Assessing Quality of End-of-Life Communication and Documentation in Intensive Care Patients using a Conceptual Framework and Quality Indicators

Student: Tammy Pham

7831768

Phamt347@myumanitoba.ca

Mentored by Dr. Allan Garland

agarland@hsc.mb.ca

University of Manitoba

Health Sciences Centre

Master of Physician Assistant Studies

Rady Faculty of Health Sciences

Max Rady College of Medicine, University of Manitoba

Winnipeg, Manitoba, Canada

May 15, 2019

ABBREVIATIONS

ACP	Advanced Care Planning
APACHE II	Acute Physiology, Age, Chronic Health Evaluation II
APS	Acute Physiology Score
ECMO, v-aECMO, v-vECMO	Extracorporeal membrane oxygenation, veno-arterial ECMO, veno-venous ECMO
GCS	Glasgow Coma Scale
GOCD	Goals of Care Discussion
HSC	Health Sciences Center
ICMS	Intensive Care Medical Surgical unit
ICCS	Intensive Care Cardiac Sciences unit
ICU	Intensive Care Unit
MICU	Medical Intensive Care Unit
PCH	Personal care home
QI	Quality indicator
SICU	Surgical Intensive Care Unit
St. B	Saint Boniface Hospital
WRHA	Winnipeg Regional Health Authority

1.0 ABSTRACT

Most deaths in Canada occur in hospitals, and almost one in five occurs in intensive care units. The goal of this study is to assess the quality of end-of-life (EOL) communication in two important groups in intensive care in Winnipeg: (i) those who live in personal care homes (PCH) and (ii) those with severe cardiovascular and/or respiratory failure placed on an artificial life support called extracorporeal membrane oxygenation (ECMO). Two domains of EOL communication were studied: Goals of Care Discussion and Documentation. We used a validated conceptual framework for the quality of EOL communication and documentation, operationalized by 18 specific quality indicators. We performed a retrospective, manual review of hospital charts (107 charts from the PCH subgroup and 103 charts from the ECMO subgroup) to extract these 18 quality indicators. Overall, the quality of EOL communication and documentation was poor or good driven mostly by poor GOCD as Documentation was largely excellent. Despite the ECMO cohort being the sicker group with worse in-hospital mortality rates, the quality of EOL communication was significantly worse compared to PCH group. Quality of EOL communication was highly influenced by patient physiologic status adjusted for age, sex, year of admission, disease category, socioeconomic quintile and urban status.

2.0 INTRODUCTION

2.1 End-of-Life Issues in Intensive Care Units (ICU)

Most deaths in Canada occur in the hospital, (1) with 19% of them occurring in intensive care units (ICU). (2) Canada has one of the highest proportion of cancer patients dying in acute care; it also has some of the highest hospital expenditures near end-of-life (EOL). (3,4) These findings may indicate the need for improved EOL care. Improving EOL communication and decision-making are important to: ensure that the care provided reflects patients' preferences, improves satisfaction of both patients and their loved ones with EOL care, and lower EOL healthcare costs. (5,6) Indeed, there are gaps in EOL communication: no discussion or poorly detailed records of discussion around EOL care, and poor concordance with patient expressed preferences such as receiving inappropriate treatment. (7–9) In this study I assessed the quality of EOL communication and documentation in two specific subgroups of critically ill patients: (i) those who reside in personal care homes (PCH), and (ii) those with severe cardiovascular and/or respiratory failure placed on extracorporeal membrane oxygenation.

2.2 Epidemiology of Critical Illness in Residents of Personal Care Homes

Approximately 0.6% of adult Manitobans are admitted to an ICU each year, which means 8% of those in hospitals need critical care. (10) Of those, greater than two-thirds of patients are aged 60 years or older. (10–12) This older group has higher rates of mortality and longer ICU stays. (12,13) Though nursing home residents make up only 2.8% of the adult ICU population, they were admitted at drastically higher rates

compared to residents from private homes. (13) For patients admitted to ICU from a nursing home, one-third die in-hospital, and one-third of those that survive die within a 3-month period. (13) Higher functional dependency of nursing home residents prior to ICU admission was correlated with increased mortality rates. (14) For our study, we expanded the nursing home population to personal care homes (PCH), which includes nursing homes, long term care homes, retirement homes, assisted living homes, and residential homes.

2.3 EOL Issues in PCH Residents in ICUs

There is an increasing need to improve EOL care in PCHs in order to decrease their high levels of inappropriate admissions to hospital at EOL. (14) Despite PCHs having great potential in providing high quality EOL care, they are often staffed by a low-paid workforce with limited access to appropriate sources and training, and they have inadequate levels of staffing. (14,15) Due to the high proportion of patients in ICU from PCHs, ensuring high quality EOL care and communication (16,17) for these patients upon admission is equally important to make sure the care matches the patient's values, wishes or preferences; to reduce harm for bereaved family members; and to minimize healthcare costs. (5,6)

2.4 Extracorporeal membrane oxygenation (ECMO)

ECMO is an advanced form of life support. It supports patients with severe cardiac and/or lung failure by exchanging oxygen and carbon dioxide in blood outside the body and then returning the blood back to the body. It is expensive, invasive (requiring

insertion of large vascular catheters), and associated with high risk of complications. (18) There are two types of ECMO. Veno-venous ECMO (v-vECMO) and veno-arterial ECMO (v-aECMO) both provide respiratory support, but v-a ECMO additionally provides cardiovascular support. (18) v-vECMO is considered for adult patients with severe acute respiratory distress syndrome (ARDS), (19) a condition of impaired gas exchange that can be caused by a host of different pulmonary insults, leading to acute diffuse inflammation of the alveoli, alveolar edema and alveolar damage. (20)

2.5 EOL Issues in Critical Care Patients on ECMO

The Conventional ventilation or ECMO for Severe Adult Respiratory failure (CESAR) trial published in 2009 is the first and only randomized controlled trial comparing ECMO to conventional supportive critical care in adults with ARDS. (21) Its interpretation remains controversial. UK patients with ARDS patients were randomly allocated to remain in their original hospitals (which were not capable of providing ECMO) or be transferred to a central hospital capable of providing ECMO. The results shows that the patients randomized to go to the central hospital experienced higher survival without severe disability, with greater cost effectiveness. (22) Since the CESAR trial there has been an increase in ECMO use and an increase in the number of specialized centers providing ECMO. (21,23,24) Interpretation of CESAR is complicated by the fact that one third of patients transferred to the central hospital did not receive ECMO. (22) As this centralized hospital, but not the others, had evidence-based protocols to otherwise improve care of ARDS patients, it is possible that the trial results reflect better ARDS supportive care rather than better effect of ECMO. (25,26) Some

reports argue that ECMO is more costly than conventional care; (22,27) and hospital mortality remains high despite its increasing use. (28)

With increasing use of ECMO, there has been an increase in discussion on ethical considerations. For example, patients may be offered ECMO when no other treatments are available; yet they still demonstrate poor prognosis for recovery. Over a 9-year period, an average 51.7% of these post-ECMO patients die, with 43.8% of survivors readmitted within 1 month and 60.6% of survivors readmitted within one year. Elderly survivors had even higher readmission rates. (29) Often it comes down to the families and loved ones to decide whether the patient would want ECMO in a process called "shared decision-making" which becomes challenging when there is conflict of opinions. (30) Altogether, these issues highlight the importance for high quality EOL communication such as advanced care planning and goals of care discussions occurring prior to ECMO initiation.

2.6 Definition of the Conceptual Framework

One conceptual framework for EOL care begins with communication and development of advanced care plans in the community setting that is carried over into institutional and hospital settings. These are documented, and re-visited with onset and progression of illness (Figure 1). (31) The goal is to ensure that EOL life care is consistent with the patient's values, wishes and preferences. This framework was tested and showed feasibility in a multicentre survey. (32)

Advanced care planning (ACP) is a communication process that produces guidance for future medical decisions when the person cannot make decisions for

themselves. It includes reflection, deliberation, and determination of a person's values, wishes or preferences for treatments at end-of-life. (31) It should include communication with the person's loved ones, future substitute decision maker(s), and healthcare provider(s).

Goals of Care Discussions (GOCD) is a communication process related to ACP, but occurs in-hospital, is governed by laws or healthcare acts around informed consent, and results in medical decisions. Here, the patient may not be competent, so the communication may occur between healthcare providers and substitute decision maker(s), while taking into consideration the patient's previously expressed values, wishes or preferences in the context of the current clinical situation. (31)

Documentation captures medical orders resulting from the ACP or GOCD, but are distinct from "advanced care plans", "advanced directives" or "living wills" which are not medical orders. (31)

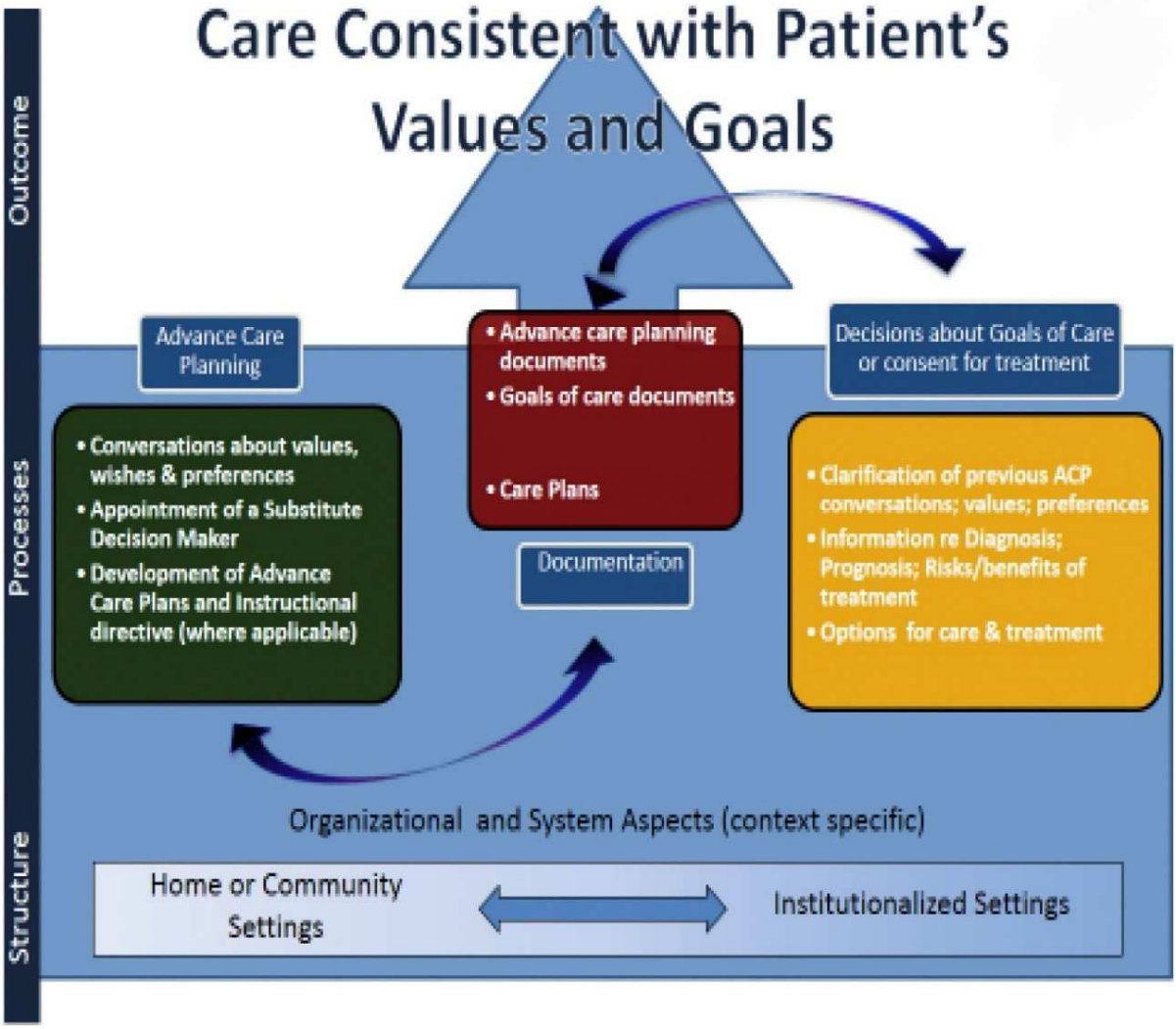


Figure 1. Conceptual framework for improving end-of-life communication and documentation. Modified from Sinuff *et al.*, 2015. (31) Advanced Care Planning (ACP) begins in the community setting and is carried over into institutionalized settings. In institutions, Goals of Care Discussion (GOCD) are facilitated by the health care team and its consensus outcomes are recorded in Documentation. These GOCD and its documentation update the ACP as they occur and are carried back to the community setting. The goal is to provide care consistent with patient's values, goals and wishes.

2.7 Definitions of patient and illness characteristics

2.7.1 **Cohort:** PCH cohort are patients who are PCH residents prior to ICU admission, and ECMO cohort are patients who received ECMO at any point in ICU stay in accordance with inclusion and exclusion criteria (Section 2.8, 3.1-3.2).

2.7.2 **Age:** age of patient on ICU admission

2.7.3 **Sex:** sex of patient, male or female, on ICU admission

2.7.4 **Year of admission:** year of ICU admission

2.7.5 **Hospital length of stay:** calculated from the date of hospital admission (day 1) to date of hospital discharge, which includes the ICU stay as described in the inclusion criteria (Section 3.1.a).

2.7.6 **Hospital mortality:** if death occurred during hospital stay

2.7.7 **Public trustee:** if medical chart had a public trustee documented at any point in hospital stay

2.7.8 **Socioeconomic quintile:** where 1st quintile represents the lowest socioeconomic status, and 5th quintile represents the highest socioeconomic status. This data was generated from the 2006 Canadian Census of median household incomes by postal code of residence. Stratifying socioeconomic groups by postal code in proxy of household income using tax-validated data has been a validated approach for chart reviews. (33) Since the socioeconomic quintile was generated from postal codes, it is only available for the ECMO cohort as the postal code of a person's PCH will not represent their socioeconomic status.

2.7.9 **Urban status:** urban or rural residential status based on postal code according to the 2006 Canadian Census. According to the Canadian Census definition, urban

area is defined a having a population of ≥ 1000 people and a density of 400 ≥ people per km². Rural area is defined by areas not meeting the urban definition. (34) Since the residential status was generated from postal codes, as in Section 2.7.8.

2.7.10 **ECMO type:** for ECMO cohort, categorized as either v-aECMO (which could include an interval before or after on v-vECMO), and v-vECMO alone.

2.7.11. **Disease category:** defined as disease category of leading diagnosis on ICU admission and categorized as below. This disease categorization was similarly used to compare diagnostic testing in different types of ICUs. (35)

1. Cardiovascular
2. Infectious
3. Respiratory
4. All others

2.7.12 **Advanced Care Planning (ACP) – Goals of Care status**

Since 2005, all Winnipeg Regional Health Authority (WRHA) hospitals have utilized a form called "The ACP – Goals of Care" to document consensus on goals of care. This form is then filed behind the designated tab in the patient's health record and should be reviewed: on each admission; whenever there is an unanticipated change in the patient's clinical status; at the request of the patient or substitute decision maker, or the health care team member; and at a minimum reviewed annually as per the Winnipeg Regional Health Authority (WRHA) – Goals of Care Policy (Policy no. 110.000.200). There are three options to this

form: ACP status of "R" indicates that possible forms of medical care, including attempted resuscitation, can be used; "M" indicates care that can be offered excludes attempted resuscitation, and "C" indicates care excludes attempted resuscitation and is "directed by maximal comfort, symptom control and maintenance of quality of life". (36)

In this study, the ACP status was categorized by ACP–R without M or C status at any point during hospital stay, ACP–M without C status at any point during hospital stay, and ACP–C status at any point during hospital stay. The latter two are considered statuses that limit care.

2.7.13 **Timing of ACP status:** measured as number of days after hospital admission for first documentation of ACP status i.e. first date that quality indicator D1 (Section 3.5.3) occurred.

2.7.14 **Acute Physiology, Age, Chronic Health Evaluation II (APACHE II):** APACHE II scoring system is a validated and commonly used system for assessing the severity of illness in critically ill ICU patients. The APACHE II total score is comprised of three components: (1) Acute Physiology Score (APS), (2) Age Score, and (3) Chronic Health Score. The APS is scored based on twelve routine physiologic measurements taken within 24 hours of ICU admission: rectal temperature, mean arterial pressure, heart rate, respiratory rate, oxygenation (measured by A-aDO2 or PaO2 depending on FiO2), arterial pH (or bicarbonate level if arterial blood gas unavailable), serum sodium, serum potassium, serum

creatinine, hematocrit, white blood count, and Glasgow Coma Score (GCS). The APACHE II score ranges 0 to 71 where a higher score indicates greater severity of illness and correlates to risk of in-hospital death; subsequent risk of ICU death; thus, allowing for differential prognosis of acutely ill patients and comparison of different patient care for their efficacy. (37)

2.7.15 **Glasgow Coma Score (GCS):** Of note, the GCS score is the only neurological measurement in APS. It is measured by motor responsiveness, verbal performance, and eye opening. GCS ranges 3-15 where a higher score represents consciousness and a lower score represents impaired consciousness or coma. GCS highly correlates to duration of coma and allows for prediction of coma prognosis and comparison of different patient care for their efficacy. (38)

2.7.16 **APS without neurological score (APS-neuro):** This score was created from APS and GCS scores from the Winnipeg Adult ICU database as APS-(15-GCS) in order to compare influence of neurological physiology (GCS) and non-neurologic physiology (APS-neuro) on patient outcomes.

2.8 Research Goal, Objectives and Purpose

The goal of this research is to assess the quality of EOL communication and documentation for two subgroups of ICU patients. This will be based on the conceptual framework previously described (Section 2.6, Figure 1). (31) We will focus on two

categories (i) Goals of Care Discussion (GOCD) and (ii) Documentation, operationalized by 18 specific quality indicators (QIs) developed by a group of experts, using a Delphi process as described by Sinuff *et al.* (31) These QIs were shown valid and feasible in assessing EOL communication and documentation in a multicentre survey from hospitals across four provinces in Canada. (32)

Objective 1: Create three data extraction forms based on inclusion and exclusion criteria: (1) Master Identifier List; (2) De-Identified Records List; (3) Quality Indicators List.

Objective 2: Extract data on patient and illness characteristics, and QIs from medical charts using the three data extraction forms.

Objective 3: Evaluate test-retest reliability of chart audits.

Objective 4: Assess the quality of EOL care as indicated by the QIs in the two patient subsets.

3.0 METHODOLOGY

The database used to identify patients meeting inclusion and exclusion date (Section 3.1-3.2) was the Winnipeg Adult ICU database. Patients were identified from Health Sciences Center (HSC) and Saint Boniface Hospitals (St. B). Four ICUs in Winnipeg were chosen: (1) HSC Medical Intensive Care Unit (MICU), HSC Surgical Intensive Care Unit (SICU), St. B Intensive Care Medical Surgical (ICMS) unit , and St. B (Intensive Care Cardiac Sciences unit) ICCS.

Objective 1: Create three data extraction forms based on the inclusion and exclusion criteria: (1) Master Identifier List; (2) De-Identified Records List; (3) Quality Indicators List.

3.1 Patient cohorts, Inclusion criteria

3.1.a Two cohorts were assessed separately, each of individuals ≥18 years of age with admission to any of 4 WRHA as listed in Section 3.0. The PCH cohort included admission dates between 1/1/2013 to 12/31/2017. The ECMO cohort included admission dates between 1/1/2000 to 12/31/2017. These dates were chosen for a similar sample size of each ~100.

3.1.b The two cohorts, considered separately:

i) PCH cohort: Were PCH residents prior to hospitalization. For PCH patients with multiple hospital stays that include ICU admission, only the first meets inclusion criteria.

ii) ECMO cohort: Received ECMO at any point in their ICU stay. For patients with multiple hospital stays that included ICU admission with ECMO, only the first meets inclusion criteria.

iii) If a person qualifies for the PCH cohort and separately qualifies (in the same ICU stay or in a separate ICU stay) for the ECMO cohort, that patient will be included in both analyses.

3.2 **Exclusion criteria:** ICU length of stay < 24 hours.

3.3 **Data extraction forms:** were developed (Appendix 1-3). The Master Identifier List contained the individuals and their confidential information. The De-Identified Records List contained individuals from the Master Identifier List without confidential data along with patient and illness characteristics. The Quality Indicators List detailed the 13 QIs under the GOCD category and 5 QIs under the Documentation category. Data was extracted from hospital stay charts where "0" indicated absence of that QI in the chart and "1" indicated presence of that QI (Appendix 3).

3.4 **Independent variables:** Patient and illness characteristics were extracted from the Winnipeg Adult ICU database or from the medical charts used for data analysis as defined in Section 2.7. The independent variables chosen for confounding analysis are cohort, age, sex, year of admission, APACHE II score,

GCS, APS-neuro score, disease category, hospital mortality, hospital length of stay, ACP status, timing of ACP status, socioeconomic quintile, and urban status.

3.5 **Quality Indicators**:

3.5.1 The QIs are listed in order of importance in each category, GOCD and Documentation, which was decided by Delphi process. Quality indicators were ranked on a scale of 1 to 7 by a panel of multidisciplinary experts, where 1 is least important and 7 is most important, generating mean weights of importance for each QI (Appendix 4). (31) These weights of importance were used in this research; however, the QIs were modified according to criteria below (Section 3.5.1a-b) and listed in Section 3.5.2-3.5.3.

3.5.1a Quality indicators were extracted from medical record documentation from the full hospital stay, rather than only the ICU stay. This includes medical charts transferred from different hospital departments to ICU, different hospitals or medical institutions to the ICU hospital, or after transfer from ICU to different department in the same ICU hospital if included in the medical chart extracted from Winnipeg Adult ICU database according to inclusion and exclusions criteria (Section 3.1-3.2).

3.5.1b All of the GOCD QIs in the medical chart could include at minimum one member of the healthcare team and the patient and/or their substitute decision maker, rather than certain QIs necessitating practitioner-patient discussion without allowing proxy.

3.5.2 **Quality indicators for GOCD category modified for this study:**

G1. 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.

G2. Since hospital admission, member of the health care team has talked to patient and/or substitute decision maker about artificial life support.

G3. 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.

G4. Since hospital ICU admission, member of health care team has arrange or attempted to arrange a time when patient/substitute decision maker/family can meet with the doctor to discuss treatment options and plans.

G5. Since hospital admission, member of health care team has asked or allowed patient or substitute decision maker to express patient's prior discussions or written documents about the use of life-sustaining treatments.

G6. Since hospital admission, member of health care team has asked or discussed with patient what treatments they prefer to have or not have if they develop a life-threatening illness.

G7. Since hospital admission, member of health care team has asked or discussion with patient/substitute decision maker/family what is important to them as they consider health care decisions at this stage of the patient's life.

G8. 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.

G9. Since hospital admission, member of health care team has given patient opportunity to express their fears or discuss what concerns them.

G10. Since hospital admission, patient and/or substitute decision maker has been informed that they may change their minds or brought up the topic of changing their minds regarding their decisions around goals of care

G11. Since ICU admission, patient and family have been offered an opportunity to discuss with members of the health care team issues around capacity and consent with regards to ACP; specifically, what actions would take place or what actions would they have wanted to take place in the possible event or in the event of losing capacity to consent to care.

G12. Since hospital admission, patient & family have been offered or received support from the allied health care team (e.g., spiritual care, social work, and clinical nurse specialist) as needed.

G13. Since hospital admission, member of health care team provided patient/family information about GOCD to look at before conversations with the doctor.

3.5.3 **Quality indicators for Documentation category modified for this research:**

D1. Documentation of any goals of care, including but not limited to Goals of Care QIs in Section 3.5.2, is present in medical record.

D2. Goals of Care present in the medical record is consistent with patient's stated preferences, specifically, in regard to ACP status and preferences around artificial life support.

D3. 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.

D4. Documentation of ACP conversation is in patient's medical record beyond the ACP status.

D5. 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, or their legal documents are present in the medical chart.

Objective 2: Extract data on patient and illness characteristics, and the QIs from medical charts using the three data extraction forms.

3.6 Medical charts from HSC were by paper, scanned electronic online, or film format. Medical charts from St. B were by paper or electronic medical records format.

Objective 3: Evaluate test-retest reliability of chart audits.

3.7 Test-retest Reliability Testing

To ensure intra-rater reliability during data extraction of the medical charts, 10% random sample of all abstracted charts were re-extracted. Test-retest reliability was

assessed as the Cohen's kappa coefficient, where values > 0.7 are considered satisfactory agreement between test and retest data extraction. (33,39–41)

Objective 4: Assess the quality of EOL care as indicated by the QIs in the two patient subsets.

3.8 Primary analysis: Overall quality of EOL communication and documentation in PCH and ECMO cohorts

The quality of EOL communication in PCH and ECMO cohorts was assessed by:

3.8.1 The weighted percent score for each category (GOCD and Documentation) and both categories together (Composite category). The weighted percent score was calculated from the sum of the weighted QI scores as extracted from medical charts divided by the total weighted QI score of all QIs. This ratio ranges 0 to 100%. This weighted percent scoring system was previously used to validate the QIs as a measurement of EOL communication and documentation. (32)

3.8.2 The frequency of each QI by Composite category, GOCD category and Documentation category.

3.8.3 The average frequency of all QIs by Composite category, GOCD category and Documentation category, and compared between the two cohorts. For this study, average frequency of QIs < 50% was considered poor, 50-70% was graded good, and >70% was marked excellent EOL communication and documentation.

3.8.4 The distribution of weighted percent scores among Composite category, GOCD category and Documentation category

3.9 Secondary analysis: The influence of confounder variables on EOL communication and documentation

3.9.1 First, the independent variables (Section 3.4) were tested for multi-collinearity using variance inflation factor (VIF). Variables with moderate to high collinearity were screened out using the backwards stepwise method while maximizing R^2 in order to maintain variable estimation value on outcomes. (42)

3.9.2 Second, the non-collinear independent variables as in Section 3.9.1 were assessed for their prediction value, meaning the variable must occur within 48 hours of hospital admission to allow intervention on outcomes. These are named the predictor variables.

3.9.3 Third, the predictor variables from Section 3.9.2 were categorized into basic predictor variables if they were variables available for both PCH and ECMO cohorts, and extended predictor variables if they were only collected from the ECMO cohort.

3.9.4 Regression Model 1: The weighted percent scores were analyzed by multivariable linear regression analysis using the basic predictor variables including the cohort variable.

3.9.5 Regression Model 2: The weighted percent scores for the PCH cohort were analyzed by multivariable regression using the basic predictor variables excluding the cohort variable.

3.9.6 Regression Model 3: The weighted percent scores for the ECMO cohort were analyzed by multivariable linear regression using the basic plus extended

predictor variables excluding the cohort variable. Multiple sub-models were generated in order to meet maximized R^2 due to high number of categories.

3.10 Statistical analysis

For comparison of means, Student's t-test was used. For comparison of medians, Mann-Whitney U test was utilized. The influence of confounder variables on EOL communication and documentation was expressed as a regression coefficient. In multivariable regression analysis, the most common subcategories were chosen as the reference category. Stata 15 software was used for statistical analysis (StataCorp, College Station, TX). *P* values less than 0.05 were considered significant.

3.11 Ethics and funding

This research was approved by the Health Research Ethics Board of the University of Manitoba. Tammy Pham was supported by the University Manitoba Graduate Fellowship for this research.

4.0 RESULTS

For the PCH cohort, a total of 107 charts were reviewed out of the 109 charts that met inclusion and exclusion criteria. For the ECMO cohort, a total of 103 charts were reviewed out of the 104 charts. The remaining two PCH charts and one ECMO chart were not available from HSC and St. B health records at the time of this study.

4.1 Test-retest reliability of chart audits

Across the 10% of the randomly selected charts, Kappa's coefficient was 0.93 indicating very high agreement between first and second data extraction by the same data extractor. Therefore, test-retesting of chart audits is reliable in this study.

4.2 Patient and illness characteristics

Baseline data is shown in Table 1. The average age of PCH cohort was 68 years at time of admission, with more men (55.1%) than women (44.9%) (Table 1). Relatively, most PCH cohort cases were admitted in 2017 (29.0%) (Table 1). The average length of hospital stay was 47 days with 37.4% of these hospital stays resulting in death. Relative majority of PCH cohort patients had limiting status to care (29.9 to 40.2%) at any point in hospital stay (Table 1). Only one medical chart in the PCH cohort did not have ACP status documented (Table 1). PCH patients (33.6%) were admitted mostly due to an infectious process such as pneumonia or sepsis relative to respiratory or cardiac causes (Table 1). On average, PCH cohort APACHE II score was 21.8 (Table 1).

The average age of ECMO cohort was 46 years old at time of admission, with more men (57.3%) than women (42.7%) (Table 1). Most ECMO cohort cases were admitted in 2011 (19.4%) with the least number of cases (only one) in 2008 (Table 1). 52.4% of these ECMO cases involved v-vECMO alone (Table 1). The average length of hospital stay was 33 days with 48.5% of these hospital stays resulting in death (Table 1). ECMO cohort patients had limiting status to care any point (40.8-42.7%). Thirteen medical charts in the ECMO cohort did not have

ACP status documented (Table 1). On average, ECMO cohort APACHE II score is 28. Relative majority of patients (50.5%) were admitted due to cardiovascular cause (50.5%) (Table 1).

Table 1. Patient and illness characteristics. Values reported as (number of patients, % of patients) unless otherwise indicated. "--" indicates not applicable. SE: standard error; IQR: interquartile range; ACP: advanced care planning (R: resuscitation, M: medical management, C: comfort care); APACHE II: acute physiology, age, chronic health evaluation II; GCS: Glasgow coma scale; APS-neuro: acute physiology score without neurological score.

	PCH (N=107)	ECMO (N=103)	p-value
Age (years)			
mean ± SE	67.7 ± 1.4	46.0 ± 2.2	<0.0001*
median (IQR)	69 (62,78)	52 (31,63)	0.81
Hospital length of stay (days)			
mean ± SE	22.6 ± 3.6	32.8 ± 3.5	0.76
median (IQR)	11 (6,20)	19 (9,45)	0.36
Timing of ACP status			
mean ± SE	3.0 ± 0.7	9.5 ± 1.8	0.0003*
median (IQR)	1 (1,2)	4.5 (1,13)	0.31
APACHE II score			
mean ± SE	25.0 ± 0.5	28.2 ± 0.8	<0.0001*
median (IQR)	22 (17,25)	27 (22,35)	0.27
GCS			
mean ± SE	11.8 ± 0.3	8.3 ± 0.5	<0.0001*
median (IQR)	13 (9,15)	7 (3,13)	0.71
APS			
mean ± SE	9.39 ± 0.5	11.6 ± 0.7	0.01*
median (IQR)	10 (6,13)	12 (6,16)	0.42
APS-neuro score			
mean ± SE	9.4 ± 0.5	11.6 ± 0.7	0.01*
median (IQR)	10 (6,13)	12 (6,16)	0.42
Hospital mortality	40 (37.4%)	50 (48.5%)	--
Sex			
male	59 (55.1%)	59 (57.3%)	--
female	48 (44.9%)	44 (42.7%)	
Year of admission			--
2008	--	1 (1.0%)	
2009	--	7 (6.8%)	
2010	--	5 (4.9%)	
2011	--	20 (19.4%)	
2012	--	8 (7.8%)	
2013	19 (17.7%)	10 (9.7%)	
2014	16 (15.0%)	16 (15.5%)	
2015	21 (19.6%)	9 (8.7%)	
2016	20 (18.7%)	18 (17.5%)	
2017	31 (29.0%)	9 (8.7%)	
ACP status			
ACP – R without M or C	31 (29.0%)	42 (40.8%)	
ACP – M without C	43 (40.2%)	4 (3.9%)	
ACP – C at any point	32 (29.9%)	44 (42.7%)	
Missing ACP status	1 (0.9%)	13 (12.6%)	
Public trustee	12 (11.2%)	2 (1.9%)	--
First disease category for admission			--
Cardiovascular	21 (19.6%)	52 (50.5%)	
Infectious	36 (33.6%)	23 (22.3%)	
Respiratory	22 (20.6%)	23 (22.3%)	
All others	28 (26.1%)	5 (4.9%)	
Neuropsychiatric	*14 (13.1%)*	*0*	
Gastrointestinal	*7 (6.5%)*	*0*	
Ears, nose, throat	*2 (1.9%)*	*1 (1.0%)*	
Renal	*2 (1.9%)*	*0*	
Trauma	*1 (0.9%)*	*0*	
Metabolic	*1 (0.9%)*	*0*	
ECMO type	--		--
v-aECMO without v- vECMO		49 (47.6%)	
v-vECMO at any point		54 (52.4%)	
Socioeconomic quintile	--		--
1st quintile (lowest income)		28 (27.2%)	
2nd quintile		21 (20.4%)	
3rd quintile		11 (10.7%)	
4th quintile		17 (16.5%)	
5th quintile (highest income)		21 (20.4%)	
Urban status	--		--
Urban		72 (69.9%)	
Rural		26 (25.2%)	
Out of province or PCH resident		5 (4.9%)	

4.3 Frequency of EOL QIs

The overall quality of EOL communication for the PCH and ECMO cohorts were assessed by the frequency of each QI (Appendix 5).

4.3.1 In the PCH cohort, the most frequent QIs among both GOCD and Documentation categories and the Documentation category alone, are listed below, with almost all medical charts including these QIs: D1-D4.

D1. Documentation of any goals of care, including but not limited to Goals of Care QIs in Section 3.5.2, is present in medical record.

D2. Goals of Care present in the medical record is consistent with patient's stated preferences, specifically, in regard to ACP status and preferences around artificial life support.

D3. 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.

D4. Documentation of ACP conversation is in patient's medical record beyond the ACP status.

4.3.2 The most common QIs of the GOCD category for the PCH cohort was: G4, G2, and G6.

G4. Since hospital ICU admission, member of health care team has arranged or attempted to arrange a time when patient/substitute decision maker/family can meet with the doctor to discuss treatment options and plans.

G2. Since hospital admission, member of the health care team has talked to patient and/or substitute decision maker about artificial life support.

G6. Since hospital admission, member of health care team has asked or discussed with patient what treatments they prefer to have or not have if they develop a life-threatening illness.

4.3.3 On the other hand, the least common QIs in the PCH cohort GOCD category was: G13, G11, G9.

G13. Since hospital admission, member of health care team provided patient/family information about GOCD to look at before conversations with the doctor.

G11. Since ICU admission, patient and family have been offered an opportunity to discuss with members of the health care team issues around capacity and consent with regards to ACP; specifically, what actions would take place or what actions would they have wanted to take place in the possible event or in the event of losing capacity to consent to care

G9. Since hospital admission, member of health care team has given patient opportunity to express their fears or discuss what concerns them.

4.3.4 In the ECMO cohort, the most frequent QIs among both GOCD and Documentation categories was: D1, D2 and G2.

4.3.5 In the GOCD, the most frequent QIs in the ECMO cohort was: G2, G1, G4.

G2. Since hospital admission, member of the health care team has talked to patient and/or substitute decision maker about artificial life support.

G1. 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.

G4. Since hospital ICU admission, member of health care team has arranged or attempted to arrange a time when patient/substitute decision maker/family can meet with the doctor to discuss treatment options and plans.

4.3.6 In contrast, the least frequent QIs among the GOCD category in the ECMO cohort was G13, G11, G5.

G13. Since hospital admission, member of health care team provided patient/family information about GOCD to look at before conversations with the doctor., G11, G5.

G11. Since ICU admission, patient and family have been offered an opportunity to discuss with members of the health care team issues around capacity and consent with regards to ACP; specifically, what actions would take place or what actions would they have wanted to take place in the possible event or in the event of losing capacity to consent to care.

G5. Since hospital admission, member of health care team has asked or allowed patient or substitute decision maker to express patient's prior discussions or written documents about the use of life-sustaining treatments.

4.3.7 The least frequent QI among the Documentation category of both the PCH and ECMO cohorts was D5 as no medical charts documented this QI.

D5. 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, or their legal documents are present in the medical chart.

4.4 Overall quality of EOL communication and documentation in ICU patients

Overall the quality of EOL communication and documentation was poor to good for PCH and ECMO patients in ICU with mean composite weighted percent scores of 53.7% and 49.6%, respectively, without difference between the two cohorts (Table 2). These low weighted percent scores were mostly contributed by poor quality of GOCD with mean weighted percent scores 43.1% for PCH cohort and 45.5% for ECMO cohort (Table 2). However, the quality of EOL documentation was good to excellent with 81.1% mean weighted percent score in PCH cohort and 60.1% mean weighted percent score in ECMO cohort. Documentation was 1.3 times significantly better in the PCH cohort compared to the ECMO cohort (Table 2).

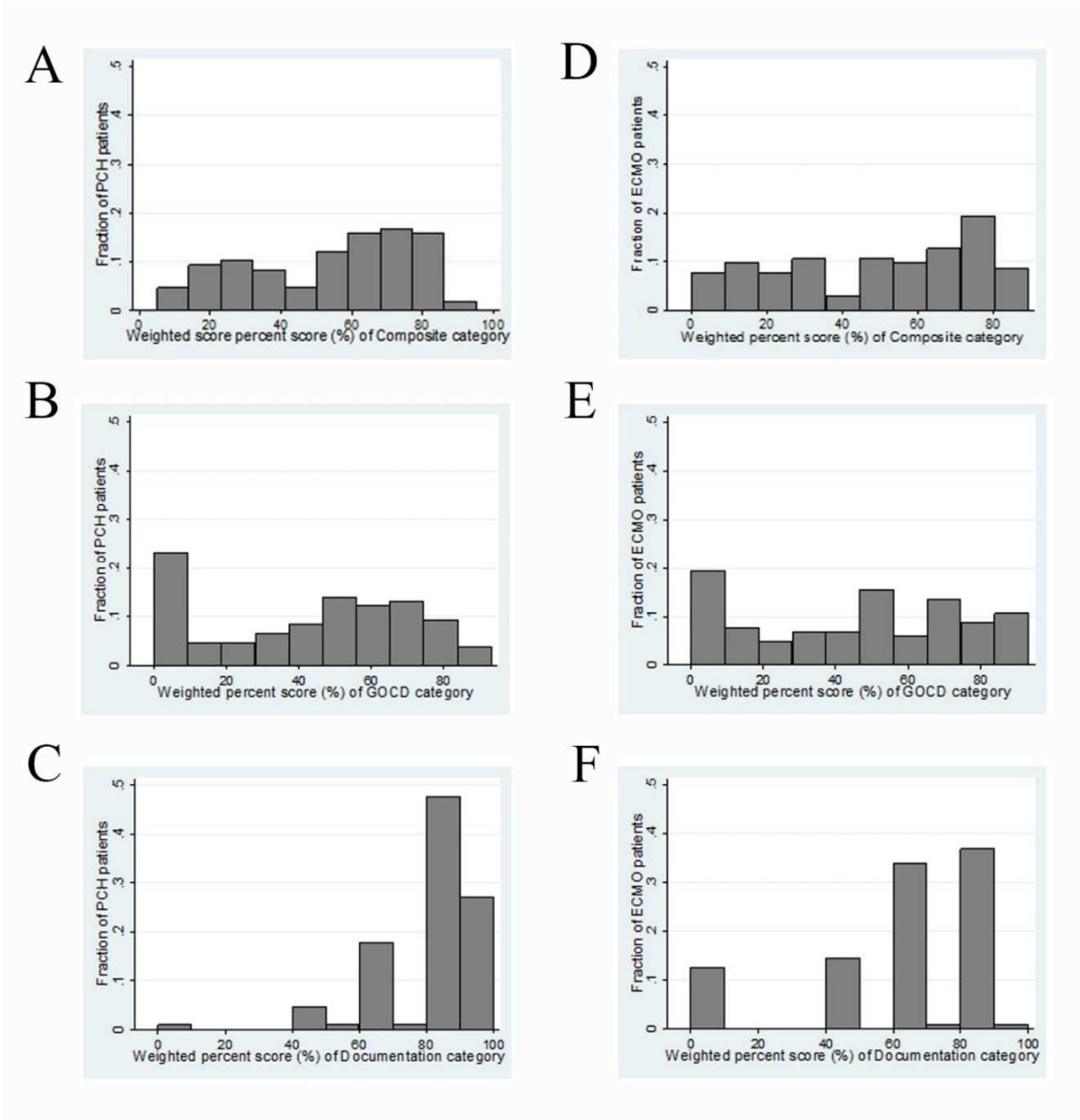
Table 2. In intensive care units (ICU), the quality of end-of-life (EOL) communication and documentation in personal care home (PCH) and extracorporeal membrane oxygenation (ECMO) cohorts was low overall mostly contributed by poor goals of care discussion (GOCD) scores as Documentation scores were good or excellent. Mean weighted percent scores ± standard error (SE) were compared by Student's t-test analysis. Medians (IQR=interquartile range) were compared by Mann-Whitney U test (*p<0.05).

	PCH (N=107)	ECMO (N=103)	p-value
Composite score			
Mean ± SE	53.7% ± 2.2	49.6% ± 2.6	0.22
Median (IQR)	61.4% (33.0,72.9)	56.2% (23.9,74.1)	0.53
GOCD category			
Mean ± SE	43.1% ± 2.7	45.5% ± 2.9	0.54
Median (IQR)	47.0% (15.0,70.4)	48.8% (15.3,70.8)	0.48
Documentation category			
Mean ± SE	81.1% ± 1.6	60.1% ± 2.7	<0.0001*
Median (IQR)	83.5% (79.1, 100)	63.8% (42.9, 83.5)	0.75

The distributions of quality of EOL communication are bi-modal for PCH and ECMO cohorts, with modal distributation through 15-40% and 45-98% (Figure 2a,d). Looking at the GOCD category alone, the quality of EOL communication was poor with one-fifth PCH patients

and ECMO patients having little to no GOCD during hospital stay at weighted percent scores between 0-10 (Figure 2b,e). The quality of EOL Documentation had heavily distribution, >50% of patients, with mean weighted percent scores between 80-100% (Figure 2c,f).

Figure 2. Quality of EOL communication and documentation expressed as a weighted percent score for PCH patients in (a) Composite score, (b) Goals of Care Discussion (GOCD category), and (c) Documentation category. Distribution of quality of EOL communication in ICU patients that were placed on extracorporeal membrane oxygenation (ECMO) during hospital stay expressed as a weighted percent score in (d) Composite category, (e) GOCD category, and (f) Documentation category.



4.5 The influence of confounder variables on quality of EOL communication and documentation in Composite cohort

4.5.1 The independent variables not used in the analysis were APACHE II score and hospital mortality which were collinear with GCS. Of the non-collinear independent variables, those without predictive value (as defined in Section 3.9.2) on EOL communication outcomes for critical patients were hospital length of stay, timing of ACP status, and ACP status. Hospital length of stay does not have predictive value as it is not known until patient discharge, transfer or hospital mortality.

4.5.2 Similarly, ACP status and its first documentation often occurred at end of life for those that died. On average, ACP status documentation occurred 3.0 days after admission of PCH patients who eventually died in hospital, and significantly 3.2 times later for EMCO patients who died despite similar hospital length of stay in both cohorts (Table 1, Appendix 7). Given late documentation of ACP status, almost all patients who died had care limited by ACP status M or C prior to death (Appendix 7). 76.7% had ACP status C at any point while 16.7% had M status without C status. Indeed, ACP - M or C status was highly related to mortality compared to ACP – R status (Appendix 7). Therefore, first documentation of ACP status occurs late in hospital stay, and often occurs and is directed by the day of death; thus, has less predictive value.

4.5.3 The basic predictor variables were cohort, age, sex, year of admission, GCS, APS-neuro score, and Disease category. The extended predictor variables were socioeconomic quintile and urban status.

4.5.4 Regression Model 1: The quality of EOL communication and documentation is significantly ~10 weighted points worse in the ECMO cohort compared to the PCH

cohort (Table 3), despite having 1.25 times higher hospital mortality and significantly worse APACHE II total, GCS and APS-neuro score based on means (Table 1). This cohort analysis is adjusted by age, sex, year of admission, neurological and non-neurological status, and disease category. The mean age of the ECMO cohort is significantly younger at 46.0 compared to 67.7 with minimal difference in sex rates (Table 1). Furthermore, increased quality of EOL communication and documentation is closely associated to worsening neurological and non-neurological status of the patient on ICU admission (Table 3).

4.5.5 Regression Model 2: In PCH cohort, the quality of EOL communication and documentation is significantly reduced by ~13 weighted points for patients admitted to ICU for infectious diseases, and ~17 weighted points for respiratory diseases (Table 4) compared to cardiovascular cause. The comparison is adjusted by age, sex, year of admission, GCS, and APS-neuro (Table 4).

4.5.6 Regression Model 3: In ECMO cohort, the quality of EOL communication and documentation is significantly improved by ~2 weighted points with worsening neurological status (Table 5a,b), which is not affected by urban status nor socioeconomic quintile (Table 5a). These comparisons were adjusted for age, sex, year of admission, GCS, APS-neuro score (Table 5a,b) and the former (Table 5a) was adjusted for disease category as well.

4.5.7 11.2% of the PCH cohort involved a public trustee during hospital stay (Table 1) and this is associated to 1.4 times higher quality of EOL communication though not statistically significant when adjusted for age and sex (p=0.84). 1.9% of the ECMO cohort involved a public trustee during hospital stay (Table 1) and this was associated to 18.7 times higher

quality of EOL communication though not statistically significant when adjusted for age and sex (p=0.32).

Table 3. Regression Model 1: The quality of end of life (EOL) communication and documentation in patients receiving extracorporeal membrane oxygenation (ECMO) compared to patients residing in personal care homes (PCH) in intensive care units. SE: standard error (*p<0.05).

Predictor variable	Regression coefficient ± SE	P-value
Cohort	-9.97 ± 4.99	0.047*
Age (year)	0.16 ± 0.09	0.076
Sex	-3.15 ± 3.32	0.343
Year of admission	0.21 ± 0.85	0.807
GCS (per point)	-1.84 ± 0.51	0.000*
APS-neuro score (per point)	0.72 ± 0.34	0.033*
Disease category		
Cardiovascular	Reference	
Infectious	-7.75 ± 4.5	0.084
Respiratory	-8.19 ± 4.6	0.076
Other	-5.24 ± 5.4	0.334

Table 4. Regression Model 2: The quality of end of life (EOL) communication and documentation in patients residing in personal care homes (PCH) in intensive care units (ICUs). SE: standard error (*p<0.05).

Predictor variable	Regression coefficient ± SE	P-value
Age (year)	0.28 ± 0.16	0.081
Sex	-1.11 ± 4.45	0.803
Year of admission	-0.93 ± 1.56	0.553
GCS (per point)	-0.70 ± 0.78	0.373
APS-neuro score (per point)	-0.00 ± 0.49	0.999
Disease category		
Cardiovascular	Reference	--
Infectious	-13.0 ± 6.30	0.041*
Respiratory	-17.3 ± 7.40	0.022*
Other	-9.06 ± 6.65	0.176

Table 5a. The quality of end of life (EOL) communication and documentation in patients who received extracorporeal membrane oxygenation (ECMO) in intensive care units (ICUs) with urban status. SE: standard error (*p<0.05).

Predictor variable	Regression coefficient ± SE	P-value
Age	0.11 ± 0.13	0.426
Sex	-2.24 ± 5.57	0.688
Year of admission	0.23 ± 1.18	0.849
GCS	-2.37 ± 0.78	0.003*
APS-neuro score	1.07 ± 0.51	0.039
Disease category		
Cardiovascular	Reference	Reference
Infectious	-7.31 ± 7.39	0.325
Respiratory	-5.83 ± 6.84	0.396
Other	-2.50 ± 13.8	0.856
Urban status	1.92 ± 6.29	0.761

Table 5b. The quality of end of life (EOL) communication and documentation in patients who received extracorporeal membrane oxygenation (ECMO) in intensive care units (ICUs) with socioeconomic quintile. SE: standard error; (*p<0.05).

Predictor variable	Regression coefficient ± SE	P-value
Age (year)	0.09 ± 0.13	0.505
Sex	-2.14 ± 5.51	0.698
Year of admission	0.30 ± 1.16	0.800
GCS (per point)	-1.99 ± 0.73	0.008*
APS-neuro score (per point)	0.76 ± 0.47	0.110
Socioeconomic quintile		
1st quintile	Reference	Reference
2nd quintile	2.62 ± 7.34	0.722
3rd quintile	10.5 ± 9.32	0.262
4th quintile	8.09 ± 7.87	0.307
5th quintile	-2.91 ± 7.69	0.706

5.0 DISCUSSION

5.1 Despite ECMO cohort being the sicker group with disease severity on admission and worse prognosis during hospital stay (Table 1), quality of EOL communication and documentation poor overall and worse than PCH cohort (Table 2-3, Figure 2e, Appendix 5). GOCD was more thoroughly and frequently covered in the PCH cohort; however, ECMO cohort had higher rate of QI G1 (Appendix 5). Indeed, we expect higher communication rates of poor prognosis and limited remaining lifespan as the ECMO cohort is the sicker population with higher in-hospital mortality rate (Table 1). Frequency rates are lower for goals of care discussion (GOCD) especially indicators involving discussion of patient fears and concerns (G9) and involving patient competency and consent (G11) in either cohort.

While there is little data in literature on the quality of EOL communication and documentation for patients on ECMO, guidelines have been published to improve goals of care discussions. (52) Consistent with the frequencies of QIs, the low weighted percent scores of GOCD diminishes the overall quality of EOL communication and documentation in Composite, PCH and ECMO cohorts as Documentation weighted scores were good to excellent. EOL documentation in PCH cohort was especially higher quality compared to ECMO cohort, likely due to higher incidence of previous ACP documents and previous conversations with family from the community that were carried into the hospital stay (Appendix 5, G5, D5).

5.2 Most medical charts had thorough EOL documentation with QI D1-D4 being present over 60% of the time in PCH cohort and over 50% in ECMO cohort (Appendix 5). Though QI D5 was poorly documented (Appendix 5), Heyland et al. have suggested its omission from assessment in order to maintain internal consistency. (32) These results show that healthcare members are very good or excellent at documenting ACP status and conversations around artificial life support.

5.3 The QI frequencies were consistently and greatly higher in PCH and ECMO cohorts compared to the general intensive care (ICU) population (Appendix 5). Exceptions where ICU population had slightly higher frequencies than PCH and ECMO, though still low rates, involved discussion of patient's fears and concerns, capacity and consent, information on GOCD, and documentation of ACP conversation (G9, G11, G13, and D4). These differences between our cohorts and ICU population may reflect the wide variance in EOL communication and documentation between hospitals across Canada, though inter-rater reliability has not been tested. Challenges to some of these QIs can also be explained by barriers to EOL communication and documentation, which has been explored in literature and can be categorized into limitations of the healthcare member's knowledge, attitudes and practice. (50,51) Some examples that may be applied to this study: knowledge creates limits if training for communication with patient and their families is insufficient; attitudes are affected by whether the family is available for discussion or if the health care member found discussion unnecessary; and practice inhibits communication if it is assumed that decision-making should be postponed until all treatment options must have been exhausted. (50,51)

5.4 PCH patients experience clinically significant worse quality of EOL communication and documentation with ICU admission diagnosis of infectious or respiratory cause compared to cardiovascular etiology (Table 4). It is interesting the cardiovascular disease on admission predicts better quality of EOL care considering these ICU patients were admitted with better disease severity scores compared to those admitted for non-cardiovascular diseases. (13) However, our data shows disease category being associated to non-neurological disease severity score (APS-neuro) by chi squared test (*p=0.043), and not APACHE II score nor GCS. Despite worse non-neurological status, cardiovascular diagnosis is not associated to increased mortality (p=0.13).

5.5 It is known that outcomes for patients on ECMO for admitting diagnosis of cardiac arrest are worse compared to respiratory causes with in-hospital mortality of >50%, prolonged length of stay, and high survivor readmission rates. (29,53) Good outcomes have been reported for patients on ECMO support due to severe bacterial septic shock. (49) Interestingly, age in addition to body mass index, immunocompromised status, prone positioning, length of days on mechanical ventilation, sepsis-related organ failure assessment, plateau pressure and positive end-expiratory pressure have been together composed into a PRESERVE score for severe ARDS to predict short-term mortality on ECMO and to stratify intensive care patients for ECMO candidacy. (53)

5.6 The patients in our cohorts were sicker than the general Manitoba ICU population with APACHE II scores 1.6-1.8X that of the general average 15.74 (10,13), though APS

scores were similar to the Manitoba average of 11.0 (Table 1) (likely due to discordant neurological and non-neurological measures). Hospital mortality was much higher in PCH and ECMO cohorts at rates 2.2-2.9X that of the provincial rate as expected in these elderly and/or sick patients. (5,10,28,45–48,12–14,21–24,26) The ECMO mortality rate in this study was consistent with the 47-50% in-mortality rate reported in literature including in CESAR. (22,29,49) Consistent with provincial data, the poorest socioeconomic group was most likely to be admitted to ICU and receive ECMO support. The rate of ECMO initiation decreased with increasing socioeconomic status as expected except for the 5th quintile which was similar to the 2nd quintile (Table 1). (10,13)

5.6 In our study, our cohorts PCH cohorts were older and our ECMO cohort was younger than the provincial average in ICU. The mean age of the PCH cohort, 68 years old, was similar to the mean age of all ICU patients in Manitoba, 64.5 years old. Both PCH cohort and general ICU age peaked at 75 to 80. However, rates rose later for the PCH cohort at 62 years old rather than at 40 years old in the general ICU population. The mean age of the ECMO cohort was much younger than that of all ICU patients - 0.7X that of the general ICU average (Table 1). (10,13) The male: female ratio was 1.23 for the PCH cohort and 1.43 for the ECMO cohort, which were slightly lower compared to 1.75 for the general ICU population in Manitoba. (10,13)

In keeping with the provincial trend, the number of PCH resident admission to ICU increased over time; however, the number of patients on ECMO in ICU fluctuated over time (Table 1). (10,13) The mean hospital length of stay in this study is lower at 0.5-

0.8X that of the provincial average of 43 days (Table 1). (43) The most common disease categories that lead of ICU admission were cardiovascular, infectious and respiratory causes consistently in both PCH and ECMO cohorts (Table 1) and in comparison to the general ICU population in Manitoba. (35)

5.7 At the time of this research, no other studies were found with quantitative parameters to assess quality of EOL communication and documentation. The quality of EOL communication in ICUs has been qualitatively assessed by patient and family member satisfaction via surveys and interviews. Interventional studies have shown improved EOL care with advanced care planning based on measures of increased involvement of the patient in decision-making, increased patient and family satisfaction. (5) In another interventional study, Connors *et al.* tasked a skilled nurse in the healthcare team to help provide timely and reliable prognostic information, and to convene meetings so as to elicit and document patient and family preferences and their understanding of the disease progression and treatment. The research group aimed to incorporate 14 elements of EOL communication and documentation with early intervention in the hospital admission to prompt better EOL communication and decision-making for severely ill patients. (44) Though this study reported no impact on rate and timing of documentation, patient-physician communication, physician awareness of existing EOL documents for their patients, number of days spent in ICU, number of days on artificial life support, or comatose before death, it is one of the only studies to quantify quality indicators and its intervention to improve EOL care. Despite the existence of numerous EOL communication skills training in the healthcare community, assessing the effect of this

intervention has been difficult due to poor reporting and weak methodology. (45) Different groups have developed quality indicators for EOL communication with overlapping content, but these have not been validated nor tested for feasibility. (46)

5.8 This study was limited by documentation practices of healthcare members as QIs including discussion indicators were extracted from what was recorded in the paper or electronic medical charts. QIs not documented does not necessarily mean QIs were not discussed and not handed over to healthcare team members. Indeed, it would be impractical to document every time the patient and family members were notified that they may change their mind around goals of care at any point. However, the standard for documentation necessitates ACP – Goals of Care revision on each admission and whenever there is an unanticipated significant change in clinical status. (47) Our hospital length of stay and extraction of QIs was inconsistent as we could only access hospital length of stay from the medical charts from our two hospitals. If the patient had been transferred to HSC or St. B from a different hospital, or if the patient was transferred from HSC or St. B to a different hospital without copies included in the HSC or St.B medical chart then there are gaps of data in the hospital stay. Also, this research does not compare QIs as documented in medical charts for their concordance with patient's preferences, goals and wishes. Though consistency between documented ACP status and care provided was high, some of this care may not have been wanted in review of the medical charts. The sample sizes of each cohort were small, given the number of categories for analysis especially for the ECMO cohort. Furthermore, our findings may not be generalizable to non-teaching hospitals as only two hospitals in Winnipeg, both

teaching hospitals were included in this research. We did not assess the inter-rater reliability of these QIs which could lead to discrepancy in our comparisons with Heyland *et al*.'s study (32). Finally, we did not assess long-term outcomes after discharge or transfer from HSC or St. B, though some patients were transferred back to PCHs or centers for palliative care.

6.0 CONCLUSION

In conclusion, we assessed the quality of end-of-life (EOL) communication and documentation in two subgroups of intensive care unit (ICU) patients: (i) those who reside in personal care homes (PCH) and (ii) those with severe respiratory failure placed on extracorporeal membrane oxygenation (ECMO). Overall the quality of EOL communication and documentation was poor or good with need for improvement in GOCD, and for patients who receive ECMO support. Addressing these gaps in EOL care are important to improve patient-centered care and reduce harm for these especially ill and/or elderly patients, while significantly lowering healthcare costs.

7.0 ACKNOWLEDGEMENTS

We would like to thank Julie Mojica for her aid in extracting and compiling data from the Winnipeg Adult ICU database.

8.0 REFERENCES

1. Statistics Canada. Deaths in hospital and elsewhere, Canada, provinces and territories. 2015.
2. Heyland DK, Lavery J V, Tranmer JE, Shortt SE, Taylor SJ. Dying in Canada: is it an institutionalized, technologically supported experience? J Palliat Care [Internet]. 2000 Oct [cited 2017 Nov 27];16 Suppl:S10-6. Available from: http://www.ncbi.nlm.nih.gov/pubmed/11075528
3. Bekelman JE, Halpern SD, Blankart CR, Bynum JP, Cohen J, Fowler R, et al. Comparison of Site of Death, Health Care Utilization, and Hospital Expenditures for Patients Dying With Cancer in 7 Developed Countries. JAMA [Internet]. 2016 Jan 19 [cited 2017 Nov 27];315(3):272. Available from: http://jama.jamanetwork.com/article.aspx?doi=10.1001/jama.2015.18603
4. DeCaria K, Dudgeon D, Green E, Moxam RS, Rahal R, Niu J, et al. Acute care hospitalization near the end of life for cancer patients who die in hospital in Canada. Curr Oncol [Internet]. 2017 Aug 31 [cited 2017 Nov 27];24(4):256–61. Available from: http://www.current-oncology.com/index.php/oncology/article/view/3704/2510
5. Detering KM, Hancock AD, Reade MC, Silvester W. The impact of advance care planning on end of life care in elderly patients: randomised controlled trial. BMJ [Internet]. 2010 [cited 2017 Nov 27];2010(340):c1345. Available from: http://www.bmj.com/content/bmj/340/bmj.c1345.full.pdf
6. Zhang B, Wright AA, Huskamp HA, Nilsson ME, Maciejewski ML, Earle CC, et al. Health Care Costs in the Last Week of Life. Arch Intern Med [Internet]. 2009 Mar 9 [cited 2017 Nov 27];169(5):480. Available from: http://archinte.jamanetwork.com/article.aspx?doi=10.1001/archinternmed.2008.587
7. You J, Heyland D, Dodek P, Lamontagne F, Barwich D, Tayler C, et al. Opportunities to improve end-of-life communication and decision-making for seriously ill hospitalized patients and their families. BMJ Support Palliat Care [Internet]. 2012;2:190. Available from: http://dx.doi.org/10.1136/bmjspcare-2012-000250.75%0A%0A
8. Neville TH, Tarn DM, Yamamoto M, Garber BJ, Wenger NS. Understanding Factors Contributing to Inappropriate Critical Care: A Mixed-Methods Analysis of Medical Record Documentation. J Palliat Med [Internet]. 2017 Nov 1 [cited 2018 Feb 5];20(11):1260–6. Available from: http://online.liebertpub.com/doi/10.1089/jpm.2017.0023
9. Durepos P, Kaasalainen S, Sussman T, Parker D, Brazil K, Mintzberg S, et al. Family care conferences in long-term care: Exploring content and processes in end-of-life communication. Palliat Support Care [Internet]. 2017 Dec 29 [cited 2018 Feb 5];1–12. Available from: https://www.cambridge.org/core/product/identifier/S1478951517000773/type/journal_article
10. Garland A, Olafson K, Ramsey CD, Yogendran M, Fransoo R. Epidemiology of critically ill patients in intensive care units: a population-based observational study. Crit Care [Internet]. 2013;17(5):R212. Available from: http://ccforum.biomedcentral.com/articles/10.1186/cc13026
11. Fransoo R, Olafson K, Ramsey C, Yogendran M, Chateau D, Mcgowan K. The Use of Intensive Care Units in Manitoba. Winnipeg; 2012.
12. DeCoster C, Kozyrskyj A. Long-Stay Patients in Winnipeg Acute Care Hospitals.

Winnipeg; 2000.
13. Garland A, Frandsoo R, Olafson K, Ramsey C, Yogendren M, Chateau D, et al. The epidemiology and outcomes of critical illness in Manitoba [Internet]. Winnipeg; 2012. Available from: http://myaccess.library.utoronto.ca/login?url=http://site.ebrary.com/lib/utoronto/Top?id=10585999
14. Perkins E, Gambles M, Houten R, Harper S, Haycox A, O'Brien T, et al. The care of dying people in nursing homes and intensive care units: a qualitative mixed-methods study. Heal Serv Deliv Res. 2016;4(20).
15. Percival J, Johnson M. End-of-life care in nursing and care homes. Nurs Times [Internet]. [cited 2017 Nov 29];109(1–2):20–2. Available from: http://www.ncbi.nlm.nih.gov/pubmed/23431951
16. Goddard C, Stewart F, Thompson G, Hall S. Providing End-of-Life Care in Care Homes for Older People. J Appl Gerontol [Internet]. 2013 Feb 26 [cited 2017 Nov 29];32(1):76–95. Available from: http://journals.sagepub.com/doi/10.1177/0733464811405047
17. Johnson S, Bott MJ. Communication with Residents and Families in Nursing Homes at the End of Life. J Hosp Palliat Nurs [Internet]. 2016 Apr 1 [cited 2017 Nov 29];18(2):124–30. Available from: http://www.ncbi.nlm.nih.gov/pubmed/27110223
18. Bartlett R. Extracorporeal membrane oxygenation (ECMO) in adults [Internet]. UpToDate. 2017 [cited 2017 Nov 27]. Available from: https://www-uptodate-com.uml.idm.oclc.org/contents/extracorporeal-membrane-oxygenation-ecmo-in-adults?source=search_result&search=ecmo&selectedTitle=1~150
19. Robba C, Ortu A, Bilotta F, Lombardo A, Sekhon MS, Gallo F, et al. Extracorporeal membrane oxygenation for adult respiratory distress syndrome in trauma patients. J Trauma Acute Care Surg [Internet]. 2017 Jan [cited 2017 Nov 27];82(1):165–73. Available from: http://content.wkhealth.com/linkback/openurl?sid=WKPTLP:landingpage&an=01586154-201701000-00023
20. ARDS Definition Task Force, Ranieri VM, Rubenfeld GD, Thompson BT, Ferguson ND, Caldwell E, et al. Acute Respiratory Distress Syndrome. JAMA [Internet]. 2012 Jun 20 [cited 2017 Nov 27];307(23):2526–33. Available from: http://www.ncbi.nlm.nih.gov/pubmed/22797452
21. Sadahiro T, Oda S, Nakamura M, Hirayama Y, Watanabe E, Tateishi Y, et al. Trends in and perspectives on extracorporeal membrane oxygenation for severe adult respiratory failure. Gen Thorac Cardiovasc Surg. 2012;60(4):192–201.
22. Peek GJ, Mugford M, Tiruvoipati R, Wilson A, Allen E, Thalanany MM, et al. Efficacy and economic assessment of conventional ventilatory support versus extracorporeal membrane oxygenation for severe adult respiratory failure (CESAR): a multicentre randomised controlled trial. Lancet [Internet]. 2009;374(9698):1351–63. Available from: http://dx.doi.org/10.1016/S0140-6736(09)61069-2
23. Tiruvoipati R, Botha J, Peek G. Effectiveness of extracorporeal membrane oxygenation when conventional ventilation fails: Valuable option or vague remedy? J Crit Care [Internet]. 2012;27(2):192–8. Available from: http://dx.doi.org/10.1016/j.jcrc.2011.04.003
24. Mao J, Paul S, Sedrakyan A. The evolving use of ECMO: The impact of the CESAR trial. Int J Surg [Internet]. 2016;35:95–9. Available from: http://dx.doi.org/10.1016/j.ijsu.2016.09.081

25. Walkey AJ, Wiener RS. Utilization Patterns and Patient Outcomes Associated with Use of Rescue Therapies in Acute Lung Injury. Crit Care Med. 2012;39(6):1322–8.
26. Roussel A, Al-Attar N, Alkhoder S, Radu C, Raffoul R, Alshammari M, et al. Outcomes of percutaneous femoral cannulation for venoarterial extracorporeal membrane oxygenation support. Eur Hear J Acute Cardiovasc Care [Internet]. 2012;1(2):111–4. Available from: http://journals.sagepub.com/doi/10.1177/2048872612449417
27. Hemmila MR, Rowe SA, Boules TN, Miskulin J, McGillicuddy JW, Schuerer DJ, et al. Extracorporeal Life Support for Severe Acute Respiratory Distress Syndrome in Adults. Trans . Meet Am Surg Assoc [Internet]. 2004;CXXII(NA;):193–205. Available from: http://content.wkhealth.com/linkback/openurl?sid=WKPTLP:landingpage&an=00153307-200401220-00021
28. Aso S, Matsui H, Fushimi K, Yasunaga H. In-hospital mortality and successful weaning from venoarterial extracorporeal membrane oxygenation: analysis of 5,263 patients using a national inpatient database in Japan. Crit Care [Internet]. 2016;20(1):80. Available from: http://ccforum.biomedcentral.com/articles/10.1186/s13054-016-1261-1
29. Huesch MD, Foy A, Brehm C. Survival Outcomes Following the Use of Extracorporeal Membrane Oxygenation as a Rescue Technology in Critically Ill Patients. Crit Care Med [Internet]. 2018 Jan [cited 2019 May 12];46(1):e87–90. Available from: http://www.ncbi.nlm.nih.gov/pubmed/29112078
30. Bein T, Brodie D. Understanding ethical decisions for patients on extracorporeal life support. Intensive Care Med. 2017;43(10):1510–1.
31. Sinuff T, Dodek P, You JJ, Barwich D, Tayler C, Downar J, et al. Improving End-of-Life Communication and Decision Making: The Development of a Conceptual Framework and Quality Indicators. J Pain Symptom Manage [Internet]. 2015 Jun 1 [cited 2017 Nov 25];49(6):1070–80. Available from: http://www.ncbi.nlm.nih.gov/pubmed/25623923
32. Heyland DK, Dodek P, Mhsc M, You JJ, Msc M, Sinuff T, et al. Validation of quality indicators for end-of-life communication: results of a multicentre survey. C | JULY [Internet]. 2017 [cited 2017 Nov 26];31(189). Available from: http://www.cmaj.ca/content/cmaj/189/30/E980.full.pdf
33. Hanley GE, Morgan S. On the validity of area-based income measures to proxy household income. BMC Health Serv Res [Internet]. 2008 Apr 10 [cited 2018 Feb 19];8:79. Available from: http://www.ncbi.nlm.nih.gov/pubmed/18402681
34. Statistics Canada. From urban areas to population centers. Standard Geographication Classification, VOlume 1. 2011.
35. Spence J, Bell DD, Garland A. Variation in diagnostic testing in ICUs: a comparison of teaching and nonteaching hospitals in a regional system. Crit Care Med. 2014;42(1):9–16.
36. Winnipeg Regional Health Authority. Advance Care Planning - Goals of Care [Internet]. 1-5. 2011 [cited 2018 Feb 20]. Available from: http://www.wrha.mb.ca/about/policy/files/110.000.200.pdf
37. Knaus WA, Draper EA, Wagner DP, Zimmerman JE. APACHE II: a severity of disease classification system. Crit Care Med [Internet]. 1985 Oct [cited 2018 Feb 20];13(10):818–29. Available from: http://www.ncbi.nlm.nih.gov/pubmed/3928249
38. Teasdale G, Jennett B. Assessment of coma and impaired consciousness: a practical scale. Lancet. 1974;2(7872):81–4.
39. Paiva CE, Barroso EM, Carneseca EC, de Pádua Souza C, Dos Santos FT, Mendoza López RV, et al. A critical analysis of test-retest reliability in instrument validation studies

of cancer patients under palliative care: a systematic review. BMC Med Res Methodol [Internet]. 2014 Jan 21 [cited 2018 Mar 24];14:8. Available from: http://www.ncbi.nlm.nih.gov/pubmed/24447633
40. Shoukri M. Sample size requirements for the design of reliability study: review and new results. [cited 2018 Mar 24]; Available from: http://journals.sagepub.com.uml.idm.oclc.org/doi/pdf/10.1191/0962280204sm365ra
41. Ock M, Lee S, Jo M-W, Lee JY, Kim S-H. Assessing Reliability of Medical Record Reviews for the Detection of Hospital Adverse Events. J Prev Med Public Health [Internet]. 2015 Sep [cited 2018 Mar 24];48(5):239–48. Available from: http://www.ncbi.nlm.nih.gov/pubmed/26429290
42. Fox J. Collinearity. In: Sage University Paper Series on Quantitative Applications in the Social Sciences, editor. Regression Diagnostics. 07–079 ed. Newbury Park, CA: SAGE Publications; 1991. p. 11–21.
43. Management I. Manitoba Health, Seniors and Active Living [Internet]. 2016 [cited 2019 May 12]. Available from: https://www.gov.mb.ca/health/annstats/as1617.pdf
44. Connors AF, Dawson N V., Desbiens NA, Fulkerson WJ, Goldman L, Knaus WA, et al. A Controlled Trial to Improve Care for Seriously III Hospitalized Patients. JAMA [Internet]. 1995 Nov 22 [cited 2018 Feb 20];274(20):1591. Available from: http://jama.jamanetwork.com/article.aspx?doi=10.1001/jama.1995.03530200027032
45. Jane Brighton L, Koffman J, Hawkins A, McDonald C, Robinson V, Khan SA. A Systematic Review of End-of-Life Care Communication Skills Training for Generalist Palliative Care Providers: Research Quality and Reporting Guidance. J Pain Symptom Manage [Internet]. 2017 [cited 2017 Nov 26];54(417). Available from: http://dx.doi.org/10.1016/j.jpainsymman.2017.04.008
46. De Roo ML, Leemans K, Claessen SJJ, Cohen J, Roeline H, Pasman W, et al. Quality Indicators for Palliative Care: Update of a Systematic Review. J Pain Symptom Manage [Internet]. 2013 [cited 2017 Nov 26];46(4):556–72. Available from: http://dx.doi.org/10.1016/j.jpainsymman.2012.09.013
47. Winnipeg Regional Health Authority. Advance Care Planning Policy - Goals of Care [Internet]. 2011 [cited 2019 Apr 27]. Available from: http://www.wrha.mb.ca/professionals/acp/index.php

9.0 APPENDIX

Appendix 1. Master Identifier List

Serial Identifier	Medical Records no.	Date of ICU admission	Date of ICU discharge	Initials	Sex	Year of birth	Age on admission	Full postal code
1								
…								
…								
…								
210								

Appendix 2. De-Identified Records List.

Serial Identifier	Cohort	Sex	Age	Date of hospital admission	Date of hospital discharge	ECMO type	ACP - M	ACP - C	Hospital mortality	Public trustee	Disease category	Socioeconomic quintile	Residential status	First date of QI D5	APACHE II	APS	APS-neuro
1																	
…																	
…																	
…																	
210																	

Appendix 3. Quality Indicators List. Quality indicators for Goals of Care and Documentation categories as written by Sinuff *et al.* (31) but used with modifications for this study.

	SERIAL IDENTIFER:	"0" or "1"
Goals Of Care Decisions and consent for medical treatments (GOCD) Category		
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.	
2	Since hospital admission, member of the health care team has talked to patient and/or substitute decision maker about artificial life support.	
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.	
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.	
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.	
6	Since hospital admission, member of health care team has asked patient what treatments they prefer to have or not have if they develop a life-threatening illness.	
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.	
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.	
9	Since hospital admission, member of health care team has given patient opportunity to express their fears or discuss what concerns them.	
10	Since hospital admission, patient has been informed that they may change their minds regarding their decisions around goals of care.	
11	Since hospital admission, patient 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.	
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.	
13	Since hospital admission, member of health care team provided patient/family information about GOCD to look at before conversations with the doctor.	
Documentation Category		
1	Documentation of a Goals of Care is present in medical record.	
2	Goals of Care present in the medical record is consistent with patient's stated preferences.	
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.	
4	Documentation of ACP conversation is in patient's medical record.	
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.	

Appendix 4. Quality indicators listed in order of most to least important in each category, goals of care discussion (GOCD) and Documentation, which was determined by Sinuff *et al.* (31) by Delphi process by of group of interdisciplinary experts who gave weighted score on a scale of 1 to 7, then expressed as a mean weighted score.

Quality Indicator	
GOCD	**Mean of importance/ Weights**
1. Since 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.	6.75
2. Since admission, member of the health care team has talked to patient and/or substitute decision maker about artificial life support.	6.63
3. Since 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.	6.63
4. Since 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	6.58
5. Since 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.	6.50
6. Since admission, member of health care team has asked patient what treatments they prefer to have or not have if they develop a life-threatening illness.	6.29
7. Since 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.	6.29
8. Since 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.	6.25
9. Since admission, member of health care team has given patient opportunity to express their fears or discuss what concerns them.	6.20
10. Since admission, patient has been informed that they may change their minds regarding their decisions around goals of care.	5.92
11. Since admission, patient 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.	5.71
12. Since 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.	5.63
13. Since admission, member of health care team provided patient/family information about GOCD to look at before conversations with the doctor.	5.42
DOCUMENTATION	
1. Documentation of a Goals of Care is present in medical record.	6.71
2. Goals of Care present in the medical record is consistent with patient's stated preferences.	6.71
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.	6.54
4. Documentation of ACP conversation is in patient's medical record.	6.17
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	5.17

Appendix 5. The most frequent quality indicators are documentation indicators in both personal care home (PCH) and extracorporeal membrane oxygenation (ECMO) cohorts

Quality Indicator	**PCH**	**ECMO**	**ICU**
GOCD	**Yes**	**Yes**	**Yes**
G1. 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.	51 (47.7%)	74 (71.8%)	55 (13.9%)
G2. Since hospital admission, member of the health care team has talked to patient and/or substitute decision maker about artificial life support.	68 (63.6%)	76 (73.8%)	57 (14.4%)
G3. 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.	45 (42.1%)	50 (48.5%)	61 (15.4%)
G4. 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	72 (67.3%)	74 (71.8%)	58 (14.6%)
G5. 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.	52 (48.6%)	32 (31.1%)	109 (27.5%)
G6. 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.	63 (58.9%)	51 (49.5%)	143 (36.0%)
G7. 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.	38 (35.5%)	40 (38.8%)	58 (14.6%)
G8. 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.	54 (50.5%)	41 (39.8%)	108 (27.2%)
G9. 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.	16 (15.0%)	24 (23.3%)	102 (25.7%)
G10. Since hospital admission, patient/substitute decision maker has been informed that they may change their minds regarding their decisions around goals of care.	62 (57.9%)	56 (54.4%)	81 (20.4%)
G11. 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.	9 (8.4%)	10 (9.7%)	42 (10.6%)
G12. 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.	56 (52.3%)	69 (67.0%)	80 (20.2%)
G13. Since hospital admission, member of health care team provided patient/family information about GOCD to look at before conversations with the doctor.	0	0	30 (7.6%)
DOCUMENTATION	**Yes**	**Yes**	**Yes**
D1. Documentation of a Goals of Care is present in medical record.	106 (99.1%)	90 (87.4%)	321 (80.9%)
D2. Goals of Care present in the medical record is consistent with patient's stated preferences.	106 (99.1%)	89 (86.4%)	113 (28.5%)
D3. 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.	95 (88.8%)	53 (51.5%)	228 (57.4%)
D4. Documentation of ACP conversation is in patient's medical record.	71 (66.4%)	59 (57.3%)	363 (91.5%)
D5. 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	43 (40.2%)	5 (4.9%)	11 (2.8%)

Appendix 6. Advanced care planning (ACP) status documentation occurs late in hospital stay especially for in-hospital deaths, and ACP status is highly related to mortality. Binary comparison between cohorts analyzed by t-test analysis while categorical variables analyzed by chi square test (*p <0.05). Values expressed as [# of deaths (% of deaths)] unless otherwise indicated. SE: standard error; IQR: interquartile range

	Total deaths = 90		
	Death in PCH (N=40)	Death in ECMO (N=50)	p-value
Timing of ACP status			
Mean ± SE	3.0 ± 0.7	9.5 ± 1.8	0.0000*
Median (IQR)	1 (1,6.75)	2 (1,9.5)	0.31
ACP status			
ACP – R without M or C	6 (6.6%)		
ACP – M without C	15 (16.7%)		0.0000*
ACP – C at any point	69 (76.7%)		
Missing ACP status	0		

Appendix 7. Higher quality of EOL communication and documentation is highly associated with limitation status on care with advanced care planning (ACP) status of M or C in Composite, PCH and ECMO cohorts. Quality of EOL communication and documentation also increases with longer hospital length of stay for PCH patients. These regression models with the non-predictor independent variables are adjusted for age, sex, year of admission, non-neurological status (APS-neuro), and neurological status (GCS) (*p<0.05).

Independent variable	Regression coefficient ± SE	P-value	95% CI	
Composite cohort (N=210)				
Hospital length of stay (days)	0.08 ± 0.04	0.035	0.01	0.15
Timing of ACP status (days)	0.02 ± 0.10	0.820	-0.18	0.23
ACP status				
ACP – R without M or C	--			
ACP – M without C	23.4 ± 3.33	0.0000*	16.8	30.0
ACP – C at any point	35.7 ± 2.94	0.0000*	30.0	41.5
Missing ACP status	Not tested			
PCH cohort (N=107)				
Hospital length of stay (days)	0.10 ± 0.12	0.041*	0.00	0.19
Timing of ACP status (days)	0.30 ± 0.23	0.194	-0.15	0.75
ACP status				
ACP – R without M or C	--			
ACP – M without C	23.6 ± 4.01	0.000*	15.6	31.5
ACP – C at any point	39.3 ± 4.25	0.000*	30.9	47.7
Missing ACP status	Not tested			
ECMO (N=103)				
Hospital length of stay (days)	0.07 ± 0.74	0.336	-0.08	0.23
Timing of ACP status (days)	-0.03 ± 0.14	0.807	-0.30	0.24
ACP status			4.77	
ACP – R without M or C	-0			
ACP – M without C	24.5 ± 9.91	0.016*		44.2
ACP – C at any point	32.3 ± 4.57	0.0000*		41.4
Missing ACP status	Not tested			