MEDICAL PRACTICE

New Horizons in Medical Ethics

Severely Malformed Children

This tape-recorded discussion was devoted to severely malformed children. Mr. Eckstein, speaking as a consultant paediatric surgeon, argues that the decision to treat or not must be taken at consultant level; Dr. Hatcher, with experience in both general practice and as a consultant paediatrician, that the most difficult problem is in supporting the parents of children who have not been treated surgically but do not die in the first few months; and Dr. Slater, that a new therapeutic approach to the basic ethical problem is needed. The working papers are printed below followed by the discussion, which was chaired by a member of the B.M.J. editorial staff.

The Problem of Selection

HERBERT B. ECKSTEIN

From a paediatric surgeon's point of view infants with major congenital abnormalities may be divided into four groups.

Group I.—Infants with abnormalities which are incompatible with life if untreated and total recovery and a normal child can be expected after surgical treatment—for example, those with oesophageal atresia, intestinal atresia, anorectal abnormalities, omphalocele, etc. Such infants are treated energetically at all times and present no moral or ethical problems.

Group II.—Infants with severe abnormalities which are incompatible with life even with present day treatment. These include anencephaly. Again, no moral or ethical complications are involved.

Group III.—Infants with abnormalities from which they would die if untreated but where surgical treatment will preserve life but the child will never be normal. This group includes meconium ileus with cystic fibrosis and duodenal atresia when associated with Down's syndrome. Selection in this group presents enormous problems and in practice most infants are treated actively as the severity of their ultimate handicap cannot be assessed in the first few days of life.

Group IV.—Infants with congenital abnormalities which are

likely but by no means certain to be fatal, and who if untreated may survive with more severe handicap than if treated. This group fundamentally embraces the whole problem of spina bifida and presents enormous moral and ethical implications.

In the years 1963 to 1970 most such infants were energetically treated but even then the overall mortality was at least 30%. As these patients became older, it has become clear that the handicaps are often severe and that facilities for their care and their education are totally lacking. For these reasons, some selection for treatment is now widely practised. It is in my opinion quite impossible to kill off such a baby, but if surgical treatment is withheld then it is only reasonable to withhold other forms of treatment such as antibiotics, oxygen, and tube feeding. Each individual baby must be assessed individually and the decision to treat or especially not to treat must be taken at consultant level. The opinion of the nursing staff must be seriously considered and is often over-riding. The parents' opinion should be considered, but in clinical practice very few parents express a strong opinion which is different from those of the medical attendants. In our own experience to date all children with myelomeningocele who were refused surgical treatment have died within a month and if a baby is not to be treated then the surgeons and nursing staff should do nothing to prolong life. If, however, such an untreated baby is obviously going to survive the policy of non-treatment may have to be reversed even if the results of this delayed treatment are far from satisfactory.

Economic Grounds No Criteria

GEOFFREY HATCHER

I agree with Mr. Eckstein's classification of severe congenital malformations but I dispute Dr. Slater's statement that "a save all policy has become the rule in our paediatric services."¹ If we omit severe congenital heart disease spina bifida is numerically by far the main problem and so we have to discuss children with myelomeningocele.

I am in the sixth year of a policy of advising that some babies should be treated and others not, with a progressive tendency to advise operation on fewer children. I am totally opposed to the view that it is a paediatrician's duty only to provide information for parents, rather than to give advice to them about decisions regarding management. It is right to provide full statistical information in terms tailored to their understanding about the rates of survival with and without surgery and the rates of mortality and morbidity from complications of the primary condition, slanting the discussion in the direction of my own opinion about the treatment in their child and stressing that immediate surgical operation will *not* bring about any long-term improvement in paralysis.

The question: "What right have I to recommend withholding treatment?" is to be off-set against another: "What

right do I have to inflict major chronic suffering on another human being and on his family?" I have always sensed that attempts to preserve life by surgery are more likely to be asked for if the prospects for the child's intelligence are good. I question the assumption that severe physical handicap (life in a wheel-chair, faecal incontinence, urinary diversion, and impotence accompanied by normal libido) is more tolerable if the intelligence is preserved than if it is not.

In practice the most difficult problem is not talking to the parents and advising them in the first few days but supporting those whose children have not been treated surgically but who do not die in the first month or so. One thing is certain and that is that we cannot expect nurses to lower their standards of basic care for a baby with a myelocoele, even though we may expect them to understand why they should not give tube feeds if the same baby does not want to suck.

I suspect I differ from both Eliot Slater and Herbert Eckstein in believing that national economic considerations are no basis for deciding whether children with spina bifida should be treated or not. Such a decision must be based on medical or ethical arguments and not on an economic one. I disagree with Herbert Eckstein's recent suggestion that selection is at present widely practised because facilities for the care and attention of children surviving with spina bifida are "totally lacking."² If this were true I should fear for the future of medicine.

Wanted—a New Basic Approach

ELIOT SLATER

Doctors have dedicated themselves professionally to the prevention of suffering and the preservation of life. Often, these aims are incompatible. Dying is usually painless, and death is the end of suffering. The preservation of life, on the other hand, is often a prolonged struggle, in which the fighting co-operation of the patient is demanded. Where primary aims are in conflict, a difficult decision devolves on the doctor. Recent practice has been to subordinate the first aim to the second. The whole resources of a technologically advanced medical service have been deployed in the pursuit of the preservation of life—for example, in intensive care units. It is becoming obvious that the costs of this policy are becoming insupportable.³ There is a limit to what the community can spend on health care, from which it follows that resources expended on one medical problem reduce the amount available for other medical problems. Thus there has to be an order of priorities: keeping some patients alive means letting others die. We must face as inescapable the duty to let some patients die.

Nevertheless, the financial costs of the ethic of preservation of life at all costs are often less important than the suffering involved. The preservation of life in the children with meningomyelocele causes a burden on the family: marital problems multiply, parents often limit their families, normal sibs often become maladjusted.⁴ Spina bifida is only one of many similar problems arising with the seriously abnormal or damaged newborn. There are similar problems in the prime of life—for example, with patients with severe head injuries—and at the end of life, when life is being preserved in the demented geriatric patient. Hence the burden on the community is progressively accumulating. It is suggested that a new approach to the basic ethical problem is called for, by which doctors could guide themselves. We should regard the prevention of suffering as our primary aim, the preservation of life as secondary and acceptable only if the

suffering involved is tolerable with the aid of modern support methods and is of short term. If we keep these two aims separate, we can, when required, move over from one aim to another. If a life is not to be preserved without unacceptable suffering, we can explain this to patient and relatives; and then devote ourselves whole-heartedly to providing the greatest possible ease, comfort, and moral support. Just as there are two different styles in doctoring called for, for these two distinct aims, so there are two different styles in nursing. Nurses must be trained also in regimens that allow the patient the greatest imaginable comfort and peace. This is just as great a service to the patient, and as in every way as honourable an application of a nurse's care and devotion.

With these principles in mind we can look at the spina bifida problem. The first doctor to meet it is the obstetrician. When he sees a baby with an open lesion, he knows at once that preservation of life will mean a long long course of suffering—for the baby and for the family. If the baby dies, it does not suffer. The suffering of the parents is very real, but incommensurably less than what they will suffer if life is maintained. Hence it becomes the obstetrician's duty to opt for the first aim, and permit the baby to die. At this stage the loss to the family in the death of the child is one which can normally be repaired within about a year. Given an abnormal child, parents will very likely limit their further reproduction; if the child is lost, they will have another one, and this time (in all probability) the child will be normal.

We should compare the difference in the lot of the family with a disabled child and that of the family with a normal child. Keeping a badly damaged child alive is likely to eliminate the potential existence of a normal one. If the obstetrician maintains life in the spina bifida baby, he is quit of his task in a matter of days. He passes on the problem to the paediatrician, who, because a decision for the maintenance of life has already been taken once, is under some pressure to continue along the same line. If there is to be a switch to my first aim, considerable strength of mind is called for. The clinical problems can be considered under

two headings: (1) viability, (2) investment of psychological capital. The viability of the damaged baby (Eckstein's group III) is very far from 100% since an independent life will be impossible; that of patients in his group I is 100%. The payment in suffering in group III is enormous, in group I negligible. By the time a child has reached several years of age, the psychological investment in his future existence has been large, both for the parents and for the child. At the time when the child is born, the investment of the parents is nine months of their lives, the investment of the child himself

is zero. My conclusion is that we should put first things first: prevention of suffering comes before preservation of life.

Appointments of Speakers

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Discussion

DR. SLATER: I'd like to start by asking whether the save-all ethic still applies in paediatrics, as I know it does to the helpless psychiatric cases in a geriatric ward where they still maintain life when only a vegetable existence is possible. We all have this shrinking from killing life.

DR. HATCHER: Most of the younger paediatricians have abandoned the save-all ethic—in fact they've grown up when this was no longer current.

DR. SLATER: I'm delighted to hear it—it was a terrible ethic while it lasted. If no baby born with an open spinal lesion was maintained wouldn't it cut the disablement figure by 90%?

DR. HATCHER: At birth the people present are midwives or junior obstetric housemen. They're not really in a position to select.

MR. ECKSTEIN: We must recognize that it's very difficult not to start active treatment. Three years ago I talked to 100 midwives about spina bifida, and showed them lots of illustrations. I pointed out that once these babies got to a paediatric surgical unit they got on to an assembly line. But the point of selection was at the maternity unit and there was no reason why the midwives should resuscitate every grossly malformed baby. There was a colossal outcry: how would I expect the midwives to decide which baby should survive and which should die?

DR. HATCHER: It's a non-nursing duty.

MR. ECKSTEIN: Yes, and it was also said that the obstetrician didn't know enough about spina bifida to select the babies that should be treated—in other words, they were passing the buck.

CHAIRMAN: Couldn't the paediatric surgeon tell the obstetrician about his criteria for operation? And when does the paediatric physician see the child?

DR. HATCHER: An increasing number of obstetric units have resident paediatric staff—and they let the registrar or the consultant know immediately about any baby born with spina bifida. But by this time the baby's wrapped up and put in a cot.

DR. SLATER: And nobody is going to unwrap it?

DR. HATCHER: Of course, but if there is a question of resuscitation at birth the concept is gradually spreading that there should no longer be a save-all policy in resuscitation.

MR. ECKSTEIN: The point that has alarmed me recently is that an increasing number of fetuses with spina bifida or hydrocephalus are now recognized before birth, by x-ray. Many of these babies are delivered by caesarean section and I have tried to persuade obstetricians not to resuscitate them if they're severely deformed—but many have objected violently.

DR. HATCHER: Again, the young obstetricians are getting the message.

MR. ECKSTEIN: This is true. Even so, we must recognize that untreated babies with spina bifida do not necessarily die.

DR. SLATER: How do you treat babies whom you don't operate on?

MR. ECKSTEIN: You don't give them antibiotics for infection, and equally I think it's wrong to tube-feed them.

DR. SLATER: The key to this problem is the nurse—she has to be inspired to do the right thing. At present they are inspired only to do the saving job; if they could be persuaded to accept nursing for comfort it would cause less distress both to the infant and to the family.

Nurses' Attitudes Vital in Decision-making

CHAIRMAN: Mr. Eckstein, you are on record as saying that the nurses' wishes are most important in making any decision.

MR. ECKSTEIN: Yes, this factor is absolutely vital—but you can't have a committee deciding on each case. The position is that if a baby is referred who fulfils all the criteria for operation, then it's operated on by the duty registrar and I see it when I next visit that hospital. If the baby is unsuitable for operation or there's any doubt, then I see the baby straight away and make the decision having talked to the senior nursing staff. Unless the decision is made by a consultant the nurses won't accept it, even if it's right. On the few occasions when we have disagreed, then I have accepted the nursing staff's advice—usually that the baby should be treated.

DR. SLATER: Such as "this baby's not completely paraplegic; therefore you should treat it."

MR. ECKSTEIN: Complete paraplegia is not necessarily a contraindication. But what has appeared in the last few months is a whole mass of children that have been treated at various unfortunately good paediatric units and come with an apologetic letter "I thought this baby would die, but it hasn't"—and then one finds oneself doing a lot of salvage surgery, which is made more difficult and produces much less satisfactory results. I saw such a child only this afternoon, with a head circumference of 66 cm; it's a cabbage.

DR. SLATER: Such a child has been subjected to a survival nursing regimen.

DR. HATCHER: We do know that in untreated children with myelomeningocele the mortality at 1 year is 90% and at 6 months is over 50%—so there is a tail-off of survivors. The striking thing is that, though they are untreated, some of them who develop meningitis or pneumonia still survive.

DR. SLATER: Even with an open lesion?

MR. ECKSTEIN: Yes, if they are covered—and if it heals up they won't then develop meningitis.

DR. HATCHER: The difficulty with the 10% survivors is that most of them will develop hydrocephalus, and unless one inserts a ventricular shunt they become extremely difficult nursing problems.

MR. ECKSTEIN: I don't hesitate to put valves into the older survivors, merely for this reason—but the operation makes no difference to the prognosis for survival or intelligence. If the valve blocks when the sutures are still open