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The ethics of withholding and withdrawing dialysis therapy in infants

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Abstract Pediatric nephrologists may encounter infants with renal failure who have either unexpectedly survived lung hypoplasia at birth or whose renal failure could be treated but comorbid conditions exist. As a member of the health care team, the pediatric nephrologist may be asked to guide therapeutic intervention with parents, family members, and other care-givers. We present a case study that illustrates some of the difficulties that may arise when conflicting social and economic pressures, as well as public opinion and legal authority, enter the decision-making process. Clinical, theoretical, legal, and economic considerations involved in the ethical decision process are presented. Some tentative guidelines for approaching such dilemmas are offered bearing in mind a goal of consensual decision making.

Key words Ethics · Dialysis · Infant

Introduction

Issues surrounding the withdrawal of dialysis treatment have presented adult renal practice with increasing ethical dilemmas [1]. Such difficulties also arise in pediatric units where nephrologists increasingly encounter babies who have either unexpectedly survived lung hypoplasia at birth or whose renal failure could be treated but comorbid conditions exist. Although one may attempt to

apply the four principles of medical ethics, i.e., autonomy, beneficence, non-maleficence, and justice [2], to the particular clinical problem, the situation is complicated by the traditional precedent that parents are entitled to make decisions on behalf of their children, as they are often regarded as the best-possible surrogate decision makers [3]. The ethical decision-making process is obviously made more difficult by family disagreement and media intrusion [4]. We describe a case study that illustrates some of the clinical, theoretical, legal, and economic considerations involved in the ethical decision process and offer some tentative guidelines for approaching such dilemmas.

Case study

An infant boy is born 3 weeks prematurely and needs immediate ventilation. Over the first few days in the intensive care unit, he is found to have a non-functioning, cystic left kidney and a grossly hydronephrotic right kidney which appears dysplastic. He has an isolated, generalized seizure, probably associated with an intracranial hemorrhage, but survives. His renal function remains very poor and the general outlook bleak.

The decision whether to continue general treatment or start specific, aggressive, renal replacement treatment with dialysis and nutritional support would be difficult enough if everyone was united, but they are not. The parents separated before the baby's birth. His mother is single, unemployed, and has little support. She is already struggling to look after three children with mild handicaps who have been in and out of local authority care. She feels that her infant son should be allowed to die. The father has developed a new relationship with a woman who has had several miscarriages and desperately wants a baby. Backed by a vociferous extended family, the father seeks to preserve the baby's life at all costs.

The clinical team continues to provide intensive care support to the baby, but in view of his prolonged ventilation needs and intracranial hemorrhage the decision is made to withhold dialysis after extensive discussions with the mother. The father attempts to secure a court order to begin dialysis, pending a search for longer-term treatment elsewhere. First local, then the national media report the story. The baby has become a cause célèbre.

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Discussion

A nightmare scenario, but in reality one that is becoming increasingly common. When little could be done for such babies, life and death decisions were made by “God or nature” [5]. Doctors tried their best and were absolved of guilt. Parents grieved their loss but were spared the uncertainty. As perinatology advanced, technology was applied indiscriminately across the board [6]. Parents might have worried about such paternalism, but were largely powerless to intervene. Now many are encouraged to ask, not just whether we can intervene, but whether we should, although a great variation exists in parental involvement across Europe [7].

Agonizing decisions have to be taken. The number of deaths in neonatal intensive therapy units due to withdrawal of therapy has increased nearly fivefold from 14% [3] to 66% [8]. But how are these decisions to be made and by whom? What structures are there for resolving a situation as complicated as that of the baby presented here? Is it a matter for any level of public debate?

Overall theoretical frameworks

With a clarity unsullied by clinical responsibilities, the philosopher offers a sliding scale of discrete options: to take all possible steps to preserve life; to take all ordinary steps to preserve life but not use extra ordinary means; not to kill, but to take no steps to preserve life; not to intend to kill but to act in such a way that death might be seen as a consequence; deliberately to kill [9].

Experienced clinicians might narrow these to three clinical options as Bunchman [10] suggests, including “aggressive management” (on the grounds that intervention must be early to catch maximum growth); “wait and see” (on the grounds that parents might want to see how the baby fares before starting therapy); “withdrawal or withholding” (on the grounds that death is an acceptable outcome).

Behind all these bland phrases, the reality is not so clear cut. The philosopher has little to say about how to choose and how to live with the guilt of that decision. Bunchman’s options might confront a “chronically sleep deprived individual taking care of a high risk infant in a stressful situation” [10] or parents bonding with a slowly dying child and deciding, all too late, to change their minds.

General rules about which babies to treat

Clinical solutions

Throughout the 1990s, attempts were made to establish criteria for identifying which babies to let die when there was “no prospect of recovering without profound disability” [11]. These have recently been rationalized in the United Kingdom into a “framework for practice” that outlines five situations in which the withholding or withdrawal of curative medical treatment might be considered (Table 1) [12]. Outside of these categories, or in cases of dissent and uncertainty, “the child’s life should always be safeguarded by all in the health care team in the best way possible” [12]. There would be an argument about which category a child like our baby might fit into, and the problem with all fixed criteria is that the ground may shift over time, as happened with children born with meningomyeloceles [13].

Quality-of-life solutions

Most clinicians would agree that there is more to their skill than the indiscriminate application of technology; compassion for the life thereafter must also play a role, but this is “a slippery concept” [14]. The human cost of survival implies all sorts of family conflict in which cold-hearted assessment of an infant’s and parents’ rights can seem quite appalling [15]. The concept of “personhood,” real or potential, scarcely carries us further, and

Table 1 Situations where the withholding or withdrawal of curative medical treatment might be considered [12]

The brain-dead Child. In the older child where criteria of brain-stem death are agreed by two practitioners in the usual way it may still be technically feasible to provide basic cardiorespiratory support by means of ventilation and intensive care. It is agreed within the profession that treatment in such circumstances is futile and the withdrawal of current medical treatment is appropriate

The permanent vegetative state. The child who develops a permanent vegetative state following insults, such as trauma or hypoxia, is reliant on others for all care and does not react or relate with the outside world. It may be appropriate both to withdraw current therapy and to withhold further curative treatment

The “no chance” situation. The child has such severe disease that life-sustaining treatment simply delays death without significant alleviation of suffering. Medical treatment in this situation may thus be deemed inappropriate

The “no purpose” situation. Although the patient may be able to survive with treatment, the degree of physical or mental impairment will be so great that it is unreasonable to expect them to bear it. The child in this situation will never be capable of taking part in decisions regarding treatment or its withdrawal

The “unbearable” situation. The child and/or family feel that in the face of progressive and irreversible illness further treatment is more than can be borne. They wish to have a particular treatment withdrawn or to refuse further treatment, irrespective of the medical opinion on its potential benefit

“pain” and “harm” are clearly not interchangeable. A newborn in acute pain could be said to have a poor quality of life, but it might be justifiable to use methods that would prolong or even increase present suffering to ensure a future with less pain [16]. All that can be said is that individuals will view the situation differently. The prospects of chronic dialysis as well as another handicapped child were more than the mother in the case study could endure; the father, with less stress and more support, saw a quality of life worth preserving. General rules about “lives not worth living” slide all too easily into self-fulfilling prophecies.

Resource solutions

Allocation of scarce resources is an issue that can no longer be avoided in an era of finite funding and escalating costs. In such a climate the unspeakable begins to be openly addressed – should the needs of the totally dependent give way to those not so disabled? It is just a short step to decision making on the grounds of compliance and all the sorts of social factors, like those in the case study? Are we far from thinking that it is useless to offer expensive treatment to “these sort of people” because they do not do very well?

Yet undeniably there is an “ethical dimension” to using allocated resources for the greater good of the population. Rationing can neither be left in the hands of individual doctors at the bedside nor should it be left to “budgets and regulations set by those who are ignorant or insensitive to medical needs and preferences” [17]. When consecutive admissions are carefully costed, few resources are “wasted” on babies with even the most-futile diagnosis [18]. Management decisions are often based on mythology.

Legal solutions

In contrast to the United States, where it took decades for clinicians to emerge from the shadow of the Baby Doe rulings and Reagan’s Moral Right [19], the United Kingdom has always fought shy of legislation, preferring to rely on case precedent. At its worst this can result in a mixture of conflicting decisions that are more hindrance than help. Thus, in 1 year, a baby with Down syndrome was ordered to be saved by doctors, against the parents’ wishes [20], and Dr Leonard Arthur, in a climate of high emotion, was found not guilty of murder or attempted murder by complying with parents’ wishes that their baby should die [21]. At its best, however, case precedent allows the clinician scope to use discretion in individual situations. Neither doctors nor parents, for example, may do anything active to hasten a handicapped baby’s death – that would be murder. A baby may be given medicines which, as a secondary effect, can shorten that baby’s life, provided that the handicap is of a kind that would lead to death in early infancy and

the medicine can be shown to relieve suffering. “The doctor is entitled to make his (the baby’s) hours on earth comfortable” [5]. There is a “duty to act” – the parents’ duty to care and the doctors duty to give proper medical aid – and cases define the scope of that duty in terms of the child’s interests. But it is difficult to see how anyone could be prosecuted now for withholding or withdrawing therapy if their actions were not manifestly “unreasonable.” That is not to say that everyday decisions are not influenced by fear of the law rather than good sense [22]. The media, of course, are only too ready to prey upon that fear, as was the case with another child who suffered from a relapse after leukemia and whose father sued the health authority for refusing to fund further chemotherapy and a second bone marrow transplant, even when the medical advice went against such treatment [23].

Individual decision making

In the end decision making for pediatric patients is in the hands of the patient, the hospital team, and the parents. Babies cannot speak for themselves; decisions must be made by proxy. In an ideal world, the fate of our case study baby would be decided by consensus, even if it required painful argument and lengthy discussion with parents and all members of the multidisciplinary team. The guiding principle would always be to do what is in the child’s best interests. In reality, a child like this baby may be a victim of contradictory opinions, each with a different idea of what those “best interests” might be. The parents in our case study had disagreed with each other all their lives and do so now with utmost acrimony. Different disciplines may argue with each other within the same hospital when, for example, nurses may feel that their day-to-day physical care gives them unique insight into the baby’s needs that is undervalued by doctors, and the doctors may feel that nurses are sometimes too close to make an objective assessment [24]. Different hospitals with different policies may compete for attention under the media spotlight. When the disputes of care-givers and family members are magnified and projected by the press, a voice on behalf of the child may be lost. The media are full of sensational battlecries: “Is the issue the price of a child’s life? [25]; “Victor or victim in a critical care war?” [26]; “The doctor left my premature daughter to die!” [27].

The American Academy of Pediatrics Committee on Bioethics [28] makes a plea for individualized decisions to be made jointly by clinicians and parents in a partnership based on full communication of facts and feelings. The agony is too great for either “side” to carry alone, but this begs the question how can the process of cooperation be achieved where the content of the decision is so divisive? The multidisciplinary team needs a regular opportunity to explore its attitudes and the personal histories from which they originate. Much research has shown that such interstaff openness can itself set the tone

Table 2 Ethical decisions: guidelines for practice

Always act in the child's best interests
Never rush the decision. Continue treatment until it can be properly made
Assemble all the available evidence
Respect the opinions of everyone in the team
Discuss the issues with the whole family
Attempt a consensus wherever possible
Make sure everyone appreciates the burden of care
Try to avoid adding to the guilt of anyone involved
Consider the child's palliative and terminal care
Offer support for all those affected, parents and staff alike
Remember, we can only do the best we can. Sometimes there is no ideal solution

for those they are trying to help. Some teams have experimented profitably with the introduction of a child psychiatrist or clinical psychologist as a regular member of the team, running case study groups, offering staff support and an outlet for parents to use without fear of upsetting those on whose physical help their child depends. Difficult ethical decisions may need a more-formal structural "raft" to hold onto in the midst of a flood of emotions.

Ethical decision making can be learned but there is little evidence of it other than interested physicians getting together to pool cases from their clinical practice [29]. Ethical grids and algorithms have been devised to help teams work their way more logically through difficult situations, making sub-decisions in layers that address practicalities, outcomes, duties, and health care principles, down to a final common pathway [30].

Full-scale ethics committees have now been accepted as part of hospital accreditation in the United States, where they were first set up in the aftermath of the Baby Doe decision, to ward off federal investigation. In the United Kingdom they barely exist, although a strong argument has been put forward that every hospital should have one [31]. They might perform a valuable role in education, policy setting, and as a sounding board in particularly difficult cases. How close they should come to actual decision making is controversial. It is doubtful whether an ethics committee consensus, even after listening carefully to all the parties involved, could have prevented the baby presented here from being passed on like a relay baton from one hospital to another once the law had been invoked by an aggrieved father, riding on the back of the media bandwagon.

Perhaps the most we can say, in a time of technological transition, is that the ethics of continuing, discontinuing, or withholding treatment is being addressed. Where the quality of a baby's life is poor, the quality of its death may be more important. Ethical instruments and committees might help with the decision-making process, while the law offers protection to those who make the choice. At a grassroots level, this means that clinicians and parents must struggle bravely to reach a compassionate decision with as much agreement as they can muster. In a case like the one we have described, the process can be agonizing indeed, but there are at least some guidelines to adhere to (Table 2).

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LITERATURE ABSTRACTS

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Th1 and Th2 cytokine mRNA profiles in childhood nephrotic syndrome: evidence for increased IL-13 mRNA expression in relapse

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Idiopathic nephrotic syndrome of childhood is thought to be associated with T lymphocyte dysfunction often triggered by viral infections, with the production of circulating factor(s) resulting in proteinuria. In view of the conflicting evidence of T cell activation and Th1 or Th2 pattern of cytokine synthesis in this disease, this study examined the mRNA expression of interleukin-2 (IL-2), interferon-gamma, IL-4, and IL-13 from CD4⁺ and CD8⁺ T cells in steroid-responsive nephrotic patients in relapse and remission. Fifty-five children with steroid-responsive nephrotic syndrome were included in this study, together with 34 normal controls and 24 patient controls with viral infections. RNA was isolated from purified CD4⁺ or CD8⁺ cells from peripheral blood and subjected to reverse transcription-PCR. Cytokine mRNA expression was measured semiquantitatively, and a cytokine index was derived from densitometric readings, with cyclophilin as the housekeeping gene. Both cross-sectional and paired data showed an increased CD4⁺ and CD8⁺ IL-13 mRNA expression in patients with nephrotic relapse as compared to remission, normal, and patient controls ($P < 0.008$). This was also associated with increased cytoplasmic IL-13 expression in phorbol myristate acetate/ionomycin-activated CD3⁺ cells ($6.66 \pm 3.39\%$) from patients with nephrotic relapse compared to remission ($2.59 \pm 1.35\%$) ($P < 0.0001$). However, there was no significant difference in CD4⁺ or CD8⁺ IL-2, interferon-gamma and IL-4 mRNA expression. IL-13 is an important T cell cytokine with anti-inflammatory and immunomodulatory functions on B cells and monocytes. It is conceivable that IL-13 may act on monocytes to produce vascular permeability factor(s) involved in the pathogenesis of proteinuria in patients with relapse nephrotic syndrome.

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Effects of interleukin-15 on vascular permeability factor release by peripheral blood mononuclear cells in normal subjects and in patients with minimal-change nephrotic syndrome

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The characteristic function of interleukin (IL)-15 appears to be its ability to mimic the stimulatory action of IL-2 on lymphocytes by utilizing part of the IL-2 receptor complex. To gain insight into the immunoregulatory properties of this cytokine in patients with minimal-change nephrotic syndrome (MCNS), we analyzed effects of IL-15 on vascular permeability factor (VPF) release in vitro. Peripheral blood mononuclear cells (PBMC) were isolated from 16 patients with MCNS, 16 patients with IgA nephropathy (IgAN) and 16 healthy controls. Cells were stimulated with concanavalin A (Con A) and the VPF was assessed using the method of Lagre with minor modifications. PBMC secreted significantly increased amounts of VPF under stimulation with Con A in patients with MCNS and IgAN patients with the nephrotic syndrome as compared with normal controls. Here we have demonstrated, for the first time, that addition of IL-15 to PBMC obtained from nephrotic patients as well as from normal controls increased Con A-induced release of VPF by 250%. This stimulatory effect was found highly significant and was dose-dependent. The effect of IL-15 on the secretion of VPF was specific, since a complete reversion was obtained with a neutralizing antibody to human IL-15. Our findings reveal that IL-15 has the potential to function as an immunoregulatory molecule of PBMC VPF release. In addition, IL-15 had similar effects to IL-2 in terms of its capacity to upregulate VPF release. Taken together, our data emphasize a positive regulatory role for IL-15 in inducing the release of VPF when present at optimal levels. Therefore, IL-15 antagonists may provide a basis for immune intervention in the pathophysiology of VPF.