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The ethical dilemma of initiating ambulatory peritoneal dialysis in a preterm neonate: an unusual experience

Abstract

This study reports on a male 35-week preterm neonate who was diagnosed with chronic kidney disease and referred for renal replacement therapy on day 10 of life. The ethical dilemma of deferring a lifesaving intervention was weighed against the best interest of the neonate and the family. By comparing the experiences in the current case to those reported previously, the authors present further insight into this challenging scenario faced by neonatologists.

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Introduction

The number of neonates who require dialysis for chronic, irreversible kidney disease is extremely low with numbers varying from seven to 12 per million age-related population [1]. The British Association of Perinatal Medicine (2010) guidelines for neonatal palliative care (NPC) state that a neonate born with an antenatal or postnatal diagnosis of a condition which carries a high risk of significant morbidity or death should be considered for palliative care. An ethical dilemma is faced by neonatologists while

managing these neonates, especially regarding the initiation of renal replacement therapy (RRT) and counselling the family members and caregivers regarding the aspects of palliative care.

Case description

A 10-day-old male 35-week preterm neonate weighing 1700 g was referred with a diagnosis of chronic kidney disease requiring ambulatory peritoneal dialysis from the interiors of Western India. The parents were explained regarding the need for dialysis before

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referral. Ultrasound of the kidney done at the centre confirmed bilateral abnormal kidneys with loss of corticomedullary differentiation and serum creatinine at admission was 6 mg/dL (normal 0.25–0.5 mg/dL) which continued to be elevated. The neonate was born with congenital bilateral hypoplastic kidneys and abnormal renal function led to hypertension, hyperkalaemia, and anaemia. The neonate had an additional calorie requirement due to the renal abnormality which was not adequately met leading to extrauterine growth restriction.

Multidisciplinary counselling was initiated involving the neonatologist, paediatric nephrologist, social worker, and clinical psychologist from the day of admission. The ethical dilemma of deferring a life-saving intervention was weighed against the best interest of the neonate and the family. Parents were told about the need for dialysis by the referral hospital and were hopeful of a definitive cure in a tertiary care centre. However, they had to be explained about the magnitude of the problem, the challenges involved and the affection of quality of life including the need for long-term dialysis and the possibility of renal transplantation in the future.

Parents were allowed into the NICU to spend time with the neonate and were an integral part of all the counselling sessions. The team had sensed from the initial discussions with the parents that it was challenging to make them even recognize the need for hospitalization for this condition and its severity as they were coming from a rural place where hospitalization for an otherwise outwardly normal-looking baby without any obvious malformations was quite uncommon. Hence, their feelings were acknowledged, allowing them to voice even the smallest uncertainty.

The main barriers encountered during these counselling sessions also included making the parents understand the concept of ambulatory peritoneal dialysis and preparing them for the same because each session concluded with the same question: "Is there a chance for alternative therapies? Can it be cured with medicines only"? To give more clarity about the treatment process, they were shown videos and were taken to the dialysis ward to witness children undergoing dialysis. "Will my small baby be able to tolerate this procedure" was the main concern of the mother. The subsequent step was determining the elements needed for home therapy to continue once the procedure was understood.

They were informed that the social worker would assist in securing a steady supply of the necessary medication as well as a neonatal dialysis kit. The main concerns included the non-availability of a designated place at home, working father with no additional help

to mother, travel expenses to be incurred during monthly visits, lack of family support, need for maintaining strict asepsis and potential lifelong care leading to financial strain, caregiver burnout and delay in the subsequent childbirth.

"We want to get our baby treated but I won't be able to do it alone and my husband needs to go to work, and he is the only bread earner in the family" expressed the mother. The decisions regarding treatment focused on helping clinicians and families to talk about prognosis openly and clearly. This was important, given the fact that the emotions caused by initiating treatment and then withdrawing it would be greater than withholding treatment. At this point, it was crucial to emphasize that with each session the constant discussion between the varied healthcare professionals also reflected their momentary internal struggle between giving the parents unconditional acceptance, detailed description of affection of quality of life and at the same time there was the challenge to convince them to opt for the treatment.

There were several multidisciplinary counselling sessions involving the parents and even extended family members. "Suffering is not a punishment from God and suffering should be relieved if possible and we wish not to let our baby suffer": parents echoed these beliefs and opted for home palliation and did not consent to dialysis. As per The British Association of Perinatal Medicine (2010) guidelines for neonatal palliative care (NPC), given significant long-term morbidity and high risk of mortality the neonate was enrolled into the NPC program. Comfort care was provided and non-pharmacological techniques of swaddling, facilitating tucking and skin-to-skin care were used to reduce pain with no unnecessary intravenous pricks. Neonate was continued on breastfeeding. Parents were encouraged to hold the baby and to create memories as this can be an important milestone for a young married couple to experience parenthood in a busy NICU. The constant psychosocial support provided by the team was a hopeful attempt to make them feel accepted and empathize at each step.

Allowing the parents time to decide and open communication in the presence of a senior doctor during all discussions with the aim of palliation and shifting the focus to ensure comfort and not appearing judgmental about parents' opinions helped in balancing the ethical dilemmas. At the end of the counselling sessions, the parents and family were satisfied. There was no guilt or feeling of any wrongdoing among the family and the healthcare providers. The neonate was continued on oral medications, breastfeeding was optimized and was discharged on day 35 of life and on regular in-person and telephonic follow-ups.

Discussion

Management of infants on RRT is laborious and is not possible without the full commitment of the family and the medical team [1]. Early palliative care involvement, in this case, facilitated medical decision-making for the family and improved care coordination while attempting to mitigate suffering for the neonate and family and helping frame quality-of-life discussions. Palliative care was initiated to alleviate the distressing symptoms of this chronic life-limiting end-of-life condition to work with other modes of therapy to prolong life [2]. These severely compromised babies are also likely to require very prolonged palliation in the form of home palliation for the suffering, even though the risk of dying immediately is less [2].

Using the conceptual framework for medical decision-making that classifies anticipated therapy and outcomes as clearly beneficial, clearly futile, or of uncertain benefit, ambulatory peritoneal dialysis a form of RRT for neonates and very young infants has long been considered of uncertain benefit due to unclear long-term outcomes [3]. However, as dialysis is more routinely offered to neonates and infants with ESRD and more published data on improved medium and long-term outcomes have become available, consideration has been given to classifying this therapy as clearly beneficial [3]. This improvement in outcomes has raised the question of whether dialysis therapy should be refused or withheld in infants, especially for those without other comorbidities as in the present case.

In various surveys conducted concerning RRT in neonates, only 12–27% of healthcare professionals including paediatric nephrologists were in favour of RRT and the remaining thought it was usually acceptable for parents to refuse treatment for their newborn [4]. In the Indian scenario in addition to the underlying comorbidities, complications and outcomes, due consideration should be provided to the socioeconomic background, family support, quality of life concerns, allocation of resources, legal issues and most importantly, the opinions of the hospital team and the parents.

Involving the parents actively in the decision-making process and discussion on the predicted quality of life for the child and family are recommended by the Paediatric Dialysis Working Group Guidelines (2014) when deciding on RRT [5]. As per the French Neonatal Society and The Nuffield Council on Bioethics (UK), the quality of life rather than the chances of survival is the determinant of whether life-saving

treatment is reasonable or unreasonable, *i.e.*, in the child's best interests [6].

It is rare to find a single "right" way to do something. Ethics, therefore, provides a means of evaluating and choosing between different, often competing, options and is about analysing values rather than facts. Many hospitals have ethical committees' whose purpose is to lead and aid discussions about difficult cases, but they are for guidance rather than formal decision-making. The role of hospital ethics committees in the process remains extremely variable. The main ethical principles followed in the present case included respect for autonomy, beneficence: acting in the best interest of the child non-maleficence, constant involvement of family members in decision-making and solving conflicts between family and clinicians in a non-authoritative manner. There was a detailed discussion on cost and benefit assessment and issues of the futility of treatment in an open and non-judgmental way.

Conclusions

In the current scenario of these ethical dilemmas about RRT in neonates, neonatal palliative care and family-centred care might be the light at the end of the tunnel in bringing out an agreement between the healthcare team and caregivers in the best interest of the child.

Article information and declarations

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Author contributions

PRR and SN — conceptualizing, design and drafting; RR — providing the social details of parents; AH — critical revision of the manuscript.

Conflict of interest

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Ethics statement

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Supplementary material

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