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Examining Palliative Care Team Involvement in Automatic Consultations for Children on Extracorporeal Life Support in the Pediatric Intensive Care Unit

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Abstract

Background: Extracorporeal life support (ECLS) is an advanced form of life-sustaining therapy that creates stressful dilemmas for families. In May 2009, Seattle Children's Hospital (SCH) implemented a policy to involve the Pediatric Advanced Care Team (PACT) in all ECLS cases through automatic referral.
Objective: Our aim was to describe PACT involvement in the context of automatic consultations for ECLS patients and their family members.
Methods: We retrospectively examined chart notes for 59 consecutive cases and used content analysis to identify themes and patterns.
Results: The degree of PACT involvement was related to three domains: prognostic uncertainty, medical complexity, and need for coordination of care with other services. Low PACT involvement was associated with cases with little prognostic uncertainty, little medical complexity, and minimal need for coordination of care. Medium PACT involvement was associated with two categories of cases: 1) those with a degree of medical complexity but little prognostic uncertainty; and 2) those that had a degree of prognostic uncertainty but little medical complexity. High PACT involvement had the greatest medical complexity and prognostic uncertainty, and also had those cases with a high need for coordination of care.
Conclusions: We describe a framework for understanding the potential involvement of palliative care among patients receiving ECLS that explains how PACT organizes its efforts toward patients and families with the highest degree of need. Future studies should examine whether this approach is associated with improved patient and family outcomes.

Introduction

Since its introduction in 1972, extracorporeal life support (ECLS) has been used in thousands of patients with life-threatening cardiorespiratory failure.[1] ECLS is an extended form of cardiopulmonary bypass and provides either respiratory support alone or combined cardiopulmonary support. Indications for ECLS in children include recovery of cardiac and pulmonary function with postoperative myocardial dysfunction following corrective congenital heart surgery, acute respiratory distress syndrome, tracheal injury, and sepsis support; it also may be used as a "bridge" to heart transplantation for children with end-stage heart failure.[2–6] Novel technologies for ECLS are

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continually being developed and indications continue to expand resulting in support of more complex, potentially "sicker" patients, and as an aid to cardiopulmonary resuscitation (E-CPR).

In 2009, Seattle Children's Hospital (SCH) instituted a policy of automatic consultations to the Pediatric Advanced Care Team (PACT) whenever an ECLS order is written. The policy change represents the first use of a trigger for early PACT involvement in the intensive care unit (ICU); automatic consultations are also done for children receiving bone marrow transplants or with diagnoses of brain tumors with a high probability of death. The ECLS policy was written in response to staff requests for more support given the complexity of the underlying illness, the high risk of mortality, and the weightiness of decisions surrounding ECLS use. We conducted a qualitative descriptive analysis of chart notes with the goal of examining how the automatic referral shaped PACT's involvement in these high risk, high stakes cases.

Methods

Population and setting

SCH has 48 ICU beds including 17 neonatal, 14 cardiac, and 17 pediatric beds. More than 560 patients have received ECLS since the program's inception at SCH in 1990. Between May 2009 and December 2010 (the study time frame), 59 patients received an automatic PACT referral.

Data collection and analysis

The SCH institutional review board approved a review of chart notes for all children who received ECLS and a PACT consultation during the study period. We analyzed all chart notes entered by PACT members and ICU social workers (as both have responsibilities for documenting care conferences and addressing family needs and support) using qualitative thematic analysis to identify patterns within and across cases and for theory generation.[7–9] Analysis involved an iterative process of reading and coding the chart notes, first within each case to understand the specifics of the child's diagnosis and the clinical interventions, then across all the cases to identify broader patterns of PACT involvement.

Three investigators (AZD, EB, HS), who were not a part of the PACT team or involved in patient care at the hospital, read each chart note to identify ways in which PACT was involved in the case, and how PACT coordinated care with the ECLS and ICU teams. We first sorted the cases by number of visit notes written by the PACT member and ordered these from low to high as a preliminary indication of level of involvement. The availability of notes was part of our definition of involvement, which included three levels: Low involvement cases had one to two visit notes, medium involvement cases had three or more visit notes but no documented care plan, and high involvement cases had care conferences and a documented care plan. With this framework in mind, we then reread the notes to describe what PACT did and the context for its varied involvement.

Results

Patient characteristics

Patients in this study were among the most critically ill in the hospital and were at high risk of dying without ECLS. Table 1 describes the characteristics of all 59 children who received ECLS as well as the level of PACT involvement. The most common indications for ECLS overall and for children with medium to high PACT involvement were congenital heart disease and respiratory failure; for low involvement cases, the leading indication was neonatal meconium aspiration.

PACT involvement

From the chart notes, we identified three domains (prognostic uncertainty, medical complexity, and care coordination) that contextualized low to high PACT involvement. We determined that prognostic uncertainty and medical complexity were influenced by many factors, including the prevalence of a medical condition, how well known and understood the trajectories of illness and treatments are, whether protocols exist for treatment, the number and type of comorbidities, the child's age, and the wide range of children's responses to illness and the difficulty of predicting outcomes. We defined coordination of care needs to include management of medical communication, social support, and other needs of families, and facilitation of communication between clinicians from multiple specialties.

Across the 59 cases, increasing hospital length of stay (LOS), ICU LOS, and duration of ECLS indicated greater medical complexity and increasing PACT involvement. Cases with low involvement by PACT ($n=15$) included children with meconium aspiration syndrome or recovery after cardiac surgery, both of which were expected to resolve within a short amount of time. PACT involvement was limited to one or two visits with the medical team and/or the family and ended after determining that the family's needs were adequately addressed by the ECLS team and that PACT involvement might contribute to duplication of effort.

Cases with a moderate level of involvement ($n=28$) were of two types: 1) those with considerable medical complexity yet resolved relatively quickly due to little prognostic uncertainty about the outcome; and 2) those with greater prognostic uncertainty but little medical complexity. An example of the first type is that of a neonate with high medical complexity due to a congenital transposition of the great arteries with bowel perforation and a large cerebral hemorrhage. The prognostic uncertainty was low because the burden of illness eliminated all options for medical intervention except for comfort care. PACT met with the family before a care conference to prepare them for the discussion about removal of life support and how the parents would like to be involved in their son's death. They also coordinated with the social worker to make referrals for legacy support and bereavement resources in the family's home community. PACT's involvement was intense but brief as these decisions all transpired within 24 hours of the child's birth.

An example of the second type is that of a child born with hypoplastic left heart syndrome (HLHS). Although HLHS is a medically complex disease with high morbidity and mortality, we classified this case as low medical complexity because the child received the well-described first-stage treatment for this disease (Norwood procedure) at 2 weeks of age. Prognostic uncertainty was the impetus for greater involvement by PACT because the child: 1) also had total anomalous pulmonary venous drainage, which increases the already high risk of mortality of HLHS; 2) was unable to be separated from cardiopulmonary bypass after surgery due to refractory hypotension of unclear etiology; and 3) had mediastinal

Table 1. Patient Demographics

	Total sample N = *59 (100%)*	*Low PACT involvement* N = *15 (25%)*	*Medium PACT involvement* N = *28 (47%)*	*High PACT involvement* N = *16 (27%)*
Sex				
Female	33 (56%)	8 (53%)	13 (46%)	12 (75%)
Male	26 (44%)	7 (47%)	15 (54%)	4 (25%)
Race				
White	27 (46%)	4 (27%)	14 (50%)	9 (56%)
Hawaiian/Pacific Islander	3 (5%)		1 (4%)	2 (13%)
Black	3 (5%)	1 (7%)	1 (4%)	1 (6%)
Am. Indian/Alaska Native	1 (2%)		1 (4%)	
Other	17 (29%)	6 (40%)	7 (25%)	4 (25%)
Declined to report	7 (12%)	4 (27%)	3 (11%)	
Missing	1 (2%)		1 (4%)	
Language				
English	43 (73%)	10 (67%)	23 (82%)	10 (63%)
Spanish	13 (22%)	4 (27%)	5 (18%)	4 (25%)
Russian	1 (2%)			1 (6%)
Hindi	1 (2%)	1 (7%)		
Somali	1 (2%)			1 (6%)
Diagnostic category				
Congenital heart disease	25 (42%)	3 (20%)	15 (54%)	7 (44%)
Shock, unspecified	3 (5%)		1 (4%)	2 (13%)
Respiratory failure	11 (19%)	4 (27%)	3 (11%)	4 (25%)
Neonatal meconium aspiration	7 (12%)	6 (40%)	1 (4%)	
Congenital syndrome	6 (10%)	1 (7%)	4 (14%)	1 (6%)
Noncardiac cardiomyopathy	3 (5%)		2 (7%)	1 (6%)
Acute E-CPR	4 (7%)	1 (7%)	2 (7%)	1 (6%)

	N = *22 (37%)*			N = *4 (27%)*			N = *10 (36%)*			N = *8 (50%)*		
Died	*Mean*	*Median*	*Range*	*Mean*	*Median*	*Range*	*Mean*	*Median*	*Range*	*Mean*	*Median*	*Range*
Age (months)	31.7	0.5	0–255	37.9	0	0–255	21.8	0	0–199	43.1	9.5	0–193
Days in hospital	55.2	34	2–332	24.1	20	4–72	56.2	34	2–332	84.6	66	6–250
Days in ICU	33.3	23	2–250	16.4	13	4–47	28.7	23	2–81	58.8	33	6–250
Days in ICU pre-ECLS	5.5	1	0–74	3.2	0	0–22	5.0	1	0–37	8.4	1	0–74
Days on ECLS	8.8	5	0–34	5.4	4	0–13	8.9	5	1–34	11.8	9	3–32

ECLS, Extracorporeal life support; E-CPR, cardiopulmonary resuscitation; ICU, intensive care unit; PACT, Pediatric Advanced Care Team.

hemorrhage after transfer to the cardiac ICU that required surgical exploration that same evening.

High involvement cases ($n = 16$) had the greatest medical complexity and prognostic uncertainty. An example from this group included a previously healthy 11-year-old girl who presented with sudden loss of consciousness, cardiac arrhythmia, and cardiopulmonary collapse of unknown etiology. The prognostic uncertainty was due to a lack of a clear underlying diagnosis and trajectory of her illness, which led the ICU team to contemplate the possibility of heart transplantion or left ventricular assist device implantation. PACT was involved for 2 weeks to organize a case conference, document a care plan, and provide family support while the parents explored what it would mean for their daughter and them if she needed a transplant. Fortunately, the patient weaned off ECLS after 5 days; PACT made another visit one week later as she transitioned to rehabilitation while awaiting surgical options.

Discussion

The use of ECLS offers hope of cure or management of what were formally terminal conditions yet also creates stressful dilemmas for children and their families because of the number and type of serious decisions that must be made regarding the child's care. The results of this study provide a preliminary framework to examine how PACT tailors its involvement to the complexity of the cases of children receiving ECLS. This review was not designed to test the effectiveness of PACT and is limited by being a qualitative review of chart notes from a single institution that did not include evaluative comments from families. Thus, we did not have independent quantitative or qualitative assessments of prognosis or uncertainty, or parents' perspectives.

Palliative care involvement in the ICU has previously been shown to support and improve communication with patients and families about goals of care and the potential treatment options.[10,11] Our experience suggests that through an automatic referral process, the neonatal, pediatric, and cardiac ICU teams have expanded their use of PACT to support families of children on ECLS, especially when prognostic uncertainty, medical complexity, and care coordination needs increase. Future studies are needed to further evaluate the role of PACT in this and other clinical settings, and to assess the effectiveness of PACT in meeting the needs of patients, families, and clinicians.

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Author Disclosure Statement

No competing financial interests exist.

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