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Brief Report

Red flags: a case series of clinician–family communication challenges in the context of CHD

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Abstract We describe three cases of newborns with complex CHD characterised by communication challenges. These communication challenges were categorised as patient, family, or system-related red flags. Strategies for addressing these red flags were proposed, for the goal of optimising care and improving quality of life in this vulnerable population.

Keywords: Communication; red flags; CHD

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Chronic critical illness, a complex syndrome affecting patients who survive acute critical illness but remain chronically dependent on intensive medical care, is a major public health burden that extends to the paediatric population.[1] Recent data suggest that the proportion of chronically ill children with a primary cardiac diagnosis is increasing, and is now >40%.[2] Care for these children involves multiple prenatal, neonatal, and paediatric subspecialists; clinician communication with families about evolving prognosis and goals of care often fractures as hospital stays lengthen.[3]

In this article, we present three cases representative of paediatric chronic critical illness related to CHD. This case series highlights patient, family, and clinician/system "red flags" – risk factors for suboptimal family–clinician communication and decision making (Table 1).

Case 1

A twin male was born at 36 weeks of gestation weighing 1700 g at a community hospital following intrauterine growth restriction. In the newborn nursery, he developed tachypnoea and cyanosis, prompting transfer to the special care unit. An echocardiogram revealed truncus arteriosus type IIIA with discontinuous branch pulmonary arteries. He was transferred to our tertiary centre, where multiple setbacks – that is, extracorporeal membrane oxygenation, sepsis, and necrotising enterocolitis – occurred, complicated by family mistrust of clinicians and cultural barriers. After an initial 102 days of hospital stay, he was transferred to a chronic-care facility, and from there to another. On day of life 229, he was re-admitted to our centre and died within 48 hours of presumed septic shock.

Case 2

A term newborn with intrauterine drug exposure and limited prenatal care was born at a community hospital with omphalocoele and cyanosis. He was transferred to our hospital. An echocardiogram confirmed single-ventricle heart disease: unbalanced atrioventricular canal, pulmonary atresia, discontinuous pulmonary arteries, and dextrocardia. His initial hospitalisation was for 262 days; he underwent multiple surgical procedures, including cardiac surgery, tracheostomy, and feeding tube placement. His

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Table 1. Three cases: red flags.

Red flags	Implications for patient	Implications for family	Implications for clinicians and care systems
Case 1			
Patient: no prenatal cardiac diagnosis; premature birth; twin; born at community hospital	No cardiac prenatal plan of care; surgery delayed and prostaglandin infusion continued for 6 weeks because of low birth weight	Delayed understanding and acceptance; no preparation for long-term hospitalisation; mother and twin at community hospital 2 hours away	No existing relationships with clinicians at the tertiary centre
Family: immigrants; language and cultural barriers; transportation and sibling care burdens	Limited bonding with the infant during hospitalisation	No local support system; visited infrequently; difficulty communicating with the medical team	Members of the care team did not establish trust with the family; father requested male clinicians
Clinician/care system: multiple sites of care across four institutions	Discontinuity of care plans over months	Limited longitudinal relationships with staff; geography limited visitation; difficulty learning new systems at each site	Lack of clinician "ownership" of management plans; barriers to information transfer across different health record systems
Case 2			
Patient: atypical and complex cardiac anatomy; extracardiac involvement	Prognosis uncertain; management not "evidence based"	Ongoing uncertainty regarding what to expect; "unique case"	Difficulty reaching consensus about treatment plan; unforeseen complications worsened trust with family
Family: poor prenatal care; substance abuse; housing insecurity; child welfare involvement	Inconsistent family decision makers; hard to incorporate social context into predicted quality of life	Mother was legal surrogate but was unlikely to care for the infant after hospital discharge	Care escalation easier than limitation given fragmented access to family; moral distress of clinicians
Clinician/care system: no regular family meetings	No clear goals of care	Limited relationship with staff	Treatment decisions were delayed while care escalations occurred by default
Case 3			
Patient: multiple anomalies, including abnormal brain anatomy	Extracorporeal membrane oxygenation, very high risk; prognosis more global than just cardiac; quality of life unclear	Easy to focus on one organ system getting "better"; family overwhelmed by infant appearance	Multiple teams/clinicians involved; no clear leader of care plan
Family: Parents divorcing; father in another state with siblings; mother with chronic medical condition; financial/transportation concerns	Legal decision-making authority initially unclear; family stressors limited visitation	Balancing best interest of infant with that of family; family chaos impedes coping	Father not consistently involved; hard for team to know who is making decisions
Clinician/care system: palliative care incompletely involved	Prenatal hospice not fully integrated, reducing chance to limit high-risk interventions; fragmented goals of care	Family not receiving full array of psychosocial supports	Prenatal hospice did not trigger postnatal palliative care; palliative care consulted on hospital day 252

course was complicated by worsening neurodevelopmental prognosis and uncertainty regarding parental legal authority to make medical decisions. He was transferred to a chronic-care facility, went home for 1 day, and was re-admitted for acute on chronic respiratory failure, due to which he passed away at 21 months of age.

Case 3

A fetus was diagnosed at 28 weeks of gestation with pulmonary atresia, double-outlet right ventricle, intrauterine growth restriction, cerebral ventriculomegaly, and polydactyly. Prenatal providers acknowledged prognostic uncertainty, and told the family that a life-limiting syndrome could preclude cardiac repair. A prenatal provider referred the family to hospice; a few other prenatal and postnatal providers knew about this. Elective caesarean section at 39 weeks of gestation was performed at our centre. The clinical course was complicated by recurrent necrotising enterocolitis and bacteraemia, multi-vessel thrombosis, and cerebral infarcts. Extracorporeal membrane oxygenation was considered more than once; there were no documented postnatal discussions regarding alternatives to aggressive interventions. The initial hospital stay was 184 days, with multiple surgical procedures (two cardiac) recorded. Patient management involved >10 subspecialties in addition to neonatal and paediatric intensive care and cardiology.

Discussion

Paediatric chronic critical illness is a relatively new term that describes prolonged or frequent ICU stays together with multi-organ involvement and dependence on life-sustaining technologies.[4] Patients with CHD, especially those with single-ventricle physiology, are at high risk of paediatric chronic critical illness.[2] Although quality of life, including neurodevelopmental outcomes, in outpatients with CHD is high overall, it is lower in those with complex anatomy and multiple surgeries.[5] Hehir et al[6] detail the non-cardiac challenges for patients in the cardiac ICU, including analgesia, anticoagulation, and feeding. Most paediatric deaths from CHD occur in the ICU following aggressive interventions and amidst significant suffering.[7] Data suggest that these patients are less likely to be seen by a palliative care team than children with other life-threatening diseases.[8]

Coordination of care, communication, and decision-making support are fundamental to improved outcomes for seriously ill children. In this study, we identified patient, family, and system "red flags" that elevate the risk for communication breakdown in the context of

Table 2. Strategies for addressing red flags.

Red flag	Implications	Strategies
Patient-related		
No prenatal diagnosis	Limited clinician–family relationships; late management choices	Improve prenatal detection by increasing access to screening ultrasound
Atypical cardiac anatomy	Poor prognostic ability; uncertainty may delay treatment recommendations	Assign primary cardiologist to follow-up these patients in hospital and proactively address the impact of uncertainty on infant care
Extracardiac disease/anomalies	Many subspecialists without clear leader for goals of care	Weekly cross-team meetings
Prematurity	Delayed surgery; poorer prognosis than for a typical patient	Develop nutrition protocols that target growth in premature infants with cardiac disease
Family-related		
Language and cultural barriers	Poor communication; different health/illness beliefs	Elicit help from interpreters, cultural brokers; implement staff cultural training
Outside stressors	Limited visitation; poor coping; potential conflict within family	Early involvement of social workers, child life specialists, chaplains; incorporate parent support groups, social media; promote non-traditional parent–family communication platforms (e.g. Skype)
Unclear surrogate	Delayed/incomplete decision making and planning around quality of life	Establish legal and moral surrogates early; be prepared for barriers to reaching family; expand family discussions beyond those required for informed consent
Clinician/care system related		
Multiple sites of care	Discontinuous management, poor coordination	Forum for cross-site, case-based discussions; assign longitudinal case manager
A few scheduled family meetings	Late discussions and decisions	Weekly family meetings for all expected long-stay patients in ICU
Inadequate palliative care	Poor continuity, limited supports to family and team	Trigger palliative care consultation at diagnosis

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CHD. Absence of prenatal diagnosis, extracardiac anomalies, cultural barriers, and social vulnerabilities were common patient and family red flags. Clinician/system red flags included involvement of multiple subspecialists, transfers between units and institutions, and lack of an identified leader responsible for navigating care goals with the family. Out of the three, two patients died without ever going home; we found little documentation of conversations with parents about end-of-life care.

Table 2 highlights potential strategies for addressing these patient, family, and system red flags for patients with CHD and paediatric chronic critical illnesses. These strategies harness different resources to anticipate and address common challenges. Designated members of the broad healthcare team could prioritise continuity of patient care planning and communication with the family. Continuity providers might be primary cardiologists who follow-up the patient throughout the hospitalisation, social workers who provide services across sites within the hospital, or palliative care teams who follow-up the patient across any site of care, starting from the prenatal period. Protocols to routinise family meetings and ICU-subspecialist team discussions are evidence-based methods to enhance communication and decision making.[4] Early clarity regarding which family members and which clinicians will play lead roles in decision making can preempt the need for care escalation by default.

As we continue to improve survival and quality of life for children with CHD and their families, it is also important to improve outcomes for those children with life-limiting disease. Although cure may not be possible, minimising burden and maximising benefit remain central goals.

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Conflicts of Interest

None.

Ethical Standards

The study was approved by the Office of Human Subjects Research Institutional Review Board at the Johns Hopkins University (IRB00043247).

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