

Advocacy, rights, and the treatment of children with kidney failure

Cyril Chantler May 22, 2008

Dr Rigden, Dr Reid, Ladies and Gentlemen,

Thank you for inviting me to the 39th meeting of the European Working Group on Psychosocial Aspects of Children with Chronic Renal Failure. The notion that this is the 39th meeting and that I remember their beginnings makes me wonder whether I should stop speaking now before I forget what I was going to say!. Indeed I recently remarked that when you cannot remember the past, or understand the present, people seem to ask you to speak about the future. Either that or to discuss some philosophical aspect of medicine because, in this area at least, recent knowledge of scientific advance is not a necessary prerequisite to having the capacity to inform.

This then is why I think I am here. I am also conscious that I am being asked to break one of my own firmly held convictions. I have always thought that an opening ceremony to a conference should be brief, preferably with a band rather than speeches to entertain, because the most important reason for the ceremony is to introduce the party which follows. As the ex- Dean of a medical school it was always my belief that the most important education took place out of the classroom, thus at a conference it is the informal conversations that count. However I will do as I have been told and with some relish because the topic I been asked to discuss is, I think, important.

Advocacy

In 1967 I was a resident senior house physician at Great Ormond Street Children's Hospital in London working for a wonderful physician, Dr Philip Evans. A girl, about 12 years old was referred one night from Plymouth, which is over 100 miles from London. She had terminal renal failure. Her kidneys were badly scarred from reflux nephropathy. The only unit in London

at that time that was capable of initiating long-term treatment for chronic renal failure, was at St Mary's Hospital. I phoned them but they could not take her. I discussed her predicament with Dr Evans and we agreed that to treat her with peritoneal dialysis when there was no long-term treatment available would be pointless and cruel. We would sedate her, if necessary, comfort her and allow her to die. She was comatose and I noticed that the nurse sitting with her was upset so I suggested that she had a break and I took her place. About half an hour later she suddenly awoke, sat up in bed and with a look of horror and fear turned to me and said "I am dying". I tried to comfort her, I told her she would be all right and that her mother and father were on their way. The last remark at least was true. She fell back against the pillows and soon afterwards she died. Why I asked myself were we not able to treat her when we knew how to do so. The first chronic dialysis and transplant programmes for adults had recently been launched and some older children had been transplanted.

In 1971 I was in San Francisco working with another remarkable and humane doctor, Malcolm Holliday. At that time the United States Congress was intent on passing legislation to commit Medicare to provide federal support for chronic renal replacement therapy and Mac was encouraged to testify on the treatment of children. He and colleagues developed an imaginative plan for a network of properly organised centres across the USA. In the end the plan foundered because every adult centre wanted its own children's programme and would not accept that the special facilities that children require, with the numbers involved, could not justify such expenditure. I learnt two lessons. One was that strategic planning is important and the other that you have to be prepared to justify in detail and argue for what your patients need. As an aside planning and preparation is vital. I have a slide which says "the wonderful thing about not planning is that failure comes as a complete surprise and is not preceded by a long period of anxiety".

After my return to the UK in 1972 I contacted Ian Houston in Manchester and Richard White in Birmingham and we developed a plan for a network of 12 centres to cover the UK (1). We obtained support from adult physicians and

surgeons and from paediatric colleagues and argued against piecemeal, opportunistic developments for the treatment of children in adult units. Eventually the programme was approved and funded by the government but not until after 1980 and after much agitation on television and in the newspapers. A particularly difficult moral problem at that time was whether to make public the fact that children were dying of renal failure because of the lack of facilities. The dilemma now seems strange because we are more used to working openly in partnership with patients rather than taking decisions on their behalf. Twenty five years ago we were concerned that if we told the parents that there was suitable treatment for their child but we did not have the resources, their frustration would exacerbate their grief. Rather we said that the child was not suitable for renal replacement therapy; lying with the best of intentions. Finally Richard White made it clear that children could be treated if the NHS would fund our report and the rest of us followed his lead. Eventually the plan received supra-regional funding and since then all children considered suitable for treatment in the UK have been treated. Personally I believe the service that the NHS has provided for children with end stage renal failure over the last 25 years has been excellent and cost effective. Successive paediatric nephrologists have also been able to argue the case for children receiving priority for transplantation so that renal xx transplantation, not dialysis, has been the foundation of the programme.

Are there limits to advocacy? Can or should a doctor argue for the needs of one child over and above other children? I used to believe that my duty was to my patient, not to other patients. I think now that this view is wrong or is at least incomplete. The motto of Great Ormond Street Hospital is "The child first and always". The moral philosopher Professor Jonathan Glover in his Great Ormond Street lecture in 2005 entitled "Should the child live; doctors families and conflict" asked what this motto meant (2). Does it put the interests of a particular child before other children and does it mean that other people's interests - those of family members for instance, are not allowed to count at all? Actually the motto used to be "Children first and always" until 1982 and personally I prefer this version. However even allowing for this I do not think that this notion is ultimately sustainable. Professor Glover writes that

the revolution in the moral status of children is one piece of human progress in our time and that in general the interests of children should not be taken less seriously than those of others, indeed sometimes more concern for the child may be required. But, he asks, does this mean that the interests of a child patient should always over-ride any other possibly conflicting interests? Should consequences for parents and other family members also be taken into consideration? The best answer, he concludes, may be more complex than the hospital motto suggests.

Deontological ethics, or the duties of care to the individual are often in conflict with utilitarian principles or the need to have regard to the needs of all in the practice of medicine, particularly so in a publicly funded health-care system. Choices have to be made because all such systems are restricted in what can be afforded either in terms of what, when, or who. The UK NHS restricts more and more openly in terms of what through the deliberations of the National Institute of Clinical Excellence, or NICE for short. NICE calculates a QALY or 'quality adjusted life year' for specific treatments and this decision determines what the NHS provides. However specific conditions do allow specific responses so the treatment of Gaucher's disease at a cost of over £300,000 a year is funded even though the QALY limit is set at just over £20,000. Incidentally these restrictions do mean, in my view, that clinicians have a moral duty to practise medicine effectively and efficiently because profligacy in the treatment of one patient can mean denial of therapy for another. Not every child in renal failure needs growth hormone! Managers including clinicians with management responsibility, have the duty to consider the needs of all patients not just some.

But it is not just money that may be in short supply. Other resources matter, for example kidneys for transplantation. Would you argue for a kidney for your patient over the needs of another? What if your patient had serious co-morbidities likely to restrict survival? Would the kidney not be better used to help someone with a longer life expectancy?

In summary I do believe that advocacy is part of a physician's duty but it needs to be tempered by responsibility to other patients and to society. How do we judge the limits? By listening to our friends and to those who oppose us. My good friend David Baum, sadly no longer with us, once said "Never forget other people have ambitions too!"

Rights

So much for advocacy, what about rights? The United Nations Convention on the Rights of the Child has 42 articles of which four are directly relevant.

Article 6: all children have the right to life. Governments should ensure children survive and develop healthily.

Article 12: children have the right to say what they think should happen when adults make decisions that affect them and to have their opinions taken into account.

Article 23: children who have any kind of disability should have special care and support so that they can lead full and independent lives.

Article 24: children have the right to good quality health care----.

It has been a long fight in the UK to achieve good facilities for the health care of children and it is not over. The needs of children do not receive priority in the UK; a recent UNICEF report on childhood in 21 industrial countries had us bottom in the child well-being assessment. However at least there is action as set out by the Children's Commissioner, Professor Sir Al Aynsley Green, in his 2007 lecture on "Reflections on children, child health and society" (3). But we can be pleased with how we treat children with renal failure so I think we satisfy articles 23 and 24 which deal with disability and good quality health care, at least in this respect.

What about article 6, the right to life? The first duty of clinical care is to respect the life and health of patients to an acceptable standard (4). For clinicians to breach this duty is potentially a serious offence which may entail professional censure and legal, possibly criminal culpability. However it is also the case that in some circumstances clinicians are not only professionally and legally allowed not to provide, or even to withdraw, life-sustaining

treatments but it is a moral and legal imperative to do this. This is in order to follow the second duty of care which is to respect autonomy and to treat an adult who is competent against their will is to commit an assault. People have the right to refuse treatment even though death will be the consequence.

Some years ago we treated a girl who went into renal failure from focal glomerular sclerosis at 12 years of age. She had four renal transplants which failed. Her parents had separated and she been abandoned by her mother. She spent a great deal of time in hospital but had loving supportive foster parents. She seemed happy. Her ambition was to be a school teacher, to get married and have a family. She did not think this was possible because, in spite of our optimism, she did not think she could be transplanted successfully and would rather die than remain on dialysis. She was calm, competent, rational and convinced. Shortly after her eighteenth birthday, her dialysis was discontinued and she died 10 days later. Those who cared for her cared about her and we grieved. I asked myself why we had not acted before. English law allows a minor to consent to treatment if they are competent to do so but not to refuse it until the age of 18 years. Scottish law on the other hand makes no distinction between the right of a competent young person to agree or to refuse treatment. Article 12 of the UN Convention states that children have the right to be heard. Respect for the autonomy of children is important and children may not wish to continue to live with the burden that their illness imposes. There have been examples of children with cystic fibrosis who have refused heart-lung transplantation even though their parents and/or their doctors wanted the treatment to proceed.

In 1997 the Royal College of Paediatrics and Child Health in the UK issued guidelines to address the circumstances when withholding or withdrawing curative medical treatment might be considered (5). One of the circumstances was when it was considered that the child's future life would be unbearable; in the face of progressive and irreversible illness, the child and/or the family believe that further treatment is more than the child can endure with any acceptable degree of human fulfilment. Circumstances that might be regarded as unbearable would be the need for repeated dramatic and

potentially traumatic clinical interventions whose burden is deemed by parents, professional carers and perhaps the children themselves as being too great in the light of potential benefit. Such a case was a 10-year-old boy with renal failure, with dysmorphic kidneys, moderately severe learning difficulties, but with a degree of physical independence, an attractive personality, and much love from parents and siblings. After extensive discussion with the clinical team, his school, the parents of other similar affected children, social workers, and the hospital chaplain, his parents decided that dialysis should not begin. He died suddenly and without pain whilst playing in his sandpit at home six weeks later.

Obviously a problem arises if the clinical team believes that life-sustaining treatments should be withdrawn and the parents disagree (6). Alternatively the clinical team may wish to institute life sustaining treatment whilst the parents do not. Usually the wishes of the parents should be respected but sometimes it will be necessary to ask for a judicial ruling in the child's best interest. This analysis may lead to a disquieting conclusion. Children with the same clinical condition may in one situation receive life-sustaining treatment whilst in another, if their parents do not agree to treatment, their lives will be foreshortened. The moral justification for this is that since there is some indeterminacy about the child's prognosis it would be wrong to force the beliefs of the clinical team on parents who disagree. After all it is the parents, not the team, who will have to live with either committing themselves to caring for their child or with the knowledge that they participated morally in a decision that foreshortened their child's life.

It is of course the interest of the child that is paramount. Professor Glover has suggested that the key question is "Will the child have a decent chance of a good life", or put another way whether the life of the child would justify the thought "I wish I had never been born". These are questions that it is very difficult to answer but clearly the better information about the likely outcome the better we can advise the family.

When I was in practice I had real doubts regarding the advisability of treating newborn babies with chronic renal failure, particularly whether or not it was sensible to place them on chronic dialysis in the early months of life. Even now I would be doubtful about attempting to force treatment against the wishes of the family through the courts but recent results on the long-term outcomes of treating such children are encouraging, with around 60% of those treated at less than one year of age surviving for between five and 20 years (7). The quality of life is also encouraging with over 90% attending normal schools full-time. Obviously the better the information parents can be given regarding the likely development and psychological outcome for their child the easier it is to plan treatment options for the future. We do need however better information about the effects on the family and the other children of undertaking what is an arduous treatment.

The question then arises what to do if the clinicians wish to start treatment but the parents do not. In a different context, that of extreme premature babies, Professor Glover argues that there is a good case for parental autonomy to come first. He also rejects the notion that the emotional commitment of the parents might distort rational judgement indeed he argues that when the parents are properly informed about the medical issues the degree of concern and emotional involvement may deepen rather than disrupt the decisions they reach.

Conclusion

I am going to conclude by quoting the last part of Jonathan Glover's lecture in full because not only do I agree with what he writes but I know I could not express it so well. He writes;

"Of course the ideal is for the parents and the medical team to agree, and I am sure that many medical teams put in a lot of effort in trying to bring this about. And, where there are deep and irresolvable differences, the courts are rightly the judgement of last resort. Where there is parental commitment (for religious or other reasons) to a "life at all costs" view, there is a need for the child to be protected from having to pay those costs through a prolonged period of agony or distress. But the impersonality of a court decision should

be avoided if possible. As Dame Elizabeth Butler Sloss (a distinguished High Court judge) has said the mother has a duty to “listen to what is proposed by those who have a great deal of medical and nursing experience.” But it is not wrong to add a footnote to this. The medical team should also listen to those whose thinking is given the peculiar intensity and weight that comes with the involvement and intimacy of being a parent”.

References

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