value significant after adjustment for multiple comparisons using the 0.05 false discovery rate threshold.

However, they did not evaluate actual end-of-life communication or care.

Direct and early communication should occur with all ICU patients and their surrogates. Existing guidelines and expert opinion[2,43] highlight the necessity for a shared decision-making model.

Limitations

Although problems with end-of-life care and communication for ICU patients appear to be ubiquitous,[7,12,14,44–47] our study has a moderate sample size and derives from 2 patient cohorts in 4 ICUs at 2 hospitals in a single Canadian city. Although it cannot be assumed that our findings generalize to other ICU cohorts, the disparate characteristics of these 2 cohorts is not consistent with our findings being particular to a given type of patient or clinical situation. The question of generalizability of our findings beyond these few ICUs is a concern, and, beyond the above-noted ubiquity of problems in this area, can be directly addressed only by additional studies in different jurisdictions. By using manual review of hospital charts, we could not include end-of-life conversations that occurred, but were not documented. This is a fundamental challenge of doing research in this area. However, reassuringly, another study interviewed hospitalized patients and their families and found even lower scores on the same communication elements.[21] The thresholds for scale interpretation are somewhat arbitrary. We began with the idea that all 18 scale elements are important, as judged by the expert group in the original description.[3] Thus, we believe that a perfect score of 100 is desirable and attainable, producing a reasonable decision that a score of less than 50 is "extremely low." Only 1 team member conducted chart reviews and we did not assess interrater reliability.

Conclusion

The quality of end-of-life communication in ICUs is poor, and factors associated with better prognosis are also associated with worse communication. Direct and early communication should occur with all ICU patients and their surrogates, not just those who are believed most likely to die, preferably using a shared decision-making model. More research is needed to uncover practical and sustainable interventions to accelerate improvement.

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Supplemental information: For reviewer comments and the original submission of this manuscript, please see www.cmajopen.ca/content/9/2/E570/suppl/DC1.