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CASE STUDY

Where do families turn? Ethical dilemmas in the care of chronically critically Ill children

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Abstract
Advancements in early diagnosis and novel treatments for children with complex and chronic needs have improved their chances of survival. But many survive with complex medical needs and ongoing medical management in the setting of prognostic uncertainty. Their medical care relies more and more on preference-sensitive decisions, requiring medical team and family engagement in ethically challenging situations. Many families are unprepared as they face these ethical challenges and struggle to access relevant ethical resources. In this paper, Timmy's narrative, situated in the context of what is known about ethical challenges in the care of children with chronic critical illness (CCI), serves as a case study of the gap in available ethical resources to guide families in their approach to difficult decision making for children with significant medical complexity and CCI. Our author group, inclusive of parents of children with complex medical needs and medical professionals, identifies domains of ethical challenges facing families of children with CCI and we highlight the development of family/caregiver-oriented ethics resources as an essential expansion of pediatric bioethics.

Keywords Chronic critical illness · Children with medical complexity · Ethics · Decision-making

1 Timmy

Johnson Pang

The neonatologist sat down by the bed where my wife was resting. We were waiting for an in-utero fetoscopic procedure scheduled for the next day. Our baby, Timmy, had severe congenital diaphragmatic hernia such that he had a low likelihood of surviving after birth. This experimental procedure may give him a fighting chance. The

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Extended author information available on the last page of the article doctor gently reminded us that the procedure may trigger pre-term labor and asked us if we would want them to take heroic measures to save his life. Our baby was only 28 weeks in gestation. We had to process end-of-life decision-making before he was even born, and that was only the beginning of a long series of events, each of which prompted new questions and ethical challenges.

2 Introduction

Over the last decades, advancements in early diagnosis and novel treatments for children with complex and chronic medical needs have improved their chances of survival (Namachivayam et al. 2015). These children have intensive health care resource utilization and remain at risk for physical, developmental, behavioral, and emotional impairments (Cohen et al. 2011; Feudtner et al. 2014). Children with chronic critical illness (CCI) experience prolonged and/or recurrent hospitalizations and use chronic medical technology; they represent the highest resource-intense group of children with medical complexity (Shapiro et al. 2017).

The medical management of children with CCI is often associated with high risk harms and trade-offs, when straightforward treatment options have been exhausted and there is risk of death (Ruth et al. 2020). Shared decision-making between families of children with CCI and clinicians is important in these clinical situations, as decisions are often preference-sensitive– there may be multiple acceptable treatment options, unclear balance of benefit and burden, or clinical equipoise and decisions may depend on patient and family values and priorities. The traditional approach to shared decision-making is particularly difficult in these settings because of the need to make decisions with the incomplete medical evidence available in much of pediatric medical complexity (Buchanan et al. 2022), which can require medical team and family engagement in ethically challenging situations. Here we are considering ethical challenges to be situations which interact with moral principles or where those principles clash, situations that lead to moral conflict, distress or uncertainty, or those in which all the options are "bad" options. We also expect that there are some situations that are ethically challenging to families of children with medical complexity but unknown to us, so leave open the ethical challenge as defined by a patient or family member. In the words of Timmy's father: ethical challenges in pediatric medical complexity arise when making decisions that are clouded with moral uncertainty because of the complex medical conditions (of the child) and technologies (offered by medicine) involved. Many families are unprepared as they face these ethical challenges and struggle to find the support they need. This is evident in the experience shared here and an issue raised by parent professionals in our research collaborative.

3 Timmy's journey

Johnson Pang

Timmy was born prematurely at 34 weeks, went on extracorporeal membrane oxygenation (ECMO) within twelve hours, and endured five major surgeries before he exited the intensive care unit sixty weeks later. For us as a family, the difficulties only increased when he came home. We provided round-the-clock care for his needs and continued to be in and out of the hospital for the next year and half. We loved our little Timmy and his needs were enormous. Every major organ system was compromised. He had endured open heart surgery, was fed through a j-tube, and breathed with the help of a ventilator. His seizures were never fully controlled. He passed away at two years and ten months. His life was hard and had been filled with tremendous challenge.

4 Ethical challenges in chronic critical illness

Whether in the hospital, outpatient, or home setting, ethical challenges in the care for children with CCI are common. Ethical challenges known to us as a research collaborative comprised of clinicians, researchers, ethicists, and parent professionals span a wide range of topics (Table 1). Ethical tension points may be experienced simul-

Table 1 Examples of ethical tensions that arise in caring for children with CCI

High Stakes Medical Interventions
• Evaluating essential or elective nature of medical technologies • Evaluating if technologies are practical and improve quality of life • Withholding or withdrawing medical technologies or interventions • Team response when families ask for interventions the team recommends against • Team response when families prefer to forgo interventions the team recommends • How teams account for and accommodate cultural, religious, or personal preferences in approaches to shared decision-making
Difficult Decisions
• Responsibility for sharing decision-making in medically complex children with many involved medical teams: shared responsibility, single team/person's responsibility, no one takes responsibility, parents' responsibility • Balancing burden and benefit • Parent/guardian decision-making for their children (from best interests to harm threshold) • Child input in decision-making with developing maturity/competence; child/adolescent's rights to disagree with parent preferences • Health care decisions that overlap or conflict with religious teaching or guidance • Advance care planning and end-of-life decision-making
Rare Diagnoses and Medical Complexity
• Lack of guidance or frameworks specific to children with medical complexity • Research/Innovation • Clear communication of experimental nature of treatments • Adequate researcher communication of research purpose: good to others vs. good to the patient enrolled in the trial • Financial impact of complex medical care and role of financial considerations in decision-making
Prolonged and/or Recurrent Hospitalizations
• Optimizing pain and symptom management with consideration of available therapies / side effects • Advance care planning that evolves based on age, evolving needs, and goals of care • Balancing needs of all family members when one (or more) child has medical complexity and high care needs • Discharge planning, availability and coordination of multiple medical teams, rehabilitation services, home health supply vendors • Gaps in home health care

taneously by clinicians and families but also may arise at different times and over different issues. The ethical tensions that may be most familiar to clinicians revolve around medical decisions, establishing boundaries for treatment intensity, end-of-life care, and navigating conflicting values within and across medical teams and between medical teams and families (Henderson et al. 2017).

Families may struggle with these same ethical concerns, though from different vantage points. They may have a different, or sometimes limited, understanding about treatment options and potential consequences (Béranger et al. 2018). They may also feel ethical challenges that are not as readily noted by clinicians, for instance regarding pain management or discharge planning. Families of children with CCI also face challenges that are purely familial. Indeed, some ethical questions that arise may not involve medical decisions at all but rather questions about what it means to be a good parent (Weaver et al. 2020) or how to balance the complex needs of everyone in a family that includes a child with complex medical and care needs. Knowing how or whether to discuss ethical concerns with the medical team may cause families additional distress.

Several of these tensions were present for Timmy's parents from the very beginning and continued through his life.

5 Where do families turn for answers?

Johnson Pang

The complexity of Timmy's condition, the learning curve to understand the treatments involved, and the emotional ups and downs as we coped with the enormity of it all contributed to the challenge of knowing what was right to do for our child.

Every time Timmy was re-hospitalized the ethical challenges surfaced again, "Are we doing the right thing?" or "Are we doing too much?" One time, as he struggled to maintain his oxygen saturation, the emergency department could not get a line so I had to watch them drill into his leg to place an intraosseous needle. I'll never forget the anguish on my boy's face. Soon after, we decided, in consultation with many doctors and especially with the palliative care team, to make his code status Do Not Resuscitate. As we pursued different medicines and considered varying procedures, we looked for an ethical framework to help guide our decisions and to think carefully about what we were doing.

I looked in both religious and secular spheres for resources. Ethical frameworks were available through various sources, whether *Principles of Biomedical Ethics* (Beauchamp and Childress 2013), written for professionals, or *Departing in Peace* (Davis 2017), which provided a Protestant Christian perspective. But I could not find these frameworks applied in detail to medically complex cases involving children and their families. Perhaps if resources were available that applied these ethical frameworks to cases like my Timmy, or were framed from the caregiver's perspective, it would have helped us imagine how we ourselves could navigate and think through our own complex case.

The advent of new medical procedures and technologies can be a wonderful gift. Many children who either would not have survived or been severely impaired can now live with fewer comorbidities. However, children like my Timmy represent an emerging population who are born reliant upon such technologies and medicines in a way that challenges families with ethical dilemmas they did not have to face in prior generations.

6 Families need ethics resources

When ethically challenging situations arise during the care of children with CCI, medical teams can rely on a variety of resources to guide them. Most medical professionals receive basic ethics education during their training. They can also draw comparisons to previous clinical experiences and seek guidance from senior colleagues. They have ready access to ethics consultation services, ethics committees, and bioethics research and literature. But these resources tend to be academically oriented and less accessible to families, either because of their intended professional audiences or due to the gatekeeping of academic literature behind subscription services. Additionally, some bioethics resources suggest a bias in favor of clinician-driven decision-making, or present case examples that suggest that most ethical complexities arise when parents “refuse” care that clinicians recommend (McDougall et al. 2014).

Families of children with CCI who face ethical challenges do not have an array of resources to guide them. In the preparation of this manuscript, using search terms ‘ethics’, ‘decision-making’, ‘medical’, ‘framework’, ‘families’, ‘chronic critical illness’, ‘children’, these authors could not identify any resources that would be appropriate for and easily understood by families in Web of Science, Scopus, EBSCO, or PubMed, though we recognize that these academic search tools may not even be accessible to families. Using similar search terms with tools available to families, like Google, revealed only clinician-focused, academic articles, non-specific to children with CCI. Families facing medically and ethically complex situations are, therefore, limited to community resources, such as religious or spiritual centers, other families of children facing serious illness, family advocacy groups, medical team members, and hospital-based ethics committees. But some of these resources may be limited in their applicability to ethical issues that arise in pediatric chronic critical illness and accessing these resources can be challenging. For example, not all families are religiously affiliated or spiritual; and those that are may grapple with tensions between the teachings of their communities and the decisions they are needing to make in the unique and challenging situations arising for their children. Other families of children with CCI may not have the bandwidth to provide additional support; and if they do, they are likely to provide support through the lens of their own decision-making for their own child. As a result, families facing medical decisions may seek multiple family perspectives, thus needing to identify multiple families for support, further limiting this resource. Though hospital ethics committees are supposed to be accessible to patients and families according to hospital accreditation bodies, families may not know of them or find them hard to access (Sharma et al. 2022; Madrigal et al. 2022). Prior work suggests that ethics consults happen for less than 1% of hospitalized children with CCI (Boss et al. 2018). Finally, the nature of a family’s ethical dilemma regarding their child with CCI may expand beyond strictly medical concerns, such as how to balance a sibling's needs with those of the sick child, how to navigate the financial burdens of serious illness care, or how to navigate the incapacity of a caregiver. Families of children with CCI often experience confusion, conflict, distress, and trauma related to the care of their children; we hope that the availability of targeted ethics resources would help mitigate these challenges (Nuffield Council on Bioethics 2023).

7 Conclusions

As medicine and technology continue to advance, the population of children with CCI will increase, resulting in a growing number of parents and caregivers in need of family-centered ethics resources. Co-developing such resources with experienced families is an essential expansion of pediatric bioethics. These resources should encompass the range of ethical issues identified as important by families of children with CCI and should be developed expressly for a parental audience. They should incorporate the range of frameworks for ethical reasoning, including secular and religious perspectives. Though we do not believe that we can address this issue alone, as an interprofessional research collaborative with background in pediatric CCI and ethics, our group aims to help fill this gap through the development of evidence-based, family-oriented ethics resources. Optimizing shared decision-making for the sickest group of children requires preparing both clinicians and families for the ethical complexities they will face.

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