

The Factors Associated With High-Quality Communication for Critically Ill Children

abstract

OBJECTIVE: Timely, high quality communication with families is essential to family-centered decision-making. Quality communication is represented by widespread documentation of prognostic, goals-of-care conversations (PGOCC) in the pediatric intensive care unit (PICU) and should occur without variation by patient characteristics.

METHODS: Cohort included 645 PICU admissions in the top decile of risk of mortality on admission over six years. Electronic medical records were used to determine PGOCC, diagnosis on admission and complex chronic condition (CCC) status. Multivariate logistic regression and time-to-event analyses were used.

RESULTS: Overall, 31% had a documented PGOCC. 51% had CCC status. 11% had an oncologic, 13% had a cardiovascular diagnosis on admission. 94% of patients who died in the PICU had PGOCC documented, but among the 200 patients with documented PGOCC, 78% did not die in the PICU. Oncologic diagnosis on admission was associated with a higher likelihood of PGOCC compared to non-CCC patients (ARR=1.86; SE=0.26) whereas no other diagnosis category reached the level of statistical significance. Median time from admission to PGOCC was 2 days. Age, gender and CCC status were not associated with whether a PGOCC was documented or with time from admission to PGOCC documentation. 45% of PGOCC in the cohort and 50% of conversations in patients with CCC were documented by PICU physicians.

CONCLUSIONS: This study reveals the opportunity for improvement in documentation of PGOCC for critically ill children. It raises the questions of why there is variation of PGOCC across disease categories and whether PGOCC should be considered a quality measure for family-centered care. *Pediatrics* 2013;131:S90–S95

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KEY WORDS

quality improvement, pediatric ICU, family-centered care, patient care planning, doctor–patient communication

ABBREVIATIONS

ACCC—American College of Critical Care
CCC—complex chronic condition
EMR—electronic medical record
PGOCC—prognostic, goals-of-care conversation
PRISM3—Pediatric Risk of Mortality

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High-quality communication between providers and families is essential to family-centered care.¹ Within the setting of the PICU, families consistently indicate that they want timely honest information about their child's condition.^{2,3} Nonetheless, the interaction of multiple providers caring for complex patients in the PICU leads to multiple opportunities for breakdowns in communication between providers and families. When miscommunication occurs, it is more stressful for families^{4–6} and impedes their decision-making processes.⁷

Multiple professional organizations, including the American Academy of Pediatrics¹ and the American College of Critical Care (ACCC) Medicine Task Force,⁸ have developed clinical guidelines that emphasize the benefits of shared decision-making and family-centered care. After reviewing a decade of literature, the ACCC recommended that providers share the patient's current status, prognosis, and all treatment options within 24 to 48 hours of admission to the PICU with decision-makers.⁸

The primary aim of this study was to identify and determine the feasibility of a process measure for quality communication within the PICU that meets the criteria of the ACCC recommendation. We call this process measure documentation of a prognostic goals-of-care conversation (PGOCC). The second aim was to describe variation in the documentation of PGOCC by patient characteristics and by the type of provider documenting the conversations. Recognizing that there would be far more conversations that occurred than were documented, the null hypothesis was that there would be no differences in documentation by disease category or provider type. The third aim was to determine the association between having a PGOCC documented and mortality within the PICU. The concern was

that PGOCCs may occur only when death is imminent; if so, that pattern may indicate the PGOCCs are not being implemented as broadly recommended by the ACCC.

METHODS

Study Sample

We conducted a retrospective cohort study of 645 admissions to the PICU from July 2004 to July 2010 at the C. S. Mott Children's Hospital at the University of Michigan that were in the top decile (>47%) for risk of mortality on admission, as determined by the Pediatric Risk of Mortality (PRISM3) score.⁹

Data Collection and Analysis

PRISM3 score, mortality within the PICU, age, *International Classification of Diseases, Ninth Revision* categories, and gender were obtained from the Virtual PICU System¹⁰ at the University of Michigan. The electronic medical records (EMRs) from the University of Michigan provided physician and ancillary care notes, excluding nursing notes.

Two team members conducted a comprehensive EMR extraction. Using an electronic search engine designed at the University of Michigan,¹¹ the first author (Dr Walter) developed and validated search terms used in EMR patient notes to identify documentation of PGOCC. The search engine enabled

efficient searching of text documents within the chart instead of merely coded data elements. Batched searches across multiple patients were performed, looking for key terms while also accommodating potential spelling errors of these terms. PGOCC included conversations ranging from descriptions of prognostic information that was provided to families to discussions of code status and family preferences for care. Coauthor Ms Housey then completed chart extraction of 645 observations including date of first PGOCC after admission to the PICU, physician signing the PGOCC note, content of the conversation, and diagnosis on admission to the PICU. Dr Walter duplicated extraction of the initial 50 observations and then a random sample of 10% of the remaining extractions to ensure consistency of data extraction.

Dr Walter and a PICU physician (Dr Benneyworth) independently reviewed all extracted PGOCC documentation, with agreement of 87.5% regarding whether the documented content reflected PGOCC intent ($\kappa = 0.76$). To resolve disagreements, Dr Walter performed an additional extraction from the EMRs. Using *International Classification of Diseases, Ninth Revision* criteria for "complex chronic conditions" (CCCs),¹² Dr Walter determined if patients met criteria for CCCs on admission by using admission notes from the PICU and

TABLE 1 Characteristics of Patients Admitted to PICU With Mortality Risk in Top Decile

	Overall Sample (n = 645), n (%)	Subsample With PGOCC Conversations (n = 200), n (%)
Gender		
Female	283 (44)	85 (30)
Male	362 (56)	115 (32)
Age (y)		
0–1	105 (16)	36 (34)
1–9	302 (47)	84 (28)
10–23	238 (37)	80 (34)
Complex chronic condition on admission	327 (51)	98 (30)
Mortality	47 (7)	44 (94)
Median length of stay in PICU (days)	2	5
PGOCC conversation	200 (31)	—

categorized all patients' diagnoses on admission into subspecialties, using the medical history taken from admissions notes to the PICU. The diagnostic subspecialty groups on admission large enough to analyze as individual groups included neurologic, cardiovascular, and oncologic diagnoses.

TABLE 2 Characteristics of High-Risk Patients Associated With Mortality in PICU

	Adjusted Risk Ratio (SE)
Age (y)	
0–1	Reference
1–9	0.29 (0.10)*
10–23	0.40 (0.13)**
Female ^a	0.69 (0.20)
Length of stay (days)	1.01 (0.01)
Neurologic diagnosis	0.50 (0.29)
Cardiovascular diagnosis	0.63 (0.35)
Oncologic diagnosis	4.62 (1.50)*
CCC status ^b	1.04 (0.37)

^a Reference group male.

^b Reference group non-CCC status.

* $P < .001$, ** $P < .01$.

TABLE 3 Frequency of PGOCC Conversations in PICU by Diagnostic and CCC Categories

Patient Diagnosis Category on PICU Admission ^a	Frequency, <i>n</i> (%)	Frequency of Documented PGOCC, <i>n</i> (%)
Neurology	99 (15)	29 (29)
CCC	77 (78)	23 (30)
Non-CCC	22 (22)	6 (22)
Cardiology	82 (13)	18 (22)
CCC	76 (93)	16 (21)
Non-CCC	6 (7)	2 (33)
Oncology	72 (11)	38 (53)
CCC	72 (100)	38 (53)
Non-CCC	0 (0)	
Genetics	61 (9)	15 (25)
CCC	60 (98)	14 (23)
Non-CCC	1 (2)	1 (100)
Gastroenterology	48 (7)	13 (27)
CCC	41 (85)	10 (24)
Non-CCC	7 (15)	3 (43)
Pulmonary	45 (7)	15 (33)
CCC	42 (93)	13 (31)
Non-CCC	3 (7)	2 (67)
Nephrology	39 (6)	15 (38)
CCC	33 (85)	10 (30)
Non-CCC	6 (15)	5 (83)
Endocrinology	34 (5)	10 (29)
CCC	13 (38)	6 (46)
Non-CCC	21 (62)	4 (19)

^a Patients may have >1 diagnosis category attributed to them.

Using bivariate and multivariate logistic regression, we determined if patient characteristics were associated with first PGOCC documented after admission; control variables included patient characteristics (disease category, age, gender) and length of stay in the PICU. We also performed time-to-event analyses among patients with documented PGOCC to determine if patient characteristics were associated with time from admission to PGOCC. We performed linear regression controlling for physician heterogeneity (fixed effects) on time from admission to PGOCC. Finally, we used multivariate logistic regression to examine the association between mortality and documentation of PGOCC while controlling for disease category, age, gender, and length of stay.

All analyses were performed with Stata 12.1 (Stata Corp, College Station, TX). Coefficients from logistic regressions were converted to adjusted risk ratios to enhance comparisons of groups with common outcomes.¹³ Statistical significance was set at $P < .05$.

RESULTS

Sample Characteristics

Overall, among 645 admissions to the PICU with a high risk of mortality, 200 (31%) had a documented PGOCC (Table

1). About one-half (51%) of patients at high risk for mortality met CCC criteria on admission: 13% had a cardiovascular diagnosis, 11% had an oncologic diagnosis, and 15% belonged in >1 diagnosis group.

Ultimately, 47 patients (7%) died during the index hospital stay. Having a cancer diagnosis was significantly associated with a 4.6-fold increase in mortality within the PICU (adjusted risk ratio = 4.62; SE = 1.50), adjusted for demographic characteristics (Table 2). No other diagnostic patterns were associated with mortality, including CCC status overall or belonging to multiple diagnostic groups. Patient age of 1 to 9 and 10 to 23 years were significantly less likely than infants to die during the hospital stay (Table 2).

Prognostic Goals-of-Care Conversations

For most patient characteristics including gender, age category, disease category, and CCC status, the percentage of each subgroup having a PGOCC documented was indistinguishable from the overall average of 31%. The 2 exceptions to this were that PGOCCs were documented for 53% of oncology patients (Table 3) and for 94% of patients who died in the PICU (Table 1).

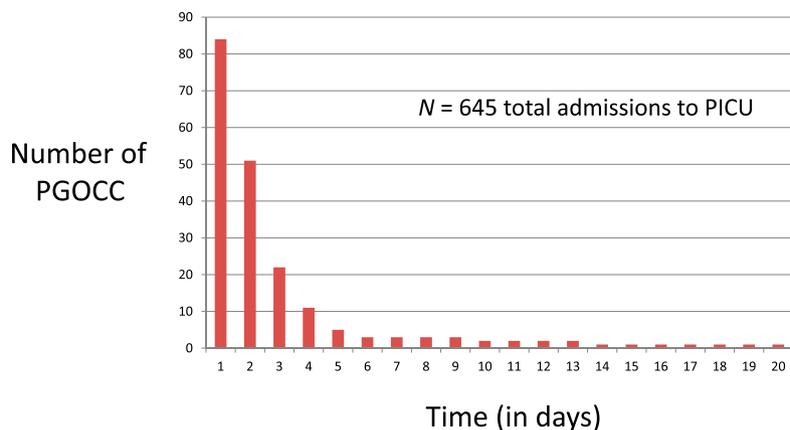


FIGURE 1

Time from PICU admission to PGOCC documentation. Data points for 4 cases with time to PGOCC >20 days are not shown.

TABLE 4 Patient Characteristics Associated With PGOCC Documented in the PICU

	Adjusted Risk Ratio (SE)
Age (y)	
0–1	Reference
1–9	0.83 (0.13)
10–23	0.96 (0.15)
Female ^a	0.95 (0.11)
Length of stay (days)	1.06 (0.01)*
Neurologic diagnosis	1.08 (0.17)
Cardiovascular diagnosis	0.73 (0.16)
Oncologic diagnosis	1.86 (0.26)*
CCC status ^b	0.85 (0.11)

^a Reference group male.

^b Reference group non-CCC status.

* $P < .001$.

Conversely, among 200 patients with a documented PGOCC, 156 (78%) did not die in the PICU.

The median length of stay in the PICU was 2 days for the full study sample, as well as for the subset of patients who died within the PICU. The median time from admission to PGOCC was 2 days (Fig 1); for those who died within the PICU, the median time from PGOCC to death was 1 day. For those with cardiovascular diagnoses, the median time from admission to PGOCC was 3 days.

Factors Associated With Having PGOCCs

Overall, patients with oncologic diagnoses were most likely to have PGOCC conversations (53%), followed by nephrology (38%), pulmonary (33%), neurology, and endocrinology (29%) (Table 3). The groups of patients with neurologic, oncologic, and cardiovascular diagnoses had sufficient numbers of patients to permit specific subgroup analyses.

In multivariate analyses examining study outcomes in the context of patient demographic and clinical characteristics (Table 4), oncologic diagnosis on admission was associated with a higher likelihood of PGOCC documentation

(adjusted risk ratio = 1.86; SE = 0.26), whereas no other diagnosis category reached the level of statistical significance. Age, gender, and CCC status were not associated with whether a PGOCC was documented or with time from admission to PGOCC documentation.

Cardiovascular diagnosis was associated with a longer time to PGOCC documentation. When controlling for physician fixed effects, those with a cardiovascular diagnosis had a PGOCC documented 3.8 days later than those without a cardiovascular diagnosis (confidence interval, 0.89–6.77 days).

PICU physicians authored the largest share (45%) of documented PGOCCs overall and for 50% of patients with CCCs. No other subspecialty group authored >25% of the PGOCC documents for patients belonging to its diagnostic group.

DISCUSSION

This is the first study that describes the documentation patterns of conversations regarding prognosis or goals of care for patients admitted to the PICU, regardless of the clinical outcome. Research conducted to identify quality measures in the PICU to improve end-of-life care has found regular communication with families as an important process measure^{5,14,15} and that documentation of treatment preferences (including withdrawal of life support) was associated with higher assessment of quality of dying by family members.¹⁶ On the basis of our findings and national recommendations for adult ICU care,^{15,17} we believe that documentation of conversations within the medical record is an appropriate and feasible process measure to ensure quality communication in the PICU between providers and families regardless of clinical outcome. Our key finding is that only one-third of the most severely ill patients admitted to PICU care have

had a documented PGOCC. Importantly, in comparison with other studies of communication, this study has been conducted retrospectively with an efficient electronic medical record search engine pioneering a method for quality assessments that could be used in real time or retrospectively to track this new process measure in communication with families.

Consistent with previous studies, our data demonstrate that communication about prognosis and goals of care often occurs shortly before death.^{18,19} Our criteria for a PGOCC were purposefully broad to capture a range of conversations and not exclusively those that would occur around limitations in treatment or withdrawal of care. Indeed, there were approximately 150 cases that met criteria for PGOCCs that were documented for patients who did not die within the PICU. However, it is reasonable to infer from our data that PGOCC documentation is strongly connected to end-of-life care decisions for many providers. Additionally, documentation of these conversations continues to happen within a very short time period of death, usually 1 day before or on the day of death. To improve this quality measure, there may need to be a change in PICU culture, with acknowledgment that these PGOCCs should occur even when death is not perceived to be imminent. Instead, documentation of these conversations serves the purpose not only of improving communication between providers but also between providers and families, with the goal of aiding families' decision-making. Understanding the perspectives of providers working in the PICU may provide insight regarding potential barriers to making these conversations more universally initiated and documented.

Distinctions in PGOCC patterns by subspecialty diagnoses are another novel finding from this study. Patients with

cardiovascular diseases had a PGOCC documented significantly later in their course than other patients, whereas patients with oncologic diagnoses were significantly more likely to have had these conversations documented overall but no more quickly than patients with other characteristics. We hypothesized that if there was a variation in documentation of conversations, it would occur between those who are chronically ill versus those who are newly ill. On the contrary, our data demonstrate that even among children with chronic conditions, these groups may differ in clinically meaningful ways. This difference may partially be attributed to the fact that, within our sample, a cancer diagnosis was more strongly associated with mortality, and although all patients had a high predicted risk of mortality on admission, oncology providers reacted to this higher probability of death as the patients' disease progressed during hospitalization. For cardiology patients, the longer time from admission to PGOCC raises the question of what led to this variation in practice. Overall, our findings suggest that subspecialty clinicians should evaluate their practices of communicating with families. Even if PGOCCs have occurred before admission to the PICU, a patient's need for PICU care indicates a significant enough change in their health status that families should be updated about what this may mean for their child's overall prognosis, and current providers should clarify care goals with adequate documentation in the medical record.

Moreover, the role of intensivists is highlighted in our analysis. Intensivists documented the largest share of PGOCCs, even in the cases where patients likely had a preexisting relationship with subspecialty providers. Further research is warranted to determine if families prefer to have

PGOCCs with any provider available or with the providers with whom they established rapport before their child's admission to the PICU and how this may affect families' decision-making. Particularly with regard to end-of-life conversations, the rapport that families have with their medical team may significantly impact the families' response to suggestions to changing care plans or withdrawing care.

Importantly, PGOCCs are not the same as documented PGOCCs. The medical record is the definitive information source for communication between providers, particularly as provider shifts shorten and there are more patient handoffs. The chart can and should serve as the official document where patient and families' preferences are documented and where all providers can look to determine what information has been shared and what remains to be discussed with families. Although this does not take the place of detailed verbal communication among providers, the medical record can serve as a reliable source for verification of verbal discussions. There is good reason to believe that documentation of PGOCC can improve family-centered care by ensuring more clear communication between providers caring for critically ill children. Additionally, the agreement we were able to demonstrate between coders regarding what constitutes a PGOCC demonstrates the feasibility of identifying PGOCCs in the medical record and allowing them to be tracked as a quality process measure.

The chief limitation of this study is that it is from a single academic institution that may not be representative of other non-academic PICUs. Additionally, PRISM3 scores with >47% of mortality were used to determine the sample, and therefore patients who were admitted to the PICU with an initially lower risk of mortality may have

become more ill during their hospitalization and had a PGOCC that was not captured by this study. Analysis of notes included all of the medical team except for nursing notes because they were not in the EMR, which may miss some documentation of conversations. Furthermore, the study relies on documentation of conversations, which shares the inherent limitations of recordkeeping common to all studies of medical records. Finally, our study was limited to evaluating conversations that occurred while patients were admitted to the PICU and does not capture or have the ability to comment on preadmission conversations that may have occurred. However, we believe conversations, even within this limited time frame, are relevant given the high risk of mortality in our sample and the families' need to make decisions for their care.

CONCLUSIONS

Communication between providers and families is a central way to improve family-centered care in the PICU. Building on other research and expert recommendations, we proposed that documentation of PGOCCs would be a useful quality measure and described both its baseline frequency and the variation in documentation of these conversations in a major academic PICU. This project demonstrates the feasibility of using PGOCCs as a quality measure and also identifies challenges to its implementation.

Additional research may provide insight into the barriers to documentation and different subspecialties' expectations of documentation in the PICU. Finally, for patients with severe exacerbations of chronic illness, it is important to better understand the subspecialty providers' role in communicating with families within the PICU about changes in status and how their presence or absence may affect parental decision-making.

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