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Beyond technical feasibility: rethinking renal replacement therapy in children with profound medical complexity

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Dear Editor,

We recently read, with great interest, the article by Kawamura et al. [1] addressing renal replacement therapy (RRT) in adults with intellectual and developmental disabilities, published in *Renal Replacement Therapy*.

The authors compellingly describe how individualized dialysis prescriptions and multidisciplinary collaboration can overcome barriers historically considered incompatible with successful treatment. Their work contributes to a much-needed re-examination of how vulnerability, functional limitations, and social context intersect with RRT. While the adult experience they report is clinically valuable, reading it prompted us to reflect on some important conceptual gaps when the same reasoning is transferred, implicitly or explicitly, to the pediatric population, particularly to medically complex children with severe neurodevelopmental impairment and extremely fragile underlying conditions. Drawing on pediatric palliative care (PPC) literature and on our clinical experience with a profoundly neurologically impaired child with end-stage kidney disease managed in a tertiary pediatric nephrology center, we argue that technical feasibility alone does not equate to meaningful benefit, and that a broader, ethically grounded understanding of "personalization" is required when considering dialysis or transplantation in such children.

The article by Kawamura and colleagues rightfully highlights how RRT can be adapted to individual needs and contexts. However, in pediatrics—and especially within PPC—technical adaptability does not necessarily translate into global well-being. Children with severe, irreversible neurological conditions often present with multisystem impairment, dependence on complex medical technologies, and a trajectory characterized by recurrent destabilizations. Several PPC studies from Italy and elsewhere show that non-oncological children may live for many years with significant symptom burden, fragile homeostasis, and high caregiver strain [2, 3], yet the goal of care for these families progressively shifts from the pursuit of cure toward stability, comfort, and maintaining meaningful interaction within family life. In this population, dialysis may correct biochemical abnormalities while simultaneously increasing the child's exposure to painful procedures, hospitalizations, sleep disruption, and unpredictability. It may also reduce opportunities for relational time, limit the child's already constrained developmental experiences, and impose logistical and emotional burdens that profoundly affect family quality

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of life. A treatment that is physiologically effective may therefore still be holistically burdensome, raising the ethical question of whether feasibility alone should drive decision-making.

Pediatric decision-making is grounded in the "best interest" standard, a principle that obliges clinicians and families not merely to consider survival or organ-specific outcomes but to weigh the balance of expected benefits, treatment burdens, foreseeable suffering, the child's current and future quality of life, and the values and coping capacities of the family. In children with profound neurodevelopmental impairment, renal transplantation or dialysis rarely modifies the overall developmental trajectory. Even when graft function improves renal parameters, the child may remain unable to interact, communicate, or engage with their environment in any developmentally meaningful way. For many families, PPC literature shows that the overarching priority becomes preserving stability, maintaining comfort, and minimizing disruptions to the delicate equilibrium of home life [4]. Offering RRT solely because it can be technically delivered risks conflating the correction of a single organ failure with genuine enhancement of the child's lived experience.

These considerations become especially visible when one applies the ethic of proportionality, which evaluates whether the expected benefit of an intervention meaningfully outweighs the anticipated burdens. In the case that inspired this reflection, a previous kidney transplant—although surgically and immunologically well conducted—resulted in months of suffering, complications, repeated hospitalizations, and profound instability before ultimately failing. Overall, 7 months were required for the child to return to the fragile baseline of comfort and predictable daily routine that the family described as "normality." The child's neurological prognosis remained static and severely compromised, with no expectation of developmental gains. Restarting dialysis or placing the child again on the transplant list would likely reintroduce recurrent infections, procedural pain, sleep–wake cycle disruption, and caregiver exhaustion, without any realistic prospect of improving cognitive functioning, relational capacity, comfort, or developmental potential. In such situations, escalating treatment may paradoxically lead to *more* suffering with *no* corresponding benefit, a pattern well described in PPC literature and increasingly recognized as a form of disproportionate care [5]. Furthermore, these scenarios have implications that extend beyond the individual patient because they raise issues of justice. Indeed, initiating or continuing disproportionate treatments hinder equitable access to care. A clear example of this is pediatric transplantation: donor organs, particularly pediatric kidneys, are among the scarcest medical resources, and their allocation must balance individual needs with ensuring fair access for all eligible children. Therefore, clinical effectiveness and distributive equity must be considered together: this is challenging because treatments should offer the greatest possible benefit to the individual patient without any form of discrimination, while remaining compatible with the fair distribution of limited resources.

PPC offers structured frameworks, such as ACCAPED, PaPaS, the Surprise Question, and complexity-based needs assessments, which can be used to evaluate whether a child with CKD stage 5 and severe multisystem impairment might benefit more from conservative kidney management than from RRT [4, 6–8]. These tools highlight dimensions frequently under-represented in nephrological evaluations: overall symptom burden, feeding and respiratory fragility, sleep quality, communication limitations, the child's comfort during handling, the sustainability of caregiving at home, and the long-term emotional and physical strain on parents. When applied to medically complex children, these models often identify a high PPC complexity category in which the focus of care should shift toward optimizing comfort, ensuring predictable routines, reducing invasive procedures, and strengthening coordinated home-based support rather than intensifying organ-specific medical interventions. The decision not to initiate peritoneal dialysis or not to relist a child for transplantation is therefore not an act of therapeutic renunciation. Instead, it represents a reorientation of care, aimed at maximizing the child's comfort, stability, and presence within family life while ensuring that caregivers receive adequate clinical, psychosocial, and home-based support.

Our clinical reflection also points toward a broader understanding of "personalized RRT." In the adult article, personalization refers to adapting dialysis modalities and prescriptions to functional abilities and social contexts. While this is undoubtedly valuable, personalization in pediatrics must be broader. It must incorporate the child's long-term neurological prognosis, the realistic potential for developmental progress, the capacity to experience comfort and connection, the family's values and vulnerabilities, and the full ethical assessment of proportionality and best interest (Table 1). In certain complex pediatric cases, the most appropriate and genuinely individualized treatment may be to *not* initiate dialysis, even when every technical component of therapy could theoretically be delivered. This is not a limitation of medicine but an affirmation of medicine's ethical compass: a recognition that "what we can do" is not always "what we should do."

In conclusion, the cases described by Kawamura et al. remind us that vulnerable patients can indeed receive

Table 1 Key determinant of best-interest evaluation when considering renal replacement therapy in medically complex children

Domain	Guiding questions
Clinical trajectory	Does RRT meaningfully modify the child's overall medical course, or merely correct biochemical derangements?
Developmental potential	Are there retained abilities or developmental goals that RRT could realistically support?
Treatment burdens	What are the expected burdens (procedural pain, hospitalization, infections, recovery time)? Are they proportionate to potential gains?
Quality of life	Will RRT enhance comfort, interaction, stability or participation, or will it prolong a state of medical fragility?
Family system	What are the family's values, expectation, coping capacity, and limits? How does the treatment impact family well-being?
Ethical proportionality	Is RRT still in the child's best interest compared with PPC-guided conservative care? Does the balance of burdens versus benefits remain ethically acceptable?

RRT successfully when properly supported. Yet in pediatrics, especially in children with profound medical complexity and severe neurodevelopmental impairment, technical feasibility should not overshadow the ethical and palliative frameworks essential to determining global benefit. We therefore suggest expanding the concept of personalized RRT to include not only the optimization of dialysis modalities but also the possibility, when aligned with best interest, proportionality, and PPC-guided assessment that foregoing dialysis may represent the most compassionate and ethically sound choice, in a manner that also promotes equitable access to care. A wider recognition of this perspective may foster more transparent, collaborative, and humane decision-making processes for medically complex children and their families, ensuring that care remains anchored not only to survival but also to comfort, dignity, and quality of life [9].

Abbreviation

PPC	Pediatric palliative care

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Author contributions

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