Ethical issues and children with chronic kidney disease

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Abstract

Ethical decision making is as important as clinical management, especially as in developed countries we can now offer dialysis support to children of all ages with future kidney transplantation in mind. However, more children are being referred for treatment with major co-morbidities and the treatment, especially in infants, imposes a high burden of care and costs on the family. Withholding or withdrawing dialysis treatment may be appropriate options and this article illustrates some of the ethical dilemmas that may arise. Acting in the greater best interests of the child and consensus building are emphasised.

Keywords best interests; chronic kidney disease; ethics; infants; withholding and withdrawing treatment

Introduction

Like any chronic illness, chronic kidney disease (CKD) has a major impact upon physical growth as well as social, psychological and educational development. CKD has, in recent years, been classified into five categories with CKD5 being a glomerular filtration rate (GFR) less than 15 ml/minute/1.73 m^2. CKD5 was previously referred to as end stage renal failure and it is at this stage that dialysis and renal transplantation are considered. Many adult CKD5 patients are not suitable for transplantation, usually because of cardiovascular co-morbidities. However, chronic dialysis, with haemodialysis or chronic peritoneal dialysis, is seen as only a holding measure before transplantation in children.

In developed countries the treatment of children with CKD5 has evolved over the past 50 years from a stage when no replacement renal therapy (RRT) was offered, except to adolescents, to current times where we can now contemplate RRT in newborns. Increasing expertise and knowledge mean that we have become "victims of our own success" with survival rates for children on dialysis or transplantation being high (79%) at 10 years and improving. However, such results are obtained at potentially a great deal of social, emotional and physical upset to the child and family. In developed countries the question is often "who should we not treat with RRT" as opposed to resource-poor countries where the ethical dilemmas are "who can we afford to treat".

Ethical principles

When tackling ethical issues it is common to refer to the four principles of Beauchamp and Childress that have dominated medical ethics (Table 1). The four quadrant approach emphasises examining the indications for medical intervention, the patients' best interest, quality of life and whether it will be improved by the treatment. Religious, cultural and legal factors will also have an impact on the decision.

Children are not autonomous individuals. Hence there is widespread agreement that in the case of children we should adopt the principle of "child's best interest" as stated in Article 3 of the UN Convention on the Rights of the Child. In recent years the concept has been expanded further into greater best interests of the child recognising not only those of parents but also of extended family members, cultural and social issues. In older children it is important to remember Article 12 of UN Convention which emphasises that the child who is capable of forming his or her views has the right to express those views.

Although kidney transplantation offers the best chance of minimising the growth and developmental consequences of CKD it is not the end of the story as renal transplants have a survival rate of 50–55% at 10 years and if the transplant fails the child faces further dialysis before another transplant is available. Renal transplantation may be done pre-emptively, i.e. before dialysis is required (23% of primary transplants in UK). The kidney may be donated by a relative (usually a parent) or the child may receive a deceased donor (DD) kidney from a heart-beating or non-heart-beating donor fulfilling brain death criteria. The rules governing renal transplantation vary from country to country with cultural and religious practice precluding DD in some countries. The demand for organ transplants far outweighs the availability of organs. We are fortunate in the UK that children under 18 years do have priority on the national DD waiting list and hence waiting times for a first transplant are relatively short (less than 9 months). Such priority rating is not without its critics. Ethical dilemmas are not uncommon in the transplantation field with utilitarian issues (doing the best with the available scarce resources) versus distributive justice (the notion that patients in a similar position should be treated in a similar manner). Since transplantation may restore better health but not 'cure' the CKD then tensions do arise when children with serious co-morbidities are being considered for transplantation or alternatively re-transplantation is being considered for a younger person who has lost a previous graft due to non-adherence.

When dealing with an ethical dilemma a practical approach is to try to build a consensus viewpoint using all the relevant information and including repeated discussions with the family and staff (Table 2).

Ethical dilemma 1

An infant born by emergency caesarean section for fetal distress required ventilation from birth with suspected lung hypoplasia. He had large palpable kidneys due to autosomal recessive polycystic kidney disease (ARPKD) and was anuric from day two with rising plasma potassium and creatinine levels. The baby was born 100 miles from the tertiary paediatric nephrology unit and the local neonatologist discussed prognosis and management issues with the paediatric nephrologist on the phone and on site with the infant still on high frequency oscillatory ventilation after four days.

Relevant facts

a) ARPKD patients have been successfully treated using unilateral or bilateral nephrectomy shortly after birth but the

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Four principles approach

1. Respect for autonomy (child's best interests)
2. Beneficence (do good)
3. Non-maleficence (do no harm)
4. Distributive justice

Table 1

condition is so rare that few units have much expertise. Loss of both kidneys would obviously requirement commencement on long-term chronic peritoneal dialysis (CPD) and probably a stay of several months in the tertiary nephrology unit to establish the treatment. It will take a minimum of 2 years dialysis and aggressive nutritional support to achieve a size where the infant could receive a kidney transplant (generally more than 10 kg). Most of this care will fall on to the mother who, in effect, will be running a mini high dependency unit at home.

b) The present situation is complicated by acute kidney injury (acute renal failure) and the immediate problems with management of an anuric infant with rising potassium and creatinine levels. Dialysis treatment would necessitate transfer to the neonatal or paediatric intensive care unit attached to the tertiary children's renal centre to access the necessary expertise to carry out dialysis. Conservative measures may suffice for a few days but with no urine output dialysis will be required.

c) Although the child's oxygenation was being maintained by high frequency oscillation the neonatologists were uncertain of the degree of lung hypoplasia and prognosis for weaning from ventilation.

d) The family consisted of young healthy parents with a healthy 2 year old daughter. Father has two jobs to maintain the family income and as recent immigrants the parents had no other family support available.

e) There are reports which show improved survival for infants requiring chronic peritoneal dialysis before 28 days of age with an overall 1 and 5 year patient survival of 52 and 48% respectively between 1995 and 2004. Twelve of 23 had received a renal transplant with 83% 5 year graft survival. In 29 infants less than 1 year of age undergoing RRT in Hanover between 1997 and 2008 21 of 29 survived with renal transplantation and 5 year patient and graft survival of 95.5%. Six of 29 children died and five were on peritoneal dialysis. Attitudes of nephrologists are changing on the management of CKD5 in infants but in 2008 only 30% of paediatric nephrologists who completed a postal survey would offer RRT to all children less than 1 month of age (41% in 1998) with the most influential factor in rejecting RRT being the presence of a co-existing abnormality (approximately 20% in recent reports).

Ethical decisions – guidelines for practice

- Always act in the child's best interests
- Assemble all the available evidence
- Discuss the issues with the entire family
- Avoid second-hand or hearsay information
- Respect the opinions of everyone on the team
- Seek the wisdom of others
- Attempt a consensus whenever possible
- Consider using a clinical ethics committee if lack of consensus

Table 2

Management

Intensive discussions were held between the parents and neonatal staff and a senior paediatric nephrologist visited the referral unit. The uncertainty about the outcome of prolonged ventilation was stressed as well as uncertainty about the management of acute on chronic kidney failure at this age. The likelihood was that this would require technically demanding acute vascular access due to the lack of space in the abdomen for a peritoneal dialysis catheter without nephrectomy. The paediatric nephrologist discussed also the "greater best interest" as the family would likely have to stay 4–6 months in the tertiary paediatric nephrology unit initially followed by probable readmissions over 2–3 years before transplantation was considered. There would be a major impact upon family relationships, finances and sibling.

Outcome

Further time was given for the family to digest the information that was presented but 24 hours later they agreed their child should be discontinued from the ventilator. He died quickly in his parents arms. Further contact between the nephrology, neonatal staff and parents suggested that the consensus plan had been agreeable to all involved.

Ethical dilemma 2

A 13 year old boy with Joubert-like syndrome was found to have an elevated plasma creatinine of 200 μmol/L. Ultrasound showed small featureless kidneys and renal biopsy was consistent with juvenile nephronophthisis. A liver biopsy showed hepatic fibrosis.

Relevant facts

a) He attended a school for severe learning difficulties and had no verbal communication. He was able to stand with support but was only mobile in a wheelchair due to severe ataxia. He was able to finger feed and feed himself messily with a spoon. He was in nappies but would cooperate with sitting on a potty to defaecate. He has shouting and self-harming behaviour.

b) He is the youngest of three children with professional parents. Respite care is offered by the local social services and a hospice.

Management

A renal biopsy was felt justified initially in that it revealed no reversible cause for his CKD and that there would be an inevitable progression to requiring RRT. Over several meetings the treatment options were discussed with the parents by the multidisciplinary team and included the established local key worker. Acting with the "greater best interests" in mind and over several meetings, the consensus view was that PB would not cooperate with dialysis and repeated invasive procedures.