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Treating Vulnerable Populations

Medical Decision Making for Medically Complex Children in Foster Care: Who Knows the Child's Best Interests?

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ABSTRACT

Approximately one in 10 children in foster care are medically complex and require intensive medical supervision, frequent hospitalization, and difficult medical decision making. Some of these children are in foster care because their parents cannot care for their medical needs; other parents are responsible for their child's medical needs due to abuse or neglect. In either case, there can be uncertainty about the role that a child's biological parents should play in making serious medical decisions. Here we highlight some of the ethical challenges inherent in making these decisions for children in foster care, as seen through the lenses of a child welfare provider, an inpatient care physician, and a primary care pediatrician.

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INTRODUCTION

Nearly 440,000 children are in foster care on any given day in the United States,¹ of whom an estimated 10 percent are medically complex.² Some of these children enter foster care due to abuse or neglect that is unrelated to their medical conditions; other enter foster care because their medical needs exceed their parents' ability to care for them. In either case, child welfare and foster care providers become responsible for assuring that the child's medical needs are met. Child welfare administrators and foster care parents are generally authorized to make routine medical decisions for these children, for example, vaccines or an antibiotic for a minor infection. But when serious medical decisions arise, for example, whether or not to place a surgical feeding tube for failure to thrive, there is often confusion about whether a child's biological parents can and should participate in those decisions. Some of this uncertainty is resolved by court orders that either maintain or terminate parental rights to make medical decisions for a child in foster care. Yet ambiguity can remain about whether a biological parent's legal authority should be the only factor to consider when determining who can meaningfully judge and advocate for a child's best interests.

In this article we present a case that highlights some of the ethical challenges inherent in making

serious medical decisions for children in foster care, as seen through the lenses of a child welfare provider, an inpatient care physician, and a primary care pediatrician.

CASE

“Darlene” is a nine-year-old female admitted to the hospital for spinal fusion surgery to correct severe scoliosis.

Darlene has cerebral palsy and cognitive/developmental deficits secondary to non-accidental head trauma at age three; she is also tracheostomy and gastrostomy-tube dependent. She is nonverbal, unable to sit up unassisted, and incontinent of both bowel and bladder. Darlene has lived in a medical foster care home since the initial trauma; her mother’s and father’s parental rights were terminated.

Following scoliosis surgery, Darlene’s post-operative course is complicated by infection, respiratory failure, and uncontrollable seizures. On post-op day 14, she is not responding to any external stimuli or interacting with her environment. Although she has some spontaneous breathing, the assessment of the PICU (pediatric intensive care unit) team is that she is likely to remain ventilator dependent. They plan to discharge her to a rehabilitation facility once she becomes medically stable. It is uncertain whether the foster parents with whom she has been living can handle her care now that she is ventilator dependent.

The PICU team recommends that Darlene should have a do-not-resuscitate (DNR) order in place (with no intention of withdrawing existing care). At the request of the child welfare agency legal counsel, the hospital ethics committee is consulted. The ethics committee agrees that a DNR order is ethically permissible. Darlene’s appointed lawyer also supports the institution of a DNR order. While the child welfare agency has medical decision-making authority for Darlene, consenting to a DNR order requires the authorization of a juvenile court.

Darlene’s biological parents, who have not had legal or physical custody of Darlene in six years, are notified about Darlene’s condition and upcoming court hearing. They attend the court hearing and express their opposition to a DNR order based on their Christian religious beliefs. They also argue (through their lawyer) that Darlene, their daughter, could potentially survive for many years and that the possible short-term pain associated with CPR (cardiopulmonary resuscitation) would not, in their view, outweigh the potential significant benefits of being alive. Despite the recommendations of the

doctors, lawyers, and ethics committee, the judge does not allow the institution of a DNR order.

Given this scenario, one ethics question is: Should parents whose rights have been terminated have a say in decisions about providing or withholding life support for Darlene?

CASE COMMENTARIES

The Perspective of Child Welfare

Darlene had a scoliosis surgery that resulted in deterioration of her respiratory and mental status. This deterioration led to concerns by her healthcare team that a DNR order should be considered, and this was presented in court. Unless all parties are in agreement that a DNR order is in the child’s best interest, the courts are typically reluctant to authorize the withholding or withdrawing of life-sustaining therapies for children who are in state custody. The reasons for judicial reluctance are understandable. They are reluctant custodians for medically complex children, a role that they have taken on out of necessity in recent years.

The child welfare system was designed to provide protection and shelter for children whose homes are no longer safe. Although most children enter the system because of abuse or neglect,³ the child welfare system is increasingly responsible for children with medically complex needs whose parents are unable or unwilling to provide the care they need.⁴ Child welfare has had to design programs and recruit families to care for medically complex children. For some children, it is impossible to find a permanent adoptive family willing to take on the high burden of that care.

Children like Darlene, who require surgeries or complex medical technologies, often require complex medical decisions that involve prognostic uncertainty and substantial risk. Such decisions are usually made by healthcare professionals and parents in a process of shared decision making. This process is difficult or impossible in the child welfare system, since that system was never designed to bring its own moral values or interests into the process.

For children whose biological parents have had their rights terminated, or whose parents are not accessible, the child welfare system becomes the default decision-making authority. Case workers who visit a child one to two times per month, who have minimal involvement in the child’s daily care, and who rarely interact with the medical team, are given responsibility for providing consent for medical treatments. Case workers also change frequently, re-

ducing longitudinal understanding of a child's evolving medical needs. To reduce the lack of continuity that comes with changing case workers, many child welfare systems assign authority to give medical consent to supervisors or directors. But they are even more removed from the child than case workers. This raises multiple questions about whether the individuals who are given the legal authority to make these decisions for children have a meaningful and informed understanding of the child's best interests.

This concern is heightened as the stakes of the medical decisions become greater and the oversight becomes more rigorous. Decisions about withholding or withdrawing life-sustaining treatments for a child in foster care require court approval by a judge. Judges generally have no pre-existing knowledge of the child and no particular expertise related to making decisions for medically complex children or end-of-life care for children. When DNR orders are being considered, a judge may request an ethics consult as part of the process. An ethics committee is tasked with considering the medical decision at hand and determining whether a DNR order is considered ethically permissible after spending time with the child and other involved parties to better understand the child's medical condition and quality of life.

In Darlene's case, the medical team, the ethics committee, and her appointed attorney all agreed that a DNR order was in her best interest. Her biological parents were the only parties who testified against the DNR order. But why are parents who have no legal authority to make either routine or serious medical decisions for their child notified of court hearings and allowed to participate in making end-of-life decisions? While they are not technically a party in the case, due to their termination of parental rights, it is up to the discretion of the judge to consider their opinions or testimony.

We do not know why the judge ruled against the DNR order for Darlene and what role, if any, the parents' testimony played in the final ruling. Perhaps the judge felt the parents offered something that clarified Darlene's best interest. While judges are meant to remain impartial (that is, to be rule-based regarding a child's best interest), it would likely be challenging to override parents' pleas, regardless of legal status, and take action that may ultimately result in their child's death.

The Perspective of the Inpatient Care Team

Increasing numbers of patients in neonatal and pediatric ICUs are medically complex.⁵ Their clinicians must guide decisions regarding treatment in-

tensity as the children experience declining function and quality of life. We assume that spinal fusion was intended to improve Darlene's quality and length of life, so that she could return to her foster family with fewer daily care needs and greater comfort. Children and families do report increased quality of life after spinal fusion for neuromuscular scoliosis,⁶ although children with cerebral palsy, like Darlene, often have more limited functional improvements and a higher risk of post-surgical complications.⁷ It is unclear how Darlene's increased risk of adverse surgical outcomes informed pre-operative counseling and consent, or whether the child welfare representative who provided consent had a good understanding of Darlene's medically complex needs.

Darlene did have post-surgical complications, with severe functional deterioration that was predicted to persist. Her extremely limited quality of life is what unified the PICU team, Darlene's lawyer, and the hospital ethics committee in their recommendation against CPR in the event of an arrest. Although there was not consensus in the medical team, some clinicians advocated to reduce Darlene's treatment intensity via withdrawal of medical technology and nutrition. Those individuals worried that pain and distress are difficult to diagnose and treat in children who have severe neurologic impairment,⁸ and that if Darlene had intractable pain, anxiety, or distress, the value of mechanical ventilation or tube feedings may no longer exceed their burdens. In the end, the PICU team proceeded with a request for a DNR order, but without any intention to withdraw existing therapies.

Among all of the persons involved in the medical decision, Darlene's biological parents were the only ones who stated opposition to the DNR order. We must question what motivated Darlene's parents to show up to make their opinion known. It is unclear what the legal implications would be of Darlene's death for her parents, given the history of non-accidental trauma. If her death could lead to criminal charges against one or both of them for murder, they may have had an irresolvable conflict of interest in making decisions for Darlene. Absent such concerns, determining whether the biological parents were appropriate decision makers for Darlene should include consideration of their understanding of the benefits and burdens of her current daily care and how those could change after attempted CPR.

As the judge did hear testimony from the biological parents in the decision about a DNR order, it is important to consider the strength of the reasons

supporting the parents' opposition. We know that persons' religious and spiritual beliefs are often central to their decisions about end-of-life care.⁹ And while supporting a family's values is essential, that support should include exploring how a family's values map onto the current medical decision to be made and how they weigh against other benefits and burdens. Patients and families can misinterpret the rules of their religion related to end-of life care;¹⁰ exploring parents' beliefs may help clarify any misunderstandings and verify the presence of true value conflicts.

The Perspective of the Primary Care Pediatrician

A stable medical home for children like Darlene is a high priority for child welfare staff and pediatricians.¹¹ Pediatricians for medically complex children can coordinate care with multiple subspecialists and appreciate the "whole picture" of a child's medical needs. Assuming Darlene has had one consistent medical home (that is, one pediatrician who has continually followed her care), then Darlene's primary care pediatrician (PCP) would have a long-standing relationship with her, her foster parents, and others who may attend primary care appointments, including child welfare case workers and home nurses. If her medical home predated foster care placement, the PCP would have a prior relationship with Darlene's biological parents and potentially with her siblings. The PCP is therefore well-suited to weigh in on Darlene's medical needs, her social needs, and the competing interests of the multiple individuals involved in her care.

We are not told whether Darlene's PCP was involved in the decision-making process or if he or she is in support of the DNR order, which seems to be an evident omission in the case. For children like Darlene, advance care planning often begins in the inpatient/PICU setting, when an acute illness has occurred or death is imminent.¹² In one study, 71 percent of clinicians felt that such discussions happen too late in the clinical course, and 92 percent believed that discussions regarding the goals of care should occur upon diagnosis or during a period of medical stability.¹³ While PCPs recognize their responsibility for initiating discussions regarding the goals of care, they note that time constraints, family readiness, and a provider's lack of skill in such discussions are barriers.¹⁴

Since Darlene is in medical foster care, the common disconnect between those who know Darlene best and those who are authorized to make medical decisions may have undermined advance care planning up until this point. For children in foster care,

the ambiguity about parents' and family members' involvement can be an additional barrier to advance care planning. Pediatricians are accustomed to deferring to parents' assessment of their child's best interest, based on the assumption that they care about their child, understand the child's unique needs, and hold common family values.¹⁵

The PCP's assessment of Darlene is largely dependent on information gained through interactions with her foster parents, as they are the ones who regularly attend medical visits with her and provide updates about how she is doing. Decision-making authority is less of a question in the primary care setting, where routine decisions such as vaccines, bloodwork, and referrals do not require separate consent from the child welfare agency. On the contrary, when discussing surgeries or higher stake medical decisions in the inpatient/PICU environment, the legal need to escalate a decision to the child welfare agency or courts not only can remove foster parents from the decision-making process, but can also remove input from the pediatrician who has known the child over time.

The medical foster parents, whose opinion about a DNR order is notably absent from the court proceedings, are arguably those who are most knowledgeable about Darlene's care needs and have provided her with a safe and nurturing home environment for six years. During that time, they have had the legal authority to decide when Darlene needs medical care, have scheduled and attended her medical appointments, and have made routine medical decisions with her PCP. But without seeking adoption or guardianship, they cannot make nonroutine medical decisions about procedures or life-sustaining therapies.

So what about the biological parents? Should all biological parents, by virtue of blood alone and regardless of circumstance, be entitled to the same opportunity to speak on behalf of their child in court? In Darlene's case, in which the abuse from her parents resulted in her current medical severity, and assuming they have been uninvolved for most of her life, we would say no. If the judge's decision is meant to be informed by those who care for Darlene and can speak to her best interests, we question why Darlene's biological parents had an opportunity to provide testimony in court and her foster parents and PCP did not.

CONCLUSION

This case and associated commentaries highlight the need to further explore how medical decisions

are made for medically complex children in foster care. As Darlene's biological parents' rights were terminated six years ago, it is unlikely that they have had meaningful interaction with Darlene over the years. They appear to have no substantive moral authority to represent Darlene's best interest and should not have been included in the decision about instituting a DNR order. By better understanding and identifying who the meaningful decision-makers are for children in foster care, we may be able to inform policy and practice on how to approach serious medical decisions for this population.

The current decision-making process for children in foster care involves multiple systems, including the legal, child welfare, and healthcare systems. These systems tend to work in siloes, which can prevent approaching the child's needs and medical decisions through a more integrated model. By intentionally enhancing communication and collaboration between these systems, there is potential to learn from one another in order to address these more challenging decisions.

Unfortunately, little to no data exists on decision-making experiences or outcomes for medically complex children in foster care to guide our conversations. Additionally, court rulings in such cases are typically kept confidential, leaving us uncertain as to why the judge ruled the way he or she did. This is not surprising, as foster youth have special protections in place due to their designation as a vulnerable population.¹⁶ This designation creates barriers that limit data collection and research related to youth in foster care, including learning more about medical decision making. Such challenges and potential solutions will be discussed in the paper that follows, "Medically Complex Children in Foster Care: Do Research 'Protections' Make This 'Vulnerable Population' More Vulnerable?"¹⁷

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BLINDING

Some details of this case have been altered to protect the identities of those involved.

NOTES

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