

Parents Refusing Dialysis for a 3-Month-Old With Renal Failure

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A 3-month-old boy with failure to thrive was referred to a nephrology clinic after a diagnostic workup for failure to thrive revealed a serum urea nitrogen level of 95 mg/dL and creatinine level of 3.6 mg/dL. A renal ultrasound revealed marked bilateral hydronephrosis with little remaining renal cortex in either kidney. A voiding cystourethrogram revealed evidence of posterior urethral valves. The child had no evident comorbidities. Fulguration of the valves was successfully performed but did not lead to improvement in kidney function. The nephrologists recommended the initiation of dialysis with the hope that the child would be able to receive a kidney transplant in the future. After careful consideration, the family stated that they did not want this child to suffer with a lifetime of dialysis and transplant care. They were also concerned about the impact of this child's illness on their other 2 children and their family. They requested that their son be provided with palliative care only. Experts in nephrology, bioethics, and critical care discuss the ethical issues raised by this parental request.

abstract

One of the most difficult ethical dilemmas in pediatrics today arises when a child has a life-threatening illness for which a highly successful treatment is available, but the treatment is burdensome for parents and families. In such cases, the best interests of the patient may seem to be in conflict with the interests of other family members and the preferences of the parents. Examples of this situation include renal dialysis and transplant, home ventilation, or complex cancer chemotherapy. How burdensome does a treatment have to be for us to decide that it is ethically optional? In this Ethics Rounds, we present a case of a 3-month-old with end-stage kidney disease (ESKD). The doctors recommend dialysis. The parents would prefer that their infant receive palliative care. Experts in pediatric nephrology, bioethics, and critical care medicine analyze the ethical issues.

THE CASE

A 3-month-old boy with failure to thrive was referred to a nephrology clinic after a diagnostic workup for failure to thrive (weight 3 kg) revealed a serum urea nitrogen level of 95 mg/dL and creatinine level of 3.6 mg/dL.

The mother's pregnancy was unremarkable. A prenatal ultrasound was conducted at 19 weeks' gestation with no reported kidney abnormalities. There was no report of oligohydramnios. The child's birth weight was 3.2 kg. When questioned, the parents stated that the child had never demonstrated a strong urinary stream.

The child had no evident comorbidities. A renal ultrasound revealed marked bilateral hydronephrosis with little remaining renal cortex in either kidney. A voiding cystourethrogram revealed evidence of posterior urethral valves

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(PUV). Fulguration of the valves was successfully performed but did not lead to improvement in kidney function.

At a family meeting with the child's parents and maternal grandparents, the nephrologists recommended the initiation of dialysis with the hope that the child would be able to receive a kidney transplant in the future. The nephrologists offered to put the family in contact with other families who had children on dialysis. The family requested several days to discuss the situation. They returned 2 days later and stated that they did not want this child to suffer with a lifetime of dialysis and transplant care. They were also concerned about the impact of this child's illness on their other 2 children and their family. They requested that their son be provided with palliative care only.

What ethical issues should the nephrologists consider in response to this parental request?

**LAUREL WILLIG, MD, MS, AND
BRADLEY WARADY, MD, COMMENT**

PUVs occur in ~1 in 5000 live births.¹ Fetal interventions have no definitive impact on long-term kidney function and 20% to 30% of children with PUV progress to ESKD.^{2,3} In the case presented, the nephrology team has recommended the initiation of renal replacement therapy (RRT), starting with chronic peritoneal dialysis (CPD) and followed by kidney transplant at a later date. They convened a family meeting to help the parents make an informed decision about RRT or palliative care.

At such a meeting, doctors would have discussed both the anticipated medical outcomes as well as the psychosocial issues associated with home peritoneal dialysis (PD). After discussing this information among themselves, the family expressed their desire for palliation for 2 primary reasons: their child's suffering and their concern for the

toll PD will take on the rest of their family.

What medical management issues might have been brought up by the dialysis team that prompted the family's decision not to pursue RRT? It is possible that the parents are most concerned about the fact that infants who receive CPD require frequent hospitalizations and medical visits. Infants on CPD have high rates of peritonitis, growth retardation, and suboptimal nutritional status, in part because of oral aversion.⁴ At the same time, they should have been informed that peritonitis rates have fallen and that the combination of growth hormone therapy and supplemental tube feeding is associated with accelerated height and weight gain in infants on CPD.

Whereas infants with ESKD may also experience neurocognitive dysfunction, the frequency and severity of this complication has also decreased over time.^{5,6} Finally, the mortality rate for patients who initiate PD at <1 year is ~20% at 5 years and greatest for those children with comorbidities. However, kidney transplant often takes place at 2 to 3 years of age and success rates after transplant are actually higher for infants or young children compared with all other age groups.⁴

As for the psychosocial issues, the dialysis team would have related how home PD requires a substantial time commitment by caregivers and can be associated with financial, emotional, psychological, and social strain. Studies on the impact of home PD report that in many instances, at least 1 caregiver must give up a job to be home full-time taking care of the infant with ESKD.^{7,8} Household income can also be impaired, and some caregivers report an increased incidence of depression.⁸ Parents may find it difficult to see their children undergoing invasive procedures and feel at fault and guilty if PD-related complications occur.^{9,10} Although this type of

information may discourage a family from pursuing RRT despite the encouragement to do so by the dialysis team on the basis of their previous successful experiences, every effort should be made to fully inform these parents so that they are prepared to make the best possible decision regarding the provision of RRT for their child.

Of interest, opinions vary within the pediatric dialysis community regarding the provision of dialysis during infancy, despite increased success over the past 2 decades.¹¹ In a multinational survey, only 30% of pediatric nephrologists and pediatric dialysis nurses responded that they would offer chronic dialysis to all infants presenting with ESKD at age 1 to 12 months, and half of the nephrologists would give parents the option to refuse treatment. Coexisting conditions, anticipated morbidity, and the family's right to decide were the most important factors influencing the survey results.^{12,13}

What should the dialysis team's response be to the parents' treatment decision? The first step in this "life and death" dilemma is further discussion with the family. It should be reiterated to the family that because of the absence of comorbidities, their child has a high likelihood of doing well on dialysis and ultimately receiving a kidney transplant (but also has a likelihood of requiring several additional transplants over a lifetime). Medical facts are often misunderstood during times of stress and an attempt by the dialysis team to better understand the suffering about which the family is most concerned is important. Given the complexity of ESKD care, this perceived suffering may be the result of misconceptions about dialysis or transplant. The family's perception of harm versus benefit may change with further clarification and discussion. At the same time, it is also possible that the family understands the issues and that their decision is well

informed and/or that their opinion may have been influenced by the opinion of 1 or more dialysis team members who themselves may not be completely supportive of choosing a lifetime of RRT for this young infant.

This family also professed concerns about the suffering that might be experienced by their other children, and both the dialysis team and the parents must consider the impact of CPD during infancy and long-term RRT on the entire family. In addition to the provision of professional psychosocial support from dialysis team members, this family should ideally also be given the opportunity to meet or speak with another family who has cared for their own infant with ESKD, because such a family is likely to be a creditable source of information regarding the everyday realities of ESKD care.

In summary, the dialysis team is in favor of home dialysis because of its promise of at least a short- and medium-term benefit, but the team acknowledges that there is no cure for ESKD. The team is optimistic about the child's likely outcome and finds it difficult to contemplate palliative care but also recognizes the challenges to be faced by this family should they choose to pursue RRT. In turn, if the family's decision remains unchanged at the end of the subsequent conversations, we do not believe that it would be in the child's best interest for the dialysis team to either force the parents to undertake this therapy against their will or to recommend separation of the infant from the family and placement in medical foster care. At the same time, recognition that there are likely many ethical and legal issues that have not been considered by either the medical team or the family, we would opt to obtain the opinion of the hospital ethics committee before making a final decision.

D. MICAH HESTER, PHD, COMMENTS

Parents are typically the primary persons to make decisions for their children, and for good reasons. Parents have more invested in their own children than others do, they typically know their own children better than others, and they should want what is best for them. Moreover, it is through familial bonds that many values are imparted and that children develop significant aspects of their moral characters.¹⁴ Parents also bear a direct cost for decisions that they make for their children.

But although parents should typically be afforded the authority they deserve, authority is never limitless. It is suggested that parental authority is limited when they fail to do what is in the best interest of their child. The "best interest" standard obligates both parents and providers to "do what is best" for children in their care.^{15,16} However, the standard is not always a useful concept under practical conditions. Aspirational conceptions of the standard suggest that we are to do "what will maximally promote the patient's good."¹⁷ But how can others determine what is "maximal" promotion of the good for this particular individual, and how do you adjudicate between differing ideas of that "good"? Other versions of the standard are more pragmatic, recognizing a kind of "good as we can get" or even "good enough," rather than an idealized "best," standard.^{18,19}

Children's interests are ascribed to them, not expressed by them.²⁰ For example, even if we say that they have a basic interest in "living," it is because many of us have a basic interest in living, and we assume this should apply to all other human beings. Of course, it does not apply universally. Many cases both in and outside of medicine prove this. So, the complexity of the source and scope of interests must be addressed.

Furthermore, a child's interests are never those of the child alone. Any version of the best interest standard would need to recognize that the interests of the family, and other intimate parties, may need to be considered as well. After all, a child's interests are not protected if the process of protecting them impoverishes or destroys the family unit.

Given these complexities and ambiguities, it may be more practical not to place full weight on aspiring to the best interest standard. Instead, it may be more practical to simply delimit the lower threshold of care; that is, to determine identifiable, substantive, and preventable harm.^{21,22} Diekema²³ suggests that the "harm principle" should replace the best interest standard. The principle is summed up by the following question: "Does the decision made by the parents significantly increase the likelihood of serious [and imminent] harm as compared with other options?" If not, then the parents should retain authority. If so, then the state should intervene.

Taken from the perspective of harm to the child, the correct moral path becomes clear. Not providing dialysis will clearly harm the child. Transplant graft survival for young children with renal failure is >87% at 5 years.²⁴ Without dialysis and transplant, he will die. We know that his 1 substantial problem is his kidneys, and their function can be mimicked through the technology of dialysis, leading (hopefully) to a later transplant. With dialysis and eventual transplant, this child could have normal cognitive and physiologic development.

The parents in this case indicate that they believe the child will "suffer with a lifetime of dialysis and transplant care." Further, they note that their family (including 2 other children) would be unduly burdened by the care of their newest child. These implications of

treatment are serious and need to be seriously considered. However, we do not know whether the burdens of treatment will harm the family, and even if we did, burdensome is not equivalent to unreasonable, unwarranted, or even unnecessary.

There is strong reason to believe that a good life is possible, and, as such, the harm of allowing this child to die without attempting beneficial interventions would be a grave harm. The intervention is necessary to prevent that harm. Given that a good life is possible with treatment, and that death is inevitable without it, I would recommend intervening to get the state involved.

Now, note that this seems to speak only to state involvement, not whether to do dialysis. This is because, in most jurisdictions for most kinds of cases, physicians are not authorized simply to do what they wish when they disagree with the parents. The state retains that authority through the doctrine of *parens patriae*. But frankly, the moral implication that follows from health care providers involving the state in cases like these is that doctors view the parental position as unacceptable. The doctors should try to convince the judge that, in this case, dialysis is ethically obligatory.

ERIN PAQUETTE, MD, JD, MBE, COMMENTS

In response to this parental request for palliative care only, the nephrologists should consider how ethical decisions are generally made for pediatric patients, whether that standard has been met in this particular case, and whether all potential options have been provided to this family in a way that best helps them to make this decision. For pediatric patients, medical decisions are generally based on the best interests principle.

When deciding what is in a particular child's best interests,

the decision-maker should weigh the benefits and burdens of each potential course of action. Traditionally, we work with parents to make this judgment and guide them with our medical knowledge. Parents are generally best situated to determine what is in the best interests of their particular child in the context of their family. We respect parents' decisions as long as their choices fall within a range of ethically acceptable options.

While parents provide informed permission or refusal, rather than consent, on behalf of their children, they must be able to meet the core elements of consent in making their decision. Informed consent requires that the decision-maker has capacity, has received adequate information, and makes a voluntary choice. The nephrologists should determine, first, whether the parents in this case have the capacity to make a decision regarding their child. To demonstrate capacity, the parents must be able to understand the relevant information presented to them, the consequences of various courses of action, and the ability to manipulate information rationally. To address this, the nephrologists should assess what the parents understood at the time the refusal was made. In particular, the team should ensure that the family understands their child will not survive long-term without dialysis, as well as what the expectations for their child are if they were to pursue either a palliative course alone or dialysis. Importantly, they should also explain that the choice of dialysis and palliative care is not an either/or choice. Their child could receive dialysis and palliative care simultaneously should they choose to pursue dialysis. This might address their concerns about suffering and ensure continued assessment of their goals of care.

The team has appropriately offered the parents an opportunity to meet with other families whose children

have required dialysis to learn more about the potential impact on their child and family. It is unclear whether the parents elected to contact other families before returning to the team with their decision to forego dialysis. At that time, they expressed concerns over their son's suffering, as well as over the impact dialysis and transplant may have on their family and other children. It is important for the nephrologists to explore the parents' reasoning further to assess their perception of suffering and to correct any misconceptions.

Once the team has determined that the parents have the capacity to decide and has addressed gaps in understanding, the team should next consider the ways in which the family is balancing the interests of the sick child with the interests of other family members. The parents' choice may be influenced not only by the child's circumstances but also by the circumstances of others within the family. The nephrologists should therefore consider whether and how the family considers the needs of their other children in making a decision for this child. It is reasonable and important for families to consider the broader impacts of the medical decisions they make for their children to reasonably determine if a particular course of action is the correct choice for their family. Although the best interests standard sets up a paradigm to consider 1 child's interests in isolation, in reality, the interests of any child intersect in unavoidable ways with the interests of other family members.²² Parents are best positioned to weigh these interests against each other. However, if the family's choice to limit the option of dialysis for their child is motivated mainly by concern for their other children, the medical team may question whether family circumstances constrain their ability to care for a child receiving dialysis so greatly that they feel

there is no other option except to forego dialysis. In this circumstance, the voluntariness of the parents' decision may be questioned, and the team should determine if there are resources that might aid the family to alleviate this stressor. If the parents are choosing to forego dialysis primarily because it is in the interests of other family members to do so, this would not be ethically acceptable. In this situation, the team might explore whether the family has considered adoption or other placement for the child.

Palliative care alone is generally not accepted as an option in situations in which treatment offers a reasonable likelihood of 5-year survival.²³ But there are aspects of dialysis, particularly when initiated during infancy, that may modify this judgment. A lifetime of either dialysis or ongoing posttransplant care is associated with significant financial costs, high burdens for the family, and potentially life-limiting medical complications.²⁴ Reasonable parents, considering all these factors, may elect not to pursue these treatments.

Ultimately, the team must consider whether the family meets their obligation to decide in their child's best interests. The team may assert that many children with PUVs and intact pulmonary status survive and thrive into adulthood, although poor renal function at presentation, even in the absence of pulmonary disease, is associated with an increased risk of progression to ESKD.²⁵ To challenge the parents' decision in this case on the basis of optimism about long-term survival, the team would need to assert that a decision to forego dialysis and opt for only palliative care constitutes medical neglect. When considering refusals of recommended treatment of treatable diseases with favorable prognoses, both clinicians and courts may be inclined to override parental authority and enforce treatment.^{26,27} But courts are not consistent. They

have ruled differently on parental authority to refuse, even in good prognosis situations.²⁵

Before pursuing a claim of medical neglect on the basis of the parents' refusal, the team should question whether the parents' decision infringes unacceptably on the patient's interests (addressed above) and whether palliative care only is a reasonable option for this child. When motivated not primarily by meeting the interests of other children, but out of true concern about the potential suffering of this child, I believe that it is a reasonable option. If the family continues to prefer palliative care only after the team discusses the possibility of a trial of dialysis, with opportunities to consider discontinuation if complications occur, and the possibility of dialysis with simultaneous palliative care involvement, then the team should honor their decision.

JOHN D. LANTOS, MD, COMMENTS

Two features of this case make it particularly thorny. The first is the role of the patient's age in shaping the decision about whether to permit a decision to forego dialysis. Nephrologists are more likely to permit such a decision for infants than for older children.²⁸ This is not necessarily age-based discrimination against infants. In many cases, infants with ESKD have associated anomalies that make the prognosis worse.²⁹ And dialysis is technically more complicated in infants than in older children.³⁰ But in this case, the patient did not have associated anomalies. Thus, his prognosis for survival and an eventual kidney transplant was excellent.³¹ Such treatment would seem to be clearly in the child's best interest.

That leads to the second complex feature of this case. The parents' decision was clearly based on their consideration of the interests of the

family as well as the interests of the patient. They were concerned, apparently, that the treatment of this child would have a negative impact on their family. Groll³² analyzed such claims and concluded that "sacrifices can sometimes be demanded of some family members for the sake of others." He suggests that the interests of other family members should be "taken into account" in making treatment decisions for a sick child.

Family interests should clearly be taken into account. Infants and children need families to grow and thrive. But when the interests of the family lead to the withholding of a life-saving treatment of a child who might otherwise grow and thrive, the balancing of interests should tilt in favor of the child. The best solution might be to seek medical foster care³³ to provide the medically indicated treatment while still respecting family interests.³⁴

All of the cases in Ethics Rounds are based on real events. Some incorporate elements of a number of different cases in order to better highlight a specific ethical dilemma.

ABBREVIATIONS

CPD: chronic peritoneal dialysis
ESKD: end-stage kidney disease
PD: peritoneal dialysis
PUV: posterior urethral valves
RRT: renal replacement therapy

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