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Research paper

Neonatal renal replacement therapy: An ethical reflection for a crucial decision

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ABSTRACT

Context: Technological advances in fetal and neonatal medicine, recent changes in the French legal framework, and encouraging results of the long-term outcomes in children with neonatal renal failure provide elements for an ethical reflection.

Methods: We led a nationwide enquiry among French pediatric nephrologists, intensivists, and neonatologists, exploring the decision-making process when contemplating starting renal replacement therapy (RRT) or delivering palliative care to neonates or infants with pre-end-stage or end-stage renal disease; and the ethical quandaries at hand in such scenarios.

Results: A total of 134 responses with complete national coverage were obtained. Care to be delivered to an infant in pre-end-stage or end-stage renal disease did not achieve consensus. Pediatric nephrologists were more prone to initiate a dialysis/graft program than pediatric intensivists. When chronic kidney disease was associated with comorbidities, especially neurological impairment, physicians, regardless of their subspecialty, were more reluctant to initiate conservative treatment. Many of the doctors surveyed did not give their opinion in these prenatal and/or postnatal situations, considered to be unique and warranting a multidisciplinary reflection.

Conclusion: Such ethical dilemmas are challenging for parents and physicians. They can only be overcome by taking into account both concrete on the ground realities and general principles and values acknowledged to be a basis for respecting the individual. In this way, it ensures humaneness and humanization of a practice that must meet a variety of challenges, one by one. The answer is not simple; it is always unique to each child and can only be approached by a multidisciplinary, time-consuming, open discussion, which will never totally erase uncertainty.

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1. Introduction

End-stage renal disease (ESRD) in children is rare, but its incidence is not decreasing. In 2013 in France, the incidence and prevalence of ESRD in patients less than 5 years old were 6.9 and 15.3 per million age-related population (pmarp), respectively [1]. ESRD in children is most often due to a congenital condition. Fetal medicine allows prenatal diagnosis of congenital malformations or diseases with a neonatal or life-long impact. The incidence of termination of pregnancy (TOP) for congenital anomalies is on the rise in Western countries (> 7000 in 2010 in France) [2]. Yet,

both short- and long-term outcomes remain uncertain [3], because both the severity of renal failure and the age at ESRD in children with congenital anomalies of the urinary tract or kidney disease are unknown or unclear [4].

Since the late 1990s, significant advances have been made in treating infants with ESRD [5]. Renal replacement therapy (RRT) in infants has been facilitated by machines adapted to very low weight [6,7]. Hence, more infants are on RRT programs. Moreover, therapeutic advances in dialysis and transplantation have been successful in extending the life span of infants with severe chronic kidney disease (CKD). The views of doctors on the possible future of these children, the treatments to implement, and their potential consequences are primordial. This greatly influences the decision to continue or terminate pregnancy and to initiate conservative treatment or palliative care after birth. The attitudes of care

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providers towards treatment of infants with ESRD have evolved over the last few decades. RRT is increasingly viewed as an option to be undertaken in this age group. Nevertheless, initiating dialysis in infancy remains a difficult medical and ethical situation for many pediatricians [8].

In 2014, long-term data of the ESPN/ERA-EDTA registry provided valuable information on children who had received transplants before the age of 2 years, demonstrating improved survival with satisfactory outcomes for growth, neurological development, and quality of life in adulthood. Only neurological disorders increased the risk of death fivefold [9,10]. Nevertheless, these encouraging results should be considered, keeping in mind how much ESRDs in young children are burdensome for children and their families, and are time- and care-consuming and expensive.

There are currently no specific guidelines to decide whether or not to start RRT. Doctors and families must face complex ethical dilemmas making such decisions. An editor's note published in 1998 highlighted the gap between techniques and ethics: "The technology is available to provide care for ESRD in infants of almost any size. The question arises: should we, simply because we can?" [11].

Considering technological advances, increased information on diverse outcomes, more encouraging data on long-term outcomes in infants with RRT, and the trend towards a multidisciplinary approach to patient decision-making, we found it relevant to revisit the issue of attitudes among healthcare providers toward RRT in infants and toddlers. The objective of this study was to describe current medical practices and physicians' decisions regarding fetuses and newborns with severe congenital kidney disease, in a nationwide enquiry in France.

2. Methods

2.1. Internet survey

The survey was conducted using an online questionnaire created on Google Drive. The first part of the questionnaire concerned the general characteristics of the professionals surveyed and their medical practice: date of birth and gender; year MD degree awarded; city and healthcare service of current medical practice; size of their health region; number of hospitalizations in their unit as well as pre- and postnatal consultations a year; activity of their dialysis center if any, kidney transplant activity; and questions regarding the activity within the local CPDPN (Centre Pluri-Disciplinaire de Diagnostic Prénatal), which is the regional committee giving an opinion on the admissibility of TOP in case a fetal malformation is diagnosed.

The second part of the questionnaire probed a priori attitudes medical staff may have on ESRD in infants with or without neurological impairment.

The last part described four case reports. Prenatal and postnatal decisions were explored. These case reports were as follows:

- isolated ESRD in a full-term live-born neonate: prenatal diagnosis of unilateral renal agenesis and contralateral severe renal hypoplasia; neonatal oligo-anuria and systemic hypertension;
- postnatal diagnosis of ESRD due to autosomal recessive polycystic kidney disease (ARPKD), with severe pulmonary hypoplasia and hypoxemia;
- prenatal diagnosis of a congenital malformative syndrome, in a fetus of a 40-year-old couple, conceived with assisted medical reproduction techniques. Pre-ESRD associated with severe neurological disorders at 6 months of life;

- early prenatal diagnosis of a case of severe bilateral hydronephrosis caused by congenital posterior urethral valves, with pre-ESRD at birth in a full-term live-born neonate.

It should be noted that open comments could be recorded several times in the questionnaire.

2.2. Participants

The internet survey was emailed with an explanatory letter to doctors working in pediatric intensive care units (PICUs), neonatal intensive care units (NICUs), and pediatric nephrology units in France. At least one answer per unit was expected.

2.3. Data collection

The questionnaire was mailed in early January 2015, and responses were collected until the end of February 2015. Time to fill in the questionnaire was estimated at approximately 30 min. The physicians' responses were automatically recorded in a secure internet file, with only the study investigators having access.

2.4. Statistical analysis

Bivariate analysis was performed using χ^2 tests or Fischer exact tests when required for categorical variables. Continuous variables were analyzed using Student *t*-tests or ranked sum tests when required. Statistical significance was set at $P < 0.05$. Statistical analyses were performed using SAS (version 9.1, SAS Institute Inc., Cary, NC, USA).

3. Results

3.1. Characteristics of the physicians surveyed and their units

3.1.1. General characteristics of the professionals surveyed and their medical practice

One hundred thirty-four responses were obtained from all metropolitan French regions and Reunion Island: 104 from attending doctors (hospital practitioners and university professors) and 30 from residents (pediatric trainees and young residents). The results of the enquiry among residents are presented separately.

Fifty-four (52%) attending doctors were women and 50 (48%) men. They were (median, range) 41 years (29–67) old with 12 years of professional experience (1–37). All were pediatricians except one anesthesiologist. Thirty-one (30%) had a qualification in pediatric nephrology, 50 (48%) in neonatology, and 29 (28%) in pediatric intensive care. Of the 81 physicians working in an intensive care unit, ten (12%) worked in PICUs, 33 (41%) in NICUs, and 38 (47%) in ICUs combining pediatric and neonatal care.

Sixty-seven (64%) respondents worked in a health region with fewer than 2.5 million inhabitants. The activity of the pediatric units was variable in terms of medical consultations (median, range): 1000 (350–12,000) medical consultations per year, of which 700 (52–2600) were postnatal and 20 (0–100) prenatal; and 650 (350–8000) patients hospitalized per year.

3.1.2. Renal replacement therapy techniques available in the centers

A pediatric dialysis unit was available in 61 (59%) centers; 70% centers had expertise in peritoneal dialysis. Half the centers performed hemofiltration and/or hemodialysis. Only 12 centers had treated more than six children aged less than 5 years with kidney transplantation in the last 5 years and half of the centers had not had any patients under 5 years old on hemodialysis or peritoneal dialysis during the past 5 years.

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