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Patient and Family Engagement During Treatment Decisions in an Intensive Care Unit: A Discourse Analysis of the Electronic Health Record

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Abstract

Objective: Shared decision making is recommended for critically ill adults who face major, preference-sensitive treatment decisions. Yet, little is known about when and how patients and families are engaged in treatment decision making over the longitudinal course of a critical illness. We sought to characterize patterns of treatment decision making by evaluating clinician discourse in the electronic health record (EHR) of critically ill adults who develop chronic critical illness or die in an intensive care unit (ICU).

Design, Setting, and Patients: We conducted qualitative content analysis of the EHR of 52 adult patients, admitted to a medical ICU in a tertiary medical center from January 1 through December 31, 2016. We included patients who met a consensus definition of chronic critical illness (26 patients) and a matched sample who died or transitioned to hospice care in the ICU before developing chronic critical illness (26 patients).

Measurements: Characterization of clinician decision-making discourse documented during the course of an ICU stay.

Main Results: Clinician decision-making discourse in the EHR followed a single, consistent pattern across both groups. Initial decisions about admission to the intensive care unit focused on specific interventions that can only be provided in an ICU environment (intervention-focused decisions). Following admission, the documented rationale for additional treatments was guided

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by physiologic abnormalities (physiology-centered decisions). Clinician discourse transitioned to documented engagement of patients and families in decision making when treatments failed to achieve specified physiologic goals. The phrase “goals of care” is common in the EHR and is used to indicate poor prognosis, to describe conflict with families, and to provide rationale for treatment limitations.

Conclusions: Clinician discourse in the EHR reveals that patient physiology strongly guides treatment decision making throughout the longitudinal course of critical illness. Documentation of patient and family engagement in treatment decision making is limited until available medical treatments fail to achieve physiologic goals.

Keywords

Decision Making; End-of-Life Care; Physician-Patient Relationship; Critical Illness; Electronic Health Records; Goals

INTRODUCTION

When caring for critically ill adults in an intensive care unit (ICU), intensivists face the complex challenge of ensuring that potentially life-saving but burdensome medical treatments align with each patient’s preferences, goals, and values. While many older adults with serious illness report preferences to avoid high-burden medical treatments and to optimize quality of life and comfort, some adults prioritize life extension and accept the use of life-sustaining treatments (LSTs) such as mechanical ventilation.(1–5) Moreover, accurate prognostication for critically ill patients is challenging, many patients and families are unfamiliar with ICU treatments and their potential outcomes, and patient preferences may change over time or when faced with the possibility of death.(6–13)

To address these challenges, critical care professional organizations recommend the process of shared decision making (SDM),(14–16) which requires the engagement of patients or their surrogates in decision making and the deliberation about patient goals and preferences.(14, 17–20) While not all medical decisions require SDM, this process is recommended for treatment decisions that involve high uncertainty or risk, or potential outcomes that may be unacceptable to patients (i.e., preference-sensitive decisions).(14, 21–23)

Efforts to evaluate SDM in the ICU have primarily focused on organized family meetings,(24–30) although many treatment decisions are made outside of these meetings.(31) Patients with critical illness experience a constant series of tests, procedures, and treatments as their clinical course unfolds over days to weeks,(32–34) and ICU physicians make numerous treatment decisions, often in quick succession. Many of these urgent, daily decisions involve considerable uncertainty, risk, and have preference-sensitive outcomes, thereby meeting the threshold for SDM. However, when and how patients and families are engaged during these multiple treatment decisions over the course of critical illness remains poorly understood.

Understanding the longitudinal nature of SDM in the ICU is particularly important for the 400,000 patients in the United States who receive prolonged LSTs because of a syndrome known as chronic critical illness (CCI).(35) Most patients with CCI spend weeks to months

in an ICU, and face many decisions about LSTs over the course of their illness. The one-year mortality rate for patients with CCI is approximately 60%, and few survivors return home or to their prior functional status.(36–42) Thus, the use of prolonged LSTs in CCI is considered a highly preference-sensitive decision that calls for patient and family engagement.(42)

This study sought to characterize patterns of treatment decision making in the ICU for patients at risk for poor outcomes, to understand how and when patients and families are engaged in treatment decisions over the longitudinal course of critical illness. We conducted a multiple-case, qualitative analysis (28) of clinician discourse in the electronic health record (EHR) for patients who developed CCI or died in the ICU before the onset of CCI (decedents). We expected to find that discourse about patient and family engagement and patient goals, values, and preferences would be different in decedents compared to patients who develop CCI.

MATERIALS AND METHODS

Case Selection

We identified adult patients admitted to a medical ICU (MICU) in a tertiary care medical center from January 1 through December 31, 2016. We identified patients who developed CCI based on a published, consensus definition: ≥ 8 days in an ICU and one of six qualifying conditions (prolonged mechanical ventilation, tracheostomy, stroke, traumatic brain injury, sepsis, or severe wounds).(35) We used purposive sampling(43) to enrich the CCI group by excluding patients who did not meet one of three additional criteria: discharge to long-term acute care hospital, receipt of tracheostomy, or hospitalization ≥ 21 days. We generated a matched (1:1 by age, sex, ICU day 1 Sequential Organ Failure Assessment (SOFA) score (44–46)) decedent group with the same qualifying conditions as the CCI group who died or transitioned to hospice in the ICU before developing CCI. Supplemental Appendix A provides complete CCI and decedent group definitions. The Northwestern University Institutional Review Board approved the study and waived need for informed consent.

Data Collection

Using a standardized tool (Supplemental Appendix B), we abstracted all EHR notes from each patient's ICU stay, including notes from all professions (e.g., nurses, physicians, chaplains) and professional levels (e.g., advanced practice providers, residents, fellows, and attending physicians). For patients with ICU stays ≥ 21 days, data from the first 20 ICU days and discharge documentation were abstracted. We catalogued all abstracted data by ICU day and generated a chronologic "illness log" for each patient.

Analysis

We conducted qualitative content analysis of the verbatim EHR text in each illness log. Our approach was informed by the principles of discourse analysis, which is used to expose function and meaning of naturally occurring text and language in context, including EHR text.(47–52) We coded sections of text that included discourse about treatment decision

making, prognostication, resuscitation status, patient goals, values, preferences, and patient and family interactions and communications. Two physician investigators (JMK, BTB) independently reviewed an initial six illness logs and labeled relevant text with descriptive codes. We used preliminary codes based on a conceptual model(32) and employed an inductive approach to refine the coding taxonomy. Coders independently coded the remaining logs and met regularly to compare findings, iteratively refine the coding taxonomy using constant comparison of codes, and achieve consensus for all coded sections of text. Coding continued until theoretical saturation was reached separately in the CCI and decedent groups.

Five investigators from diverse professional backgrounds (BTB, EJG, JMK, KNM, MLS) participated in higher-level analysis through axial coding(53) of the illness logs to characterize major patterns of EHR discourse. We used a contrasting-case approach to compare patterns between CCI and decedent groups. We identified "deviant" cases(54) to test findings and expose attributes of typical cases. We used NVIVO 10 (QSR International, Melbourne, Australia) and STATA/SE 15.1 (StataCorp LLC, College Station, Texas) to facilitate qualitative and quantitative analyses, respectively.

RESULTS

Our sampling strategy identified 52 study participants (Table 1). Groups were matched for SOFA score on ICU day 1, but the decedent group reached a higher peak SOFA score during the ICU stay compared to the CCI group (median peak SOFA score 12.5 [IQR 7.0–14.0] versus 8.0 [IQR 6.0–12.0] respectively; p = .03 by Wilcoxon signed-rank test). Although we abstracted EHR discourse of all professions, most treatment decision-making documentation was by physicians; thus, herein we report our findings on physician discourse.

The General Pattern of Decision-Making

The overall pattern of decision-making discourse in the EHR was similar between CCI and decedent groups (Figure 1). EHR discourse about patient admission to the ICU focused on the delivery of specific interventions only available in the ICU, typically LSTs (e.g., continuous renal replacement therapy). For example, a physician caring for a patient with cirrhosis and end-stage renal disease stated, *"If no longer tolerating intermittent HD [hemodialysis], will require MICU transfer for CVVH [continuous veno-veno hemofiltration]"* (ICU Day 1). All patients had a brief documentation of cardiopulmonary (CPR) resuscitation status in physician notes within the first two days of ICU admission (e.g., "*Code Status: Full Code")*. For some patients, physicians documented that the initial resuscitation status was validated by the patient or family (e.g., "*FULL CODE-confirmed on admission*"). In several cases, physicians acknowledged that the status was not directly confirmed by the patient or family; instead, the status was documented as "*by default*", "*presumed*," or based on medical record review (e.g., "*FULL CODE per OSH [outside hospital] records*.")

After admission, EHR discourse about treatments was physiology-centered, wherein physicians documented decisions about LSTs by reference to specific physiologic abnormalities. A MICU physician noted: *"abg [arterial blood gas] obtained in afternoon*

worsening; intubated for hypercarbic respiratory failure." Often, several physiologic abnormalities occurred simultaneously and prompted multiple medical treatments: *"She is now hyperkalemic and so will need HD [hemodialysis]. Will need VP [vasopressor] support for HD [hemodialysis]*."

However, once LSTs failed to achieve specified physiologic goals, EHR discourse transitioned to documented engagement of patients, families, or other surrogates in treatment decisions (Table 2). Physician discourse described patient or family engagement in discussions about limitations on specific procedures, such as tracheotomy, limb amputation, and central venous catheter insertion. For example, a MICU physician wrote, "*Patient currently considering whether a trach would be acceptable to her and whether she would want to be reintubated in event that extubation not successful."* Occasionally, this discourse also described future health states that patients or families deemed unacceptable: "*live in a facility", "live like this", "mind no longer here", "not a chance for meaningful recovery"*, and *"quality of life is so poor."* The documentation focused on procedures and health states that patients or families wish to avoid, with little description of outcomes or events that patients and families were hoping for or would value. In one counterexample, a palliative care physician documented a family-specified goal: "*her children would like to take her home and ensure she is comfortable with family for her remaining time."*

Because EHR discourse about patient and family engagement was substantially influenced by physiologic failure, the presence or absence and timing of engagement discourse in the EHR was closely related to a patient's severity of illness (Figure 1). For example, a neurologist recommended "*addressing GOC [goals of care] with family*" on ICU day 1 for a woman with a devastating hypoxic-ischemic brain injury (Figure 1, Patient 4) after a cardiac arrest the day of ICU admission. In contrast, for a woman with chronic, end-stage renal disease (Figure 1, Patient 1), who achieved initial hemodynamic stability through LSTs, documentation of family engagement occurred later in the ICU stay (day 7). For CCI patients whose clinical status improved enough to discontinue LSTs and leave the ICU, we did not typically find documentation of patient and family engagement in the EHR.

Divergent Cases

For several patients, clinicians documented engagement with patients and families in the *absence* of physiologic failure. In two cases, the documented rationale for patient or family engagement was that a patient was not a candidate for specific life-extending treatments prior to ICU admission (i.e., chemotherapy or liver transplantation). In two additional cases, patient and family engagement was motivated by a person outside the ICU clinical team (a primary care physician and a patient's wife).

Specific Use of the Phrase "Goals of Care"

There was pervasive use of the free-text phrase "goals of care" and of the abbreviation "GOC" (both herein abbreviated GOC) in the EHR. GOC was found at least once in 38 of the 52 illness logs (25/26 decedent logs and 13/26 CCI logs). Physicians typically used GOC after failure to achieve physiologic goals was acknowledged and documented in the EHR: "*At this point, we have established that all hemostatic interventions have been futile […]*

Agree with primary team's efforts to address realistic goals of care in the context of this end stage multisystem organ failure scenario."

Physicians used GOC to convey several distinct concepts relating to communication with patients and families about prognosis and treatment limitations (Table 3). Physicians frequently used GOC as an expression to indicate poor prognosis: "*should continue to address goals of care with family given extensive co-morbidities and subacute decline now developing into critical illness*." Physicians also used the phrase GOC to describe conflict among patients, families, clinicians: "*We need to start working with the family toward realistic goals of care."* GOC was also used as a rationale to consider limitations on specific treatments: "*clarify GOC i.e. possibility of reintubation if needed."* Although GOC was common in the EHR, physicians rarely documented specific patient or family goals or values in conjunction with this phrase. In one counterexample, an oncologist wrote: "*we will need to continue to address her goals of care. Patient's ultimate goal is to be at home"* (ICU Day 10).

DISCUSSION

In this study, we examined clinician discourse in the EHR to characterize the longitudinal progression of treatment decision making for critically ill patients at risk for poor outcomes. We hypothesized that EHR discourse would be different between patients with CCI and decedents, but, instead, we found evidence that physician decision making followed a common, physiology-centered pattern in both groups. This documentation pattern mirrored the patient's severity of illness and responsiveness to treatments, and transitioned to include engagement of patients and families in decision making when available treatments had failed to achieve physiologic goals. Failure to achieve physiologic goals in the ICU clearly signals extremely poor prognosis, yet waiting to engage patients and families in treatment decision making until physiologic failure occurs may be too late for patients and families to adjust to and fully engage in the decision-making process or express actionable preferences and goals. We found universal documentation of a resuscitation status at the onset of critical illness, but this documentation was relevant only to preferences about CPR, and was not typically accompanied by description of patient and family engagement. Our findings highlight a need for future research on the longitudinal nature of decision making in the ICU and on the impact of strategies to engage patients and families in decisions throughout the fluctuating course of a critical illness.

The EHR has become an integral feature of contemporary medical practice. It is used to facilitate communication among clinicians and provide an account of clinicians' decisions and actions for medical care delivery, financial, and legal purposes. As such, it is a unique and readily available lens through which to study the complex features of clinician decision making. Wong et al. have previously demonstrated that qualitative study of EHR documentation can provide valuable insight into clinicians' decision making about hemodialysis,(47) and our findings confirm these methods uncover important information about clinician decision making in the ICU. Given that we found clinicians regularly use the EHR to document engagement of patients and families, our results suggest the EHR could be further leveraged to facilitate this documentation, promote communication among

clinicians' about patient and family goals, and potentially prompt meaningful patient and family engagement.

Previously published studies of decision making in the ICU have evaluated how physicians communicate with patients and families about goals, values, and preferences, with a primary focus on communication during organized family conferences.(24–26, 28, 30, 40) Our study advances this body of work by evaluating the documentation, timing, and context of decision making and engagement over the longitudinal course of a patient's critical illness, beyond individual family conferences. We expand the existing model by demonstrating that shared decisions are not only influenced by the quality of communication, but appear to be influenced by a physiology-centered clinical context in the ICU. Thus, interventions to further improve SDM in the ICU may need to account for the strong system-level influences inherent to the care of critically ill patients.

Our findings have important implications for patients who develop CCI in the ICU. Consistent with prior studies, we found that patients who developed CCI are physiologically different than ICU decedents.(55, 56) Unlike patients in the decedent group who experienced rapidly progressive critical illness, patients with CCI initially stabilized and achieved physiologic goals through the use of LST. Interestingly, despite this difference, we found the same physiology-driven decision making pattern in both groups. Because patients with CCI did not typically experience early, clinically-apparent physiologic failure, EHR documentation of CCI patient and family engagement was later in the ICU stay or even absent from the EHR. To illustrate, the phrase GOC was documented in the EHR for all but one of the decedents, but only in half of the patients with CCI. We suspect this finding reflects the substantial challenge that clinicians face when engaging patients and families in decision making in the context of high prognostic uncertainty.

We previously developed a conceptual model of a system-level property of the ICU that encourages the accumulation of multiple medical treatments for an individual patient over time, known as "clinical momentum."(32) The present study illustrates features of clinical momentum, including the influence of hospital norms on treatment accumulation.(41, 42) Because hospital norms dictate that certain treatments are only delivered in an ICU setting, physician discourse at the time of an ICU admission focuses on patients' physical location rather than on health status, potential outcomes, or patient preferences. A second feature of clinical momentum, illustrated by our current study, is a phenomenon known as "cascade effects",(33, 57) whereby multiple medical treatments are automatically delivered along a cascading pathway. Because ICU decision making is focused on a patient's physiology, when one treatment (e.g., hemodialysis) causes a physiologic abnormality (e.g., hypotension), a cascade is initiated and additional treatments (e.g., a central venous line and vasopressors) invariably ensue. This study illustrates features of clinical momentum and points to system-level influences on treatment decisions as a target for disruption.

Our study has strengths and limitations. We uncovered a latent and robust pattern of treatment decision making that is undetectable through traditional quantitative analytic approaches and we characterized the clinical use of the ubiquitous phrase "goals of care." Future studies could leverage our methods to analyze the readily available EHR data that are

inaccessible to quantitative approaches. However, the EHR is clearly not a comprehensive source of clinicians' decision-making rationale or of communications between clinicians, patients, and family. In addition, the purposively selected patient sample from one tertiary care center was designed to highlight specific outcomes (CCI or death). Thus, the findings may not resonate with patients who survive and recover, who are admitted to other specialty ICUs, who have shorter ICU stays, or who develop critical illness but are not admitted to an ICU. The scope of this study was limited to treatment decision making in the ICU, and so we are unable to examine the impact of treatment decision making prior to ICU admission.

CONCLUSIONS

Clinician discourse in the EHR about treatment decision making for critically ill adults at risk for poor outcomes follows a common physiology-centered pattern. This pattern appears to bypass important opportunities to engage patients and families in decision making until the patient is very near death or has already developed CCI. Future work should evaluate whether disruption of the physiology- and intervention-focused momentum of the ICU and engagement of patients and families throughout the longitudinal course of critical illness can better align ICU care with patients' goals.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Conflicts of Interest and Sources of Funding:

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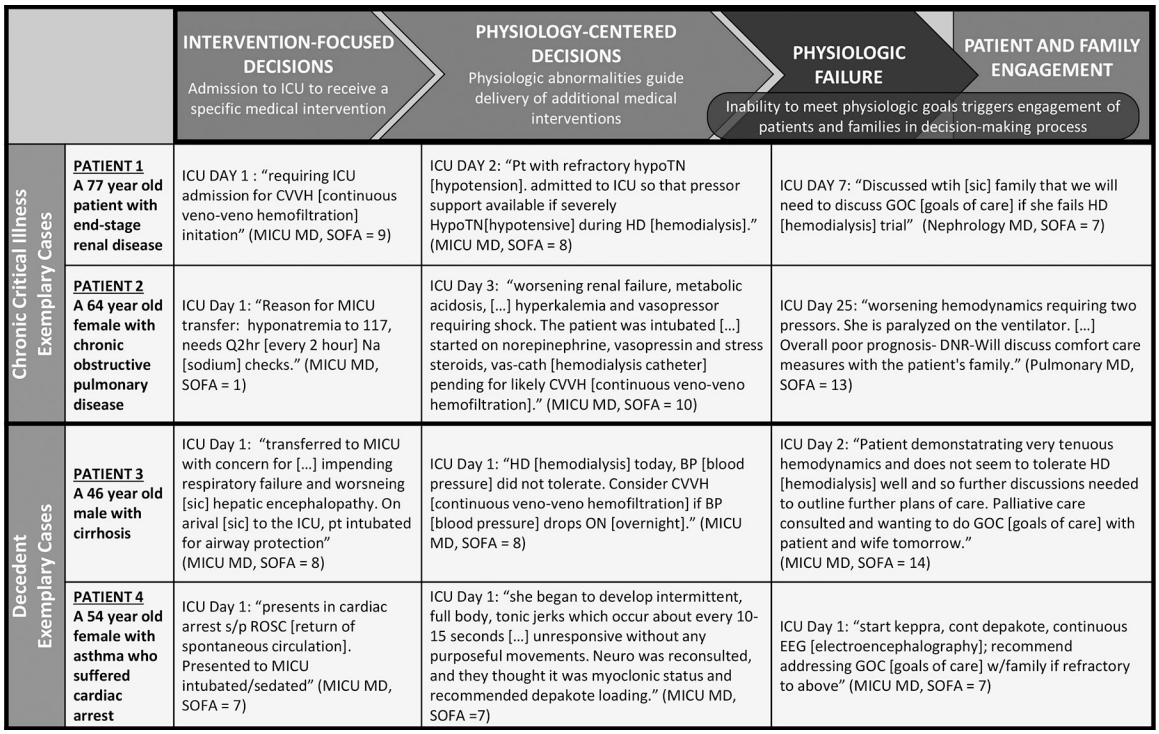
REFERENCES

1. Fried TR, Bradley EH, Towle VR, Allore H. Understanding the treatment preferences of seriously ill patients. N Engl J Med 2002; 346: 1061–1066. [PubMed: 11932474]
2. Teno JM, Fisher ES, Hamel MB, Coppola K, Dawson NV. Medical care inconsistent with patients' treatment goals: association with 1-year Medicare resource use and survival. J Am Geriatr Soc 2002; 50: 496–500. [PubMed: 11943046]
3. Barnato AE, Herndon MB, Anthony DL, Gallagher PM, Skinner JS, Bynum JP, Fisher ES. Are regional variations in end-of-life care intensity explained by patient preferences?: A Study of the US Medicare Population. Med Care 2007; 45: 386–393. [PubMed: 17446824]
4. Bryce CL, Loewenstein G, Arnold RM, Schooler J, Wax RS, Angus DC. Quality of death: assessing the importance placed on end-of-life treatment in the intensive-care unit. Med Care 2004; 42: 423–431. [PubMed: 15083102]
5. Rubin EB, Buehler AE, Halpern SD. States Worse Than Death Among Hospitalized Patients With Serious Illnesses. JAMA Intern Med 2016.

6. Auriemma CL, Nguyen CA, Bronheim R, Kent S, Nadiger S, Pardo D, Halpern SD. Stability of end-of-life preferences: a systematic review of the evidence. JAMA Intern Med 2014; 174: 1085–1092. [PubMed: 24861560]
7. Sudore RL, Schillinger D, Knight SJ, Fried TR. Uncertainty about advance care planning treatment preferences among diverse older adults. J Health Commun 2010; 15 Suppl 2: 159–171. [PubMed: 20845201]
8. Fried TR, O'Leary J, Van Ness P, Fraenkel L. Inconsistency over time in the preferences of older persons with advanced illness for life-sustaining treatment. J Am Geriatr Soc 2007; 55: 1007–1014. [PubMed: 17608872]
9. Halpern J, Arnold RM. Affective Forecasting: An Unrecognized Challenge in Making Serious Health Decisions. J Gen Intern Med 2008; 23: 1708–1712. [PubMed: 18665428]
10. Fried TR, Bradley EH, O'Leary J. Changes in prognostic awareness among seriously ill older persons and their caregivers. J Palliat Med 2006; 9: 61–69. [PubMed: 16430346]
11. Fried TR, Byers AL, Gallo WT, Van Ness PH, Towle VR, O'Leary JR, Dubin JA. Prospective study of health status preferences and changes in preferences over time in older adults. Arch Intern Med 2006; 166: 890–895. [PubMed: 16636215]
12. Barnato AE. Challenges In Understanding And Respecting Patients' Preferences. Health Aff (Millwood) 2017; 36: 1252–1257. [PubMed: 28679812]
13. Detsky ME, Harhay MO, Bayard DF, Delman AM, Buehler AE, Kent SA, Ciuffetelli IV, Cooney E, Gabler NB, Ratcliffe SJ, Mikkelsen ME, Halpern SD. Discriminative Accuracy of Physician and Nurse Predictions for Survival and Functional Outcomes 6 Months After an ICU Admission. JAMA 2017.
14. Kon AA, Davidson JE, Morrison W, Danis M, White DB. Shared Decision Making in ICUs: An American College of Critical Care Medicine and American Thoracic Society Policy Statement. Crit Care Med 2016; 44: 188–201. [PubMed: 26509317]
15. Carlet J, Thijs LG, Antonelli M, Cassell J, Cox P, Hill N, Hinds C, Pimentel JM, Reinhart K, Thompson BT. Challenges in end-of-life care in the ICU. Statement of the 5th International Consensus Conference in Critical Care: Brussels, Belgium, April 2003. Intensive Care Med 2004; 30: 770–784. [PubMed: 15098087]
16. Davidson JE, Aslakson RA, Long AC, Puntillo KA, Kross EK, Hart J, Cox CE, Wunsch H, Wickline MA, Nunnally ME, Netzer G, Kentish-Barnes N, Sprung CL, Hartog CS, Coombs M, Gerritsen RT, Hopkins RO, Franck LS, Skrobik Y, Kon AA, Scruth EA, Harvey MA, Lewis-Newby M, White DB, Swoboda SM, Cooke CR, Levy MM, Azoulay E, Curtis JR. Guidelines for Family-Centered Care in the Neonatal, Pediatric, and Adult ICU. Crit Care Med 2017; 45: 103–128. [PubMed: 27984278]
17. Charles C, Gafni A, Whelan T. Shared decision-making in the medical encounter: what does it mean? (or it takes at least two to tango). Soc Sci Med 1997; 44: 681–692. [PubMed: 9032835]
18. Charles C, Gafni A, Whelan T. Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. Soc Sci Med 1999; 49: 651–661. [PubMed: 10452420]
19. Barry MJ, Edgman-Levitan S. Shared decision making--pinnacle of patient-centered care. N Engl J Med 2012; 366: 780–781. [PubMed: 22375967]
20. Kon AA. The shared decision-making continuum. JAMA 2010; 304: 903–904. [PubMed: 20736477]
21. Whitney SN, McGuire AL, McCullough LB. A typology of shared decision making, informed consent, and simple consent. Ann Intern Med 2003; 140: 54–59.
22. Whitney SN, Holmes-Rovner M, Brody H, Schneider C, McCullough LB, Volk RJ, McGuire AL. Beyond Shared Decision Making: An Expanded Typology of Medical Decisions. Med Decis Making 2008; 28: 699–705. [PubMed: 18556639]
23. Whitney SN. A New Model of Medical Decisions: Exploring the Limits of Shared Decision Making. Med Decis Making 2003; 23: 275–280. [PubMed: 12926577]
24. Chiarchiaro J, Ernecoff NC, Scheunemann LP, Hough CL, Carson SS, Peterson MW, Anderson WG, Steingrub JS, Arnold RM, White DB. Physicians Rarely Elicit Critically Ill Patients' Previously Expressed Treatment Preferences in Intensive Care Units. Am J Respir Crit Care Med 2017; 196: 242–245. [PubMed: 28707977]

25. Scheunemann LP, McDevitt M, Carson SS, Hanson LC. Randomized, controlled trials of interventions to improve communication in intensive care: a systematic review. Chest 2011; 139: 543–554. [PubMed: 21106660]
26. Scheunemann LP, Cunningham TV, Arnold RM, Buddadhumaruk P, White DB. How clinicians discuss critically ill patients' preferences and values with surrogates: an empirical analysis. Crit Care Med 2015; 43: 757–764. [PubMed: 25565458]
27. Curtis JR, Back AL, Ford DW, Downey L, Shannon SE, Doorenbos AZ, Kross EK, Reinke LF, Feemster LC, Edlund B, Arnold RW, O'Connor K, Engelberg RA. Effect of Communication Skills Training for Residents and Nurse Practitioners on Quality of Communication With Patients With Serious Illness: A Randomized Trial. JAMA 2013; 310: 2271–2281. [PubMed: 24302090]
28. Curtis JR, Engelberg RA, Wenrich MD, Shannon SE, Treece PD, Rubenfeld GD. Missed opportunities during family conferences about end-of-life care in the intensive care unit. Am J Respir Crit Care Med 2005; 171: 844–849. [PubMed: 15640361]
29. Carson SS, Cox CE, Wallenstein S, Hanson LC, Danis M, Tulsky JA, Chai E, Nelson JE. Effect of Palliative Care-Led Meetings for Families of Patients With Chronic Critical Illness: A Randomized Clinical Trial. JAMA 2016; 316: 51–62. [PubMed: 27380343]
30. White DB, Braddock CH, 3rd, Bereknyei S, Curtis JR. Toward shared decision making at the end of life in intensive care units: opportunities for improvement. Arch Intern Med 2007; 167: 461–467. [PubMed: 17353493]
31. Seaman JB, Arnold RM, Scheunemann LP, White DB. An Integrated Framework for Effective and Efficient Communication with Families in the Adult Intensive Care Unit. Ann Am Thorac Soc 2017; 14: 1015–1020. [PubMed: 28282227]
32. Kruser JM, Cox CE, Schwarze ML. Clinical Momentum in the Intensive Care Unit. A Latent Contributor to Unwanted Care. Ann Am Thorac Soc 2017; 14: 426–431. [PubMed: 27997808]
33. Bruce CR, Fetter JE, Blumenthal-Barby JS. Cascade effects in critical care medicine: a call for practice changes. Am J Respir Crit Care Med 2013; 188: 1384–1385. [PubMed: 24328766]
34. Kaufman SR. --And a time to die: how American hospitals shape the end of life. New York: Scribner; 2005.
35. Kahn JM, Le T, Angus DC, Cox CE, Hough CL, White DB, Yende S, Carson SS, ProVent Study Group I. The epidemiology of chronic critical illness in the United States*. Crit Care Med 2015; 43: 282–287. [PubMed: 25377018]
36. Nelson JE, Cox CE, Hope AA, Carson SS. Chronic critical illness. Am J Respir Crit Care Med 2010; 182: 446–454. [PubMed: 20448093]
37. Damuth E, Mitchell JA, Bartock JL, Roberts BW, Trzeciak S. Long-term survival of critically ill patients treated with prolonged mechanical ventilation: a systematic review and meta-analysis. Lancet Respir Med 2015; 3: 544–553. [PubMed: 26003390]
38. Unroe M, Kahn JM, Carson SS, Govert JA, Martinu T, Sathy SJ, Clay AS, Chia J, Gray A, Tulsky JA, Cox CE. One-year trajectories of care and resource utilization for recipients of prolonged mechanical ventilation: a cohort study. Ann Intern Med 2010; 153: 167–175. [PubMed: 20679561]
39. Cox CE, Lewis CL, Hanson LC, Hough CL, Kahn JM, White DB, Song M-K, Tulsky JA, Carson SS. Development and pilot testing of a decision aid for surrogates of patients with prolonged mechanical ventilation. Crit Care Med 2012; 40: 2327–2334. [PubMed: 22635048]
40. Cox CE, Martinu T, Sathy SJ, Clay AS, Chia J, Gray AL, Olsen MK, Govert JA, Carson SS, Tulsky JA. Expectations and outcomes of prolonged mechanical ventilation. Crit Care Med 2009; 37: 2888–2894;. [PubMed: 19770733]
41. Cox CE, Wysham NG, Walton B, Jones D, Cass B, Tobin M, Jonsson M, Kahn JM, White DB, Hough CL, Lewis CL, Carson SS. Development and usability testing of a Web-based decision aid for families of patients receiving prolonged mechanical ventilation. Ann Intensive Care 2015; 5: 6. [PubMed: 25852965]
42. Kahn JM. Improving outcomes in prolonged mechanical ventilation: a road map. Lancet Respir Med 2015; 3: 501–502. [PubMed: 26003387]
43. Tracy SJ. Interview planning and design: Sampling, recruiting, and questioning Qualitative Research Methods: Collecting Evidence, Crafting Analysis, Communicating Impact, First ed: Blackwell Publishing Ltd; 2013.

44. Vincent JL, Moreno R, Takala J, Willatts S, De Mendonca A, Bruining H, Reinhart CK, Suter PM, Thijs LG. The SOFA (Sepsis-related Organ Failure Assessment) score to describe organ dysfunction/failure. On behalf of the Working Group on Sepsis-Related Problems of the European Society of Intensive Care Medicine. Intensive Care Med 1996; 22: 707–710. [PubMed: 8844239]
45. Vincent JL, de Mendonca A, Cantraine F, Moreno R, Takala J, Suter PM, Sprung CL, Colardyn F, Blecher S. Use of the SOFA score to assess the incidence of organ dysfunction/failure in intensive care units: results of a multicenter, prospective study. Working group on "sepsis-related problems" of the European Society of Intensive Care Medicine. Crit Care Med 1998; 26: 1793–1800. [PubMed: 9824069]
46. Ferreira FL, Bota DP, Bross A, Melot C, Vincent JL. Serial evaluation of the SOFA score to predict outcome in critically ill patients. JAMA 2001; 286: 1754–1758. [PubMed: 11594901]
47. Wong SP, Vig EK, Taylor JS, Burrows NR, Liu CF, Williams DE, Hebert PL, O'Hare AM. Timing of Initiation of Maintenance Dialysis: A Qualitative Analysis of the Electronic Medical Records of a National Cohort of Patients From the Department of Veterans Affairs. JAMA Intern Med 2016; 176: 228–235. [PubMed: 26809745]
48. Elfenbein DM. Confidence Crisis Among General Surgery Residents: A Systematic Review and Qualitative Discourse Analysis. JAMA Surg 2016; 151: 1166–1175. [PubMed: 27603429]
49. Hodges BD, Kuper A, Reeves S. Discourse analysis. BMJ 2008; 337: a879. [PubMed: 18687729]
50. McCloskey R A guide to discourse analysis. Nurse Res 2008; 16: 24–44. [PubMed: 19025104]
51. Ford-Sumner S Genre analysis: a means of learning more about the language of health care. Nurse Res 2006; 14: 7–17. [PubMed: 17100210]
52. Roberts C, Sarangi S. Theme-oriented discourse analysis of medical encounters. Med Educ 2005; 39: 632–640. [PubMed: 15910440]
53. Corbin J, Strauss A. Grounded Theory Research - Procedures, Canons and Evaluative Criteria. Qual Sociol 1990; 19: 418–427.
54. Guest G. Validity and Reliability (Credibility and Dependability) in Qualitative Research and Data Analysis Applied Thematic Analysis: SAGE Publications; 2012.
55. Iwashyna TJ, Hodgson CL, Pilcher D, Bailey M, van Lint A, Chavan S, Bellomo R. Timing of onset and burden of persistent critical illness in Australia and New Zealand: a retrospective, population-based, observational study. Lancet Respir Med 2016; 4: 566–573. [PubMed: 27155770]
56. Vanhorebeek I, Langouche L, Van den Berghe G. Endocrine aspects of acute and prolonged critical illness. Nat Clin Pract Endocrinol Metab 2006; 2: 20–31. [PubMed: 16932250]
57. Mold JW, Stein HF. The cascade effect in the clinical care of patients. N Engl J Med 1986; 314: 512–514. [PubMed: 3945278]



Chronic Critical Illness Exemplary Cases	**PATIENT 1** **A 77 year old patient with end-stage renal disease**	ICU DAY 1 : "requiring ICU admission for CVVH [continuous veno-veno hemofiltration] initation" (MICU MD, SOFA = 9)	ICU DAY 2: "Pt with refractory hypoTN [hypotension]. admitted to ICU so that pressor support available if severely HypoTN[hypotensive] during HD [hemodialysis]." (MICU MD, SOFA = 8)	ICU DAY 7: "Discussed wtih [sic] family that we will need to discuss GOC [goals of care] if she fails HD [hemodialysis] trial" (Nephrology MD, SOFA = 7)
	PATIENT 2 **A 64 year old female with chronic obstructive pulmonary disease**	ICU Day 1: "Reason for MICU transfer: hyponatremia to 117, needs Q2hr [every 2 hour] Na [sodium] checks." (MICU MD, SOFA = 1)	ICU Day 3: "worsening renal failure, metabolic acidosis, […] hyperkalemia and vasopressor requiring shock. The patient was intubated […] started on norepinephrine, vasopressin and stress steroids, vas-cath [hemodialysis catheter] pending for likely CVVH [continuous veno-veno hemofiltration]." (MICU MD, SOFA = 10)	ICU Day 25: "worsening hemodynamics requiring two pressors. She is paralyzed on the ventilator. […] Overall poor prognosis- DNR-Will discuss comfort care measures with the patient's family." (Pulmonary MD, SOFA = 13)
Decedent Exemplary Cases	**PATIENT 3** **A 46 year old male with cirrhosis**	ICU Day 1: "transferred to MICU with concern for […] impending respiratory failure and worsneing [sic] hepatic encephalopathy. On arival [sic] to the ICU, pt intubated for airway protection" (MICU MD, SOFA = 8)	ICU Day 1: "HD [hemodialysis] today, BP [blood pressure] did not tolerate. Consider CVVH [continuous veno-veno hemofiltration] if BP [blood pressure] drops ON [overnight]." (MICU MD, SOFA = 8)	ICU Day 2: "Patient demonstatrating very tenuous hemodynamics and does not seem to tolerate HD [hemodialysis] well and so further discussions needed to outline further plans of care. Palliative care consulted and wanting to do GOC [goals of care] with patient and wife tomorrow." (MICU MD, SOFA = 14)
	PATIENT 4 **A 54 year old female with asthma who suffered cardiac arrest**	ICU Day 1: "presents in cardiac arrest s/p ROSC [return of spontaneous circulation]. Presented to MICU intubated/sedated" (MICU MD, SOFA = 7)	ICU Day 1: "she began to develop intermittent, full body, tonic jerks which occur about every 10-15 seconds […] unresponsive without any purposeful movements. Neuro was reconsulted, and they thought it was myoclonic status and recommended depakote loading." (MICU MD, SOFA =7)	ICU Day 1: "start keppra, cont depakote, continuous EEG [electroencephalography]; recommend addressing GOC [goals of care] w/family if refractory to above" (MICU MD, SOFA = 7)

Figure 1.

A common pattern of decision-making discourse for adults with critical illness and high risk of poor outcomes. Patients and families are engaged in treatment decision making when treatments do not meet specified physiologic goals.

Table 1.

Patient Characteristics and Hospitalization Outcomes

Characteristic	Chronic Critical Illness Cases (n = 26)	Decedent Cases (n = 26)
Age, median (range)	64 (45–94)	65 (45–94)
Female, n (%)	10 (38)	10 (38)
Race/Ethnicity, n (%)		
White	10 (38)	5 (19)
Black or African American	8 (31)	5 (19)
Other[a]	5 (19)	10 (38)
Asian	2 (8)	0 (0)
Hispanic or Latino	1 (4)	6 (23)
ICU Admission Resuscitation Status of “Full Code”, n (%)[b]	21 (81)	26 (100)
ICU Admission SOFA score, median (IQR)	6.2 (3.0–9.0)	6.0 (3.0–7.5)
Peak SOFA score, median (IQR)[c]	8.0 (6.0–12.0)	12.5 (7.0–14.0)
ICU Length of Stay, median days (IQR)[c]	20 (13–34)	10 (8–13)
Hospital Length of Stay, median days (IQR)[c]	33 (24–45)	14 (10–18)
Hospital Discharge Disposition, n (%)		
Long-term Acute Care Hospital	7 (27)	0 (0)
Acute Inpatient Rehabilitation	7 (27)	0 (0)
Skilled Nursing Facility or Subacute Rehabilitation	5 (19)	0 (0)
Home	4 (15)	0 (0)
Death	2 (8)	23 (88)
Inpatient or Home Hospice	1 (4)	3 (12)

a: includes declined to answer, unknown, unable or no answer, and other

b: first documented status within 48 hours of ICU admission

c: $p \leq 0.05$ by Wilcoxon signed-rank test

Abbreviations: ICU= intensive care unit; SOFA = sequential organ failure assessment;

Table 2.

Rationale for Engaging Patients or Family in Decision-Making When Medical Treatments Fail to Accomplish Physiologic Goals

	Exemplary Quotes
Chronic Critical Illness Cases	*We need to start working with the family toward realistic goals of care if she is unable to do HD [hemodialysis] tomorrow. (MICU Physician, ICU Day 8, SOFA=7)*
	Family meeting planned for tomorrow to discuss end-of-life care given inability to stabilize hemodynamically. (MICU Physician, ICU Day 20, SOFA=8)
	Full code for now; discussed with wife and family at bedside that pt is still critically ill. goal is for palliative chemotherapy but if unable to liberate from ventilator then will need to readdress goals of care (MICU Physician, ICU Day 5, SOFA= 3)
Decedent Cases	*Patient clinically worsening. Now paralyzed with 4th pressor added. […] Patient still full code at this time; however no utility of CPR [cardiopulmonary resuscitation] given uncorrected underlying process and extensive support required at this time. Family to discuss DNR [do not resuscitate] status." (MICU Physician, SOFA = 10)*
	Given the inability to unload RV [right ventricle] […] as well as multi-organ failure patient's prognosis is extremely poor, would agree with pursuing further goals of care discussions with family (MICU Physician, ICU Day 12, SOFA=11)
	Patient had expressed previously she would only want to be intubated for 3–4 days, with limited critical care trial. This was discussed with daughters and POA [power of attorney]. In setting of lack of neurological recovery, resistant micro-organism infections, anuric renal failure, progressive malignancy have elected to no longer escalate care, and are planning to withdraw care […] after family has gathered. (MICU Physician, ICU Day 15, SOFA=11)

a: All SOFA scores are maximum value in 48 hours preceding quoted statement

Abbreviations: MICU= medical intensive care unit; SOFA = Sequential Organ Failure Assessment

Table 3.

The multivalent concept represented by the phrase “goals of care” in the EHR.

Concept	Exemplary Quotes
An expression to indicate poor prognosis	*Discussed goals of care with family at bedside; I communicated with family that prognosis is near certain he will not survive*
	continue GOC discussions with family given persistent hypotension, persistent encephalopathy
	I spoke with daughters at bedside today - they were asking appropriate questions regarding prognosis and GOC; we discussed from a sepsis standpoint alone his prognosis is extremely poor - prolonged refractory shock with at least 2 organ systems down
A representation of conflict among patients, families, clinicians	*looking for family meeting with ethics to try and work toward a more mutual goals of care decision*
	will continue to press for further resolution of goals of care
	recommend revisiting GOC (at prior admissions, pt was adamantly full code)
A rationale for limitations on specific treatments	*will consider thoracentesis pending GOC*
	holding home meds given goals of care
	GOC clarified yesterday: Converted to DNR yesterday, no escalation of care

Abbreviations: GOC = goals of care; DNR = do not resuscitate