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Focus: current issues in medical ethics

On the death of a baby

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Editor's note

The Journal *asked Mr and Mrs Stinson and* Atlantic Monthly *for permission to reprint their article about the short and tragic life of their very premature baby in order to stimulate further analysis of the profound problems which it raises in medical ethics. Their discussion is pursued in commentaries by two professors of paediatrics and a lawyer, all of whom are unconnected with the original story.*

Authors' introduction

Andrew was a desperately premature baby weighing under two pounds. He died after months of 'heroic' efforts in an intensive care facility. The story of his short cruel institutionalised life is a case study in the limits and excesses of modern medicine.

The night he told us our son Andrew was about to die the doctor who had taken charge of him six months before also told us we were 'intellectually tight' that we had 'no feelings only thoughts and words and strategies'. We were 'bad parents'. As the parents of a five-year-old daughter we knew the love a mother and father feels for children. Yet as Andrew's parents we were used to condemnation and insult.

Andrew was a baby born 15 weeks prematurely weighing only 1 lb 12 oz and in a state of painful deterioration almost from the start. We wanted him to be allowed to die a natural death. Andrew's story is the story of what can happen when a baby becomes hopelessly entrapped in an intensive care unit where the machinery is more sophisticated than the code of law and ethics governing its use.

The letter printed below was sent to the administrator and numerous personnel of the hospital that controlled the life and death of our son. The physician-in-chief of that hospital characterised it as a 'carefully documented critique'. The letter appears here somewhat edited and abridged and the names of people and institutions have been changed all but our own. It is the personal record of what happened to our baby and to us.

29 August 1977

DEAR MR CLARK

This letter concerns the case of Andrew Stinson who was a patient in the Infant Intensive Care Unit (IICU) of Pediatric Hospital from 24 December 1976 to 14 June 1977.

Andrew was born at Community Hospital in our town on 17 December 1976 at a gestational age of 24½ weeks and a weight of 800 grams (1 lb 12 oz) at the extreme margin of human viability. He was admitted to the Pediatric Hospital Center (PHC) weighing 600 grams on the 24 December and was placed on a respirator against our wishes and without our consent on 13 January and remained dependent on the respirator until he was finally permitted to die on the evening of 14 June.

The sad list of Andrew's afflictions almost all of which were iatrogenic reveals how disastrous this hospitalisation was. Andrew had a month's long unresolved case of bronchopulmonary dysplasia sometimes referred to as 'respiratory lung syndrome'. He was 'saved' by the respirator to endure countless episodes of bradycardia and cyanosis, countless suctioning and tube insertions and blood samplings and blood transfusions; 'saved' to develop retrolental fibroplasia, numerous infections, demineralised and fractured bones, an iatrogenic cleft palate and finally, as his lung became irreparably diseased, pulmonary artery hypertension and seizures of the brain. He was in effect 'saved' by the respirator to die five long painful and expensive months later of the respirator's side effects.

The IICU's attempt to nourish Andrew artificially was nearly as unsuccessful as its attempt to breathe for him. His bone problems, which included severe rickets secondary to hyperalimentation testify to the large amount of research still required before the nutritional needs of extremely premature, critically ill infants can be competently met. The notes in the medical record by those called in to consult about Andrew's problem show that research interest in our baby's problems was indeed high. 'The incidence of rickets here and in other IICU units is very interesting' one consultant began 'and points out the need for data. The endocrine section with your help would be interested in exploring this area.'

'Thank you' another note reads 'for interesting consult on this syndrome. The only time I have seen X-rays of more fractured bones was in an Air

Force crash victim.' One of the reasons a doctor once gave to explain Andrew's dependence on the respirator and lack of effort to breathe for himself was that with all those broken ribs it 'hurts like hell every time he takes a breath.'

Andrew's fractures did heal but he continued to suffer from severe failure to thrive, his height, weight and head circumference were listed as 'much less than third percentile' and by the final six weeks his head (i.e. brain) had stopped growing altogether. Clearly no one really knew how to provide our baby with the nourishment he needed for normal growth and development. The extraordinary technology that was marshalled to keep Andrew from dying was sufficient only to the production of new 'interesting' problems which no one as yet understands. Complicating Andrew's respiratory and nutritional difficulties was the fact that the IICU could not protect him from recurring rounds of infection. During his stay at Pediatric Hospital Andrew suffered through a prolonged case of *E coli* septicemia related to abscesses at the arterial line sites which necessitated surgical removal of gangrene and necrotic muscle down to the bone of his right leg. It was noted in the record in May that 'right foot remains limited due to severed and removed tissue'. He also had several urinary tract infections and 'multiple courses of pneumonia'.

And this was not yet the end of Andrew's problems. He also suffered from a heart defect and possible stress ulcers. He experienced a pulmonary haemorrhage in January. The question of whether there were also intracranial haemorrhages in December or January was never successfully settled but as the months went by the record noted cortical atrophy, enlarged ventricles, chronic encephalopathy, microcephaly and 'severe developmental delay'.

We have begun with a chronicle of Andrew's afflictions because we think the magnitude of the medical failure involved is quite obviously staggering. It can be argued, of course, that this could all have turned out differently. But the only reality now is that it turned out disastrously for all of us. And the meagre statistics available in this very new still largely experimental effort to save babies of 800 grams and 25 weeks or less of gestation who need extensive respiratory support indicate that the chances for survival and certainly for intact neurological survival were and are grim.

It was our position at the beginning of this case that medical knowledge was not sufficient to justify the no-holds-barred heroic attempt to simulate the last fifteen weeks of pregnancy. It is hard to feel now that our pessimism was unreasonable. We can only hope that Andrew's case has been for the doctors involved an object lesson in humility, a reminder of how pathetically doctors can still fail and how much suffering this failure can inflict on other human beings, on tiny patients and on their families.

We think the question must be raised as to whose interests were really served by this six months of imposed hospitalisation. Certainly not Andrew's. He had the misfortune of being declared 'salvageable' (the IICU's word) by people who knew neither how to salvage him nor when or how to stop. Certainly not ours. Those six months were for us a nightmare of anguish, frustration and despair. It seems clear to us that all the benefits in this case went to Pediatric Hospital and its staff. The medical residents got a chance to broaden their education by working with a baby with malfunctions of virtually every system of his body, the specialists took part in some 'interesting consults' and gathered some data and the hospital collected the mind boggling sum of $102,303.20 from the insurance company.

Although we signed a general consent form when Andrew was admitted to the hospital we did not know that we were signing away control over the events of the next months or, until later, that we could withdraw our consent. However, in our opinion, the hospital did not accord us, Andrew's parents and legal guardians, our rights of informed consent in decisions about his care. From the very first, we were treated as wholly external to the case. Our wishes, judgments, and thoughts were rarely of interest to the IICU's medical staff, who arrogated decisions to themselves as though we did not exist.

Thus, we often telephoned the hospital or arrived for a conference to discover that major decisions, literally involving life and death, had been taken with little effort to explain the problem, let alone to obtain our specific consent one way or the other. On our first visit to the hospital in December, for example, we met Dr Carvalho, the IICU's attending physician, and explained that we opposed extraordinary efforts to keep Andrew alive. If his troubled breathing failed, we opposed placing him on a respirator. Dr Carvalho told us that he and his colleagues had already decided that if the baby's severe episodes of apnea and bradycardia continued to worsen, Andrew would be ventilated (put on a respirator). When parents dissented from its decisions, he said, the hospital's policy was to obtain a court order.

A few days later we drove the many miles to Pediatric Hospital again, and this time a doctor we had not met before explained that Andrew had suffered an intracranial haemorrhage and that Dr Craft, now the IICU's attending physician, had decided that the baby would *not* be attached to a respirator after all.

Again a few more days passed, and now we met Dr Farrell. Dr Craft, we discovered, had been attending physician only over the New Year's weekend; now it was January and Dr Farrell's turn, and he had already made yet another decision. Andrew *would* be ventilated after all, Dr Farrel

said, for he was not so sure now that the baby had had an intracranial bleed. There was no effort made to win our consent to this reversal, we couldn't determine whether the reversal was due to a change in Andrew's prognosis or to the change in personnel. When we objected to the decision, Dr Farrell accused us of wanting to 'play God' and to 'go back to the law of the jungle.' Apparently not recognising his responsibility to obtain our informed consent to Andrew's treatment, he reduced the issue to its most absurd level. 'I would not presume,' he told us, 'to tell my auto mechanic how to fix my car.'

Drs Carvalho, Craft, and Farrell did not even discuss with us the long list of risks they knew were involved in ventilating infants as tiny as Andrew. Within a few more days, Andrew's breathing collapsed and he was attached to the mechanical respirator upon which he would be dependent for the rest of his life.

The EMI scan performed on 19 April is another example of serious blocking out of parental knowledge and consent. The baby's medical record shows that the staff was attempting to schedule a computer scan of Andrew's brain for nearly two weeks before it was done, but no one told us about it until it was over. The anaesthetist cautioned in the record for 18 April, 'Plan & risk of anes. will be discussed w. parents.' But *no one called*—not an attending physician, not a resident, not an anaesthetist—to discuss the 'plan and risk' which were obviously present in their minds but were kept from us.

One curious deviation from this pattern of exclusion occurred in May. When we sought out Dr Craft during a visit to the hospital on 5 May, he told us of several new developments in Andrew's case and said he now regarded Andrew as terminally ill, though Andrew could remain on the respirator for a long time before his respirator-caused lung and heart disease progressed to the point where he would die. Meanwhile, his current case of pneumonia was being successfully treated with antibiotics, and Dr Craft was close to ordering a trachaeostomy because the tube connecting Andrew to the respirator kept coming out and it was becoming more difficult to get it back in.

Then Dr Craft amazed us by doing something no one at PHC had ever done: he asked our consent. When we refused to give it, we were assured that the hospital had the power to go ahead and operate anyway. But we were by this time more cognisant of our rights—and of the hospital's penchant for not advising us fully and accurately of those rights—than we had been at the beginning of Andrew's case, and after Dr Craft received a call from our lawyer, plans for the trachaeostomy were dropped.

Andrew's prognosis

When, at the beginning of Andrew's hospitalisation, we asked specific questions about the prognosis for a baby of Andrew's severe prematurity—what, in other words, was the theoretical basis justifying the decision to place Andrew on a respirator?—the medical staff's answers were vague and unrealistically optimistic. Dr Farrell assured us that statistics show that, thanks to modern medical expertise, almost all premature babies survive and grow up to have no problems of any kind. When we pointed out that such 'statistics' were skewed because they lumped together babies of 800 grams with babies of 2000 grams and everything in between, his answer was that we should not adopt this sort of adversary relationship with the medical staff.

Dr Craft did cite evidence to support his optimism about Andrew: the 'Vanderbilt study,' which, he said, showed that of 22 babies born at under 1000 grams who survived, eighteen turned out to be totally normal. This seemed encouraging until we went, two months later, to the medical school library and discovered that there was no 'Vanderbilt study' showing anything of the kind. There had been a study of premature infants done at Vanderbilt, but it dealt with another question. We did discover the study (done in Seattle) dealing with 22 babies born at under 1000 grams (the study included 161 babies, but 87 per cent died); it showed that *none* of the babies of Andrew's weight, gestational age, and respiratory status had been successfully 'salvaged.' (The results of other studies we found later were not quite so bleak, but the prognosis in January 1977 for a baby in Andrew's condition could hardly be seen as encouraging.)

Should a parent have to spend hours in the library of a medical school to obtain answers to his or her questions? We were told later that our questions were inappropriate because the effort to save babies like Andrew is still too new for reliable data to exist, but that was, of course, precisely our point. The attending physicians were not, as they had at first maintained, guided by data: they were creating it.

Nor were our questions about the specifics of Andrew's case answered fully and candidly. Andrew was making good progress, Dr Farrell assured one of us in late January (though he had developed a major infection, couldn't breathe without the respirator, was off his regular feedings, and had problems with a distended abdomen); he might, said Dr Farrell, be a 'colicky baby' when he came home. Andrew was still 'doing all right' on 9 February when we talked to Dr Craft, though the baby was still dependent on the respirator, still hadn't been cured of the weeks-long bloodstream infection, still hadn't resumed his feedings, and hadn't been gaining weight. All this was, we were assured, 'just a technical management problem.' In March, Dr Carvalho was 'optimistic' about Andrew, though his bones were breaking because of then unresolved dietary deficiencies and he had

developed more infection. Andrew, Dr Carvalho said, should be off the respirator in 'a couple weeks'.

The situation became particularly grotesque at the end of March. The resident then in charge discussed with us the high risk that Andrew had by that time suffered serious brain damage. But when we sought an assessment of Andrew's problems and how they would affect his future from Dr Carvalho, he replied that premature babies tend to be shorter than their siblings, though we shouldn't worry that Andrew's shortness would be so pronounced as to affect him socially.

A severe crisis of confidence developed as we despaired of getting any believable information. And evidence confirms that our cynicism was not out of place. Even we were surprised when we obtained a copy of Andrew's medical record and compared the information there with the version we had been given. Andrew's bronchopulmonary dysplasia had first been noted nearly two months before we were informed of it. He had had more infections than had been reported to us, had been on more drugs of a seemingly experimental nature than we knew of, and had bone problems more severe and fractures more numerous than we had been told. We found out that Andrew had developed an iatrogenic cleft palate. We learned for the first time about the gangrene that had developed in his infected leg and of the tissue and muscle that had been cut away down to the bone; we had been told only that Andrew had an abscess which had been drained and which had 'healed nicely'.

Perhaps most serious was our discovery that pessimistic assessments of Andrew's condition and prognosis had been made by the Neurology Department though they were never mentioned to us by anyone. How many other parents would discover such omissions and distortions in what they were told about their children's cases, we wonder, if they too were to request their children's medical records?

Legal and ethical problems

We recognise that there are very real legal and ethical problems in the area of consent for medical treatment when children are involved. We were told repeatedly that 'someone must be the child's advocate.' But how is it possible to be sure in a case like Andrew's just what that means? Who can determine whether or at what point the child's true advocate is the person proclaiming his right to life or the person proclaiming his right to death? We felt that we as the child's parents were more likely to have feelings of concern for his suffering than the necessarily detached medical staff busy with scores of other cases and 'interesting' projects.

However, the 'someone' who became our child's self-appointed advocate was the attending physician of the IICU. It was argued that we were not the baby's advocates but merely the parents' advocates. By that logic, why are Drs Farrell, Craft, and Carvalho not recognised as the *doctors'* advocates? For it is useless to pretend that there was ever such a thing as an objective advocate of Andrew's rights. Is any neonatologist, who has, in addition to his ethical commitments as a human being, a professional interest in a baby's problems, a pride in his expertise and in the statistics of success in his unit, and concerns about protecting his reputation in the eyes of his associates, really the right person to be trusted as the baby's sole advocate?

Of course, we were self-interested too. As Andrew's parents, we had a heightened sense of his suffering. Also, we feared the prospect of having to care for the rest of our lives for a pathetically handicapped, retarded child. If this is considered less than noble, what then is the appropriate label for the willingness to apply the latest experimental technology to salvage such a high-risk child and then to hand him over to the life-long care of someone else?

We believe there is a moral and ethical problem of the most fundamental sort involved in a system which allows complicated decisions of this nature to be made unilaterally by people who do not have to live with the consequences of their decisions. A minister—to whom we went for counselling when our family life began to fall apart under the pressures of the hospital's handling of Andrew's case—was direct in his assessment: 'This tragedy is not an act of God but an act of man. Don't let yourselves be its victims.'

The tube connecting Andrew to the respirator came out of his throat on the night of 9 June, and when he began breathing on his own, the decision was made that when his breathing proved inadequate, as it surely must in a baby with 'irreversible lung disease,' Andrew would not be reattached to the respirator even though that meant he would die. All of this happened without our knowing anything about it. Only the accident of our telephone call to the hospital on the afternoon of 10 June revealed that Andrew was off the respirator and that the attending physicians had conferred and made their decision. It should not have surprised us that none of them thought it useful to have explicit, current expressions of our opinion or to include us in their conference. Andrew was more their baby than ours.

One of the ironic 'Catch-22's' of our relationship with PHC is that we were treated in a way practically guaranteed to produce profound psychological upset and then blamed and dismissed from further consideration because we were upset. We were categorised as 'hostile,' 'emotionally fragile,' 'under psychiatric care'.

When Andrew was transferred from our community hospital to PHC, he was already one week old. During that first week we visited him each day,

brought him breast milk, talked with both doctor and nurses daily, and together worked out a plan for his care. We agreed that Andrew would be made comfortable and given a chance to thrive if he were able, but that there would be no heroics. Community Hospital, his physician there advised us, had all the equipment and staff necessary to safeguard the baby if he should be strong enough to do well. But, unlike an intensive care centre, they did not have so much equipment that he could be subjected to extraordinary measures which might keep alive a baby whose prognosis didn't warrant aggressive intervention.

After Andrew had done surprisingly well for a week, he developed what was described to us as a minor fluid adjustment and measurement problem. 'The time for heroics is passed,' his doctor assured us, and we agreed to his transfer to PHC. Three obstetricians, a paediatrician, and numerous nurses at Community Hospital had taken our viewpoints and our anguish seriously and had treated us with competence and concern and simple human understanding. We signed the transfer paper in the naive belief that the same atmosphere would prevail at PHC.

Our initial visit to Andrew at Pediatric Hospital gave us the first shocking insight into the error we had made. When we tried to raise the same issues of extraordinary treatment and quality of life that we had all been discussing at Community Hospital, Dr Carvalho responded coolly that 'these children are precious to most parents'.

Parent-doctor communication

The succession of six principal residents, and others on night or weekend and holiday assignment, created a major obstacle to effective parent–doctor communication. Having to depend for crucial information on people we hardly knew, and having to express our deepest frustrations and most vulnerable feelings to a new stranger every month, built a special and destructive tension through all the months of Andrew's crisis.

We were told that continuity was assured by the presence of the IICU's three attending physicians, but they rotated too, and it was common knowledge that the philosophy of neonatal care varied from one attending doctor to the next. The medical record ought to have been a guarantor of continuity for Andrew. But even the record contains surprising errors and discontinuities, while basic facts concerning the circumstances of Andrew's birth and our family life are creatively elaborated from one resident to the next like whispered stories in a parlour game.

The residents' written comments reflect the lack of understanding we felt from many of them as we were dealing with them. The doctor who wrote the 'discharge summary' at the end of Andrew's life felt qualified to state definitively that we 'clearly never wanted to have Andrew'. That was not true. Another doctor concluded a discussion of Andrew's birth with, 'Not to worry tho. The parents were assured by the obstetrician that the child would die and everyone could be happy'.

What possible excuse can there be for this sort of callousness becoming a part of the official information that is reported from one doctor to another just coming on the case? How can anyone be so insensitive to the pain involved when the parents' hope for a new baby takes such a disastrous turn? We wondered frequently how many of the young doctors and nurses who felt so qualified to judge us and our feelings had ever experienced a problem pregnancy, had ever had a child at all, had ever been in a situation even remotely like the one that befell us after Andrew's birth and during his stay at Pediatric Hospital.

We do not entirely blame the residents for all of this. They too were in a real sense victims of the rotation system. It was hard for them to know us, though some tried. But in the end they all went on to other cases. We were the only ones who were not allowed to rotate. (The situation was made bearable only by the chance fact that the first resident with whom we dealt was an unusually understanding person who was willing to remain in contact with us and with Andrew's case for all the months which followed his official tour of duty in the IICU. We are grateful to Dr Perlman for his attempt to reach out beyond the confines of an impersonal system).

The medical record contains the following brief summary of Andrew's case, dated only June: 'six months bronchopulmonary dysplasia, pulmonary artery hypertension, cerebral atrophy now with seizures—? current status. Difficult parents as per chart'.

We asked ourselves again and again what the staff at PHC could have expected people in our situation to do. Did they think we didn't really mean it when we said we believed it was morally wrong to keep Andrew alive? Did anyone consider the impossible psychological position we were put into when we were systematically and casually overruled?

The whole sad case of Andrew Stinson could have been avoided if we had been given complete, accurate information about the policies and ideologies of those in charge of the IICU of Pediatric Hospital *before* we signed the admission forms, for then we would certainly never have allowed Andrew's transfer.

We recognise, of course, that providing accurate, candid information about hospital policies is not so simple as it sounds. But after spending six months agonising over what was right and what was wrong at every stage of Andrew's medical treatment, after extensive reading in the field of bioethics, after discussions with acquaintances and colleagues who are by profession philosophers, ministers,

theologians, biologists, psychologists, lawyers, and doctors, we can perhaps be excused for saying quite frankly that we are fed up with simplistic discussions of this problem. We are fed up with having to listen to the self-righteous and self-protective rhetoric of 'brain death' and 'flat EEG's' as if those concepts weren't irrelevant to the way deaths must really be 'orchestrated' (as one more candid doctor put it) in intensive care units. We are fed up with being told that it is illegal and immoral to turn off a respirator at PHC when it is somehow both legal and moral to turn it off somewhere else. We are fed up with the assumption that people disagree on 'right-to-life' issues because some of us are moral and some of us are not.

After the responses we got for daring to raise the question of when or in what circumstances Andrew's respirator could be turned off ('What do you want me to do?' asked Dr Farrell on one memorable occasion. 'Go in and put a pillow over his head?'), is it any wonder that we were surprised (and bitter about the hypocrisy of it all) when a variant of respirator withdrawal was in fact arranged—while most of the staff pretended officially that Andrew's death on 14 June was an inevitable occurrence and not arranged at all? Is waiting for a baby who is described as respirator-dependent to dislodge his own breathing tube, chance to breathe for a while for himself, and then, predictably, fail to survive, either moral or 'dignified'?

The situation now exists in which it is very easy to turn on a respirator—no one's consent is even needed—and almost impossible to turn one off. Until our legal and moral codes become sophisticated enough to cope with our machinery, parents must have the right to decide whether or in what circumstances their tiny babies should be attached to respirators. Meanwhile, patients, families, hospitals, and society as a whole will continue to be plagued by new and agonising problems created by the boom in life-support technology. As one attending physician remarked of Andrew's case after it was finally over: 'We were all lucky to get out of this as easily as we did.'

Counting the cost

At the end came a notice from the PHC business office, announcing in passionless figures that the hospital costs alone for Andrew Stinson's treatment came to $104,403.20 (of which all but $2,100 has been paid). The bill is more than an accounting of charges for daily treatment. It is a reminder that through the six months of hospital experiments, failures, and arrogance, the meter was ticking—but someone else would pay. The IICU could continue to operate in splendid isolation, not only from our protests, but also from any sense of the financial impact of their solitary decisions.

The bill also reminds us of other financial burdens, and of the many times we tried to give attending physicians, residents, nurses, and business office clerks a sense of how financially destructive this experience was. Our marriage and family life came under substantial pressure, and we began to run up uninsured bills with a family counsellor. At the same time we were forced to incur the cost of enunciating and protecting our legal rights when we retained an attorney. Hanging over our heads throughout the spring was the thought that while our medical insurance would probably pay most of the bills that were strictly medical, it listed exclusions and deductions. No matter how expensive our daily lives had become, we knew there would be hundreds and hundreds more to pay at the end.

When this nightmare began, we had a small savings account, but this spring we saw it dwindle to nothing. An annual salary of $13,600 was enough in normal times to maintain a modest living for our family. Since December, when Andrew entered PHC, we have not been able to make ends meet and will do no better in the foreseeable future.

None of this seemed intelligible to the personnel of PHC. It was a problem, perhaps, but it was, again, someone else's problem. We tried, during an extraordinary meeting with him in February, to make Dr Craft see how serious the situation was. Andrew's hospitalisation seemed completely open-ended, we said, and we were afraid that the expenses would run over the limit of our insurance. 'What will they do?' we asked. 'Will they make us declare bankruptcy and lose everything?' His reply left us speechless: 'I guess they will,' was all he said. What we needed at that moment was assurance, intercession, or, at the very least, recognition that something fundamentally intolerable could happen, was happening, to other human beings. Instead we saw but one more token of the isolation in which doctors often operate. They do not know how their business offices work and, we suspect, they do not want to know, because knowledge implies responsibility. Ignorance conveniently narrows the focus and enables them to legitimise the disowning of painful problems. Someone else will pay.

What happened at Pediatric Hospital has had a final bitter psychological cost: we have been robbed of the opportunity to grieve at the death of our child. We have friends whose baby son, brain-damaged and unable to breathe on his own, died a day after birth in a Community hospital. No respirators were available to prolong the suffering of everyone concerned, and the family was able to grieve for the baby in a normal way. The baby is buried in an old country cemetery where the parents, their older child, and their year-old normal, healthy son gather now and then to think of the child who might have been.

There can be no such scene for Andrew. By the time he was finally permitted to die, the death itself could bring only feelings of profound relief: relief

that Andrew's pain, as well as our own, was finished at last; relief that we had all escaped the clutches of Pediatric Hospital at last.

We have taken the money that might have gone under different circumstances for a graveside marker and committed it to the only memorial which can have any meaning for us now: to the sponsorship of a living child, an impoverished child whose only problem at birth was that he was born into an affluent society that does not choose to put his well-being at very high priority. For we believe Andrew's case raises broad and difficult questions which the medical profession in particular and society as a whole must face up to.

What sort of memories or thoughts could we have of Andrew? By the time he was allowed to die, the technology being used to 'salvage' him had produced not so much a human life as a grotesque caricature of a human life, a 'person' with a stunted, deteriorating brain and scarcely an undamaged vital organ in his body, who existed only as an extension of a machine. This is the image left to us for the rest of our lives of our son, Andrew.

SINCERELY YOURS

How did the hospital reply?

The administration agreed to drop the $2,100 charge and think about ways of improving parent-staff relations, but Mr Clark's response did not address seriously any of the issues Andrew's case raised. The official reply cited the progress in infant survival that had come about 'because of perseverance in units such as ours,' and regretted that we had interpreted Dr Farrell's behaviour as offensive. His 'very behaviour reflects the hospital's mission of providing tertiary care,' Mr Clark explained.

No one can deny that there has been progress in saving premature infants, and we are happy for the children and families who can benefit from the experimentation that made this possible. But there will always be a frontier to challenge neonatologists—an 'Andrew' of 600 grams or 300: of 20 weeks, or 16, or 12. Success even at these levels may someday be possible, but as doctors press onward they will inflict pain and heavy costs on tiny subjects and their families.

Who will set the limits? Can society afford to pay? If research must proceed, can't we at least limit it to consenting families?

We referred Andrew's case to the hospital's patient care committee, but without apparent result. We sent twenty copies of our letter to people involved in Andrew's life and death and asked most for a response, but only two replied.

Aren't these issues of interest? Shouldn't we all be discussing them? If there are others who do not wish to deal with hospitals whose mission is to act as Pediatric Hospital did, they must make their wishes known.

Commentary 1

R B Zachary *Department of Paediatric Surgery, Children's Hospital, Sheffield*

My immediate reaction to the story of Andrew Stinson is primarily one of horror. The faults appear to be entirely on the side of the hospital and the doctors. Over enthusiastic recourse to a multitude of treatments, many burdensome to the infant, with complications that they, the doctors themselves, should have foreseen; the lack of personal, continuous care of the infant in the hands of one senior responsible clinician; the failure to discuss the child's illness with the parents, the initiation of intricate and risky procedures without prior consent, and, finally, the threat to the parents of a Court Order to give the hospital doctors the right to carry on with their treatment, even if the parents objected.

It is impossible at this distance and time to assess the validity of such criticisms, but the fact that parents have felt impelled to write in detail of these harrowing six months, is cause enough for those with the responsibility for care of neonates to reconsider their objectives, their techniques, their capacity to keep the parents informed and, above all, the ethical basis on which their actions are based.

The emotional burden on the parents during Andrew's short life is evident from the story they write, a history which at times is couched in emotive terms, 'a desperately premature baby', 'cruel institutionalised life', 'state of painful deterioration', but this in no way invalidates their critical theme.

Relying, as we must do, only on the evidence put forward in the letter of the parents, it appears that even at the Community Hospital, where the child, although extremely premature, was able to receive ordinary baby care, the parents insisted there should be 'no heroics'. Now it may well be that if the baby had been brought to the attention of the special baby-care unit straight away, the outcome might have been different; one cannot ignore the enormous advances made in the care of very premature babies in many special-care baby units, for example at University College Hospital in London. As for 'no heroics', how do you translate such a simplistic lay term into professional care? Does it mean no intubation and assisted respiration? The point I am making is that it would be tragic if an article like this were to set parents against special baby-care units, so that they might refuse to allow their infant to be transferred to such a unit.

It appears that the parents on their *first* visit to the special baby-care unit 'tried to raise the same issues of extraordinary treatment and quality of life that we had been discussing at Community Hospital'. Although one may be critical of the tepid