Ethical Problems in Paediatric Surgery †

Herbert B. ECKSTEIN, MA MD MChir FRCS

The concept of ethics in medicine or in surgery is not new, and Hippocrates already stated ethical principles in a considerable number of his writings, some of which are still applicable today. Other commentaries of our ancient ancestors in Greek and Roman medicine are nowadays only of historic interest, for the current ethical problematic theme with regard to everyday surgery and medicine is relatively new, and in a particular manner it has really only been of deeper significance for the past 10 years. It is therefore understandable if we must ask ourselves at the start of this talk, why medical ethics has been discussed to such a great extent, particularly in the area of neonatal surgery, and why it has gained such significance for the clinical practitioner.

To start with, there is no doubt that general knowledge concerning the most important aspects of daily life and of health care has grown, and in particular concerning those things that go on in hospitals, and the population today is very much better informed than before. No doubt it is the so-called media, such as radio, television and illustrated magazines which have advanced public awareness and brought to light many ethical problems, so that today we are confronted by arguments from the general public, such as could not have been imagined 10 or 20 years ago. Although television has without doubt had great merits in the general education of the public, it must be admitted, against that, that a not inconsiderable quantity of information shows evidence of prejudice and is inaccurate. Above all, one of the difficulties lies in the fact that ethical problems as a rule only refer to one and only one quite individual case with special problems, and it is very difficult to make the selection for the television programme in such a manner that the viewers are addressed as a totality.

In Great Britain, the development of initiative groups within certain directions of belief has led to a wider knowledge, on the part of the population, of ethical problems. At present, there are the so-called "Life" organisation, which expresses, although erroneously, very loudly its opinion that on principle life must be preserved in any situation and at any price. The other extreme is an organisation with the name of "Exit", which supports euthanasia and would happily support the concept of "no treatment" ("therapia nulla"). All these groups again and again achieve considerable notice in the various media. The spokesmen of both organisations (Life and Exit) are exceptionally skilled with regard to methods that are effective with the general public, and are convincing speakers in discussions, in particular on television.

Finally, we can not afford to ignore the consequences of such activities, as in the background there is already the threat of a large number of law suits on account of allegedly inadequate or incorrect treatment in the sense of "medical malpractice", such as has already, to a considerable degree, developed in the United States. For there are already alarming signals that this flood of law suits is expanding in Great Britain and in the European states, too. I can scarcely imagine how one can get rid of this unecessary threat of a law suit with regard to the patient to be treated. Only joint efforts by the medical and legal professional organisations could provide success in this field. To the same extent as the number of unemployed lawyers and medical men increases in the entire Western world, the inclination to carry out litigation will also grow, in particular as this wretched process will create work for a certain number or potentially unemployed lawyers and doctors, and thus secures their standard of living.

However, the main reason for the increasing problem in the area of ethics is the simple fact that we know ever more, including about the human body

and the function of the various organs, and that we can recognise all possible kinds of illness that have up to now been unknown, and even before the patient or the child respectively has been born. However, our therapeutic possibilities have not been able to keep up with these enormous advances in diagnostics. To an ever increasing extent we make diagnoses for which we have no therapy that we can offer under present day conditions. For, although further progress and developments may be rightly expected for the future in the field of surgical technique, I have scarcely any doubt that there will always exist situations for which neither any surgical nor medical means of treatment will be available.

For childhood, the area of problems where ethical considerations are of importance, can be divided into the following three areas, from a didactic aspect:

1. Neonatal surgery
2. Neonatal medicine
3. Problems in infancy and childhood.

Although you are all paediatricians, I do not intend to discuss ethical problems in neonatal paediatrics, as my experience in this is very limited and you yourselves are much better acquainted with these specific problems.

Rather, I wish to start with the discussion of questions of ethical problems in the area of neonatal surgery, and, to simplify the matter, to break down the neonatal surgery into three different groups of patients.

In the first group, and also the one most familiar to paediatric surgeons, can be found an isolated congenital defect which can, as a rule, be successfully corrected; thus the child will survive and continue to develop in a perfectly normal manner. Classical examples for this are atresia of the oesophagus with and without tracheo-eosophageal fistula, the congenital diaphragmatic hernia, isolated duodenal atresia, intestinal atresia and the anorectal malformations. In a similar manner, a large number of malformations in the genital and urinary system can also be corrected completely. Here, too, the result of surgical measures is a normal child. In an untreated state, in principle, all these malformations are incompatible with life, but on the other hand one single surgical measure is sufficient for a very high chance of success. The long term result is a normal child, a normal personality, who will lead a perfectly normal life. These malformations do not demand any ethical considerations and you will no doubt agree with me that a correct and directed therapy is always indicated here.

At the other end of the scale, as concerns neonatal surgery, there is a whole range of congenital malformations for which at present there is no surgical therapy and will probably also be none with a view to the future, although it is always risky to make such a statement. The classic example in this group is a newborn with anencephaly or extremely serious malformations of the heart or the rarer case of a bilateral renal agenesia. For these children, there is no therapeutic possibility, so that life can not be preserved and the children must die within hours or days after birth. As there are no possibilities of help available to the physician or the surgeon, there logically do not exist any ethical problems, and the inevitable end is accepted both by the parents and also by public opinion and the initiative groups, without any comment.

Now, however, we come to a relatively small group of newborn with a combination of malformations, for which there exist some therapeutic possibilities, without which these children would die with certainty, or at least probably. On the other hand, for this group it is quite impossible ever to expect a normal child at the end of the treatment series, whatever treatment and however many measures are carried out. And it is just this group of infants which provide us, but also the care staff, with immense headaches but also with "heartache", from the very first day. The decision whether a treatment should be commenced, which is invasive and is to extend over years, must be taken within one, or at the latest two days from birth. Thus in the end it is more than doubtful whether a worthwhile life starts here.

In the first place in this group of newborn children with ethical problems should be mentioned intestinal obstructions, such as duodenal atresia, Hirschsprung's disease and anorectal malformations, as well, of course, as the oesophageal atresia, if these are in combination with an established Down's syndrome. Of course, the conditions listed above could, in the absence of any mongolism, be treated by the surgeon without problems and purposefully, who could then expect a normal child at the end of

his therapy. But the presence of a Down's syndrome lets us expect a child which will, in the long run, be more or less mentally retarded. I have had the experience that those cases where mongolism and intestinal obstruction occur in combination, cause far more ethical problems than any other malformation.

The decision with regard to each individual one of these patients must be made to depend on all available information and must in the end be attuned very precisely to the wishes of the parents. It is not possible to discuss the problematics of these specific cases at the present time and within this framework, for the laws have recently been amended. For in Great Britain the parents no longer have the full right to custody, and the State has reserved for itself the right of the ultimate decision, whether this be for better or for worse. This applies similarly to the surgical treatment of the oesophageal atresia, if this in combination with a so-called VATER or VACTERL syndrome, which includes, apart from the oesophageal atresia, also an anorectal agenesia, malformations of vertebra and of the heart, as well as other congenital disturbances. It is thus quite impossible in such cases to expect something like a normal child as a result of medical measures. I have at the moment quite a number of such infants who flourish surprisingly well with a gastrostomy, a colostomy, a ureterostomy and other defects simultaneously, but there is not the least hope that these children will ever become completely normal again, as essential sections of their bodies are just missing. For this problem starts right at the beginning, as the oesophageal atresia would, if untreated, lead to death, whereas most of the other malformations represent a less acute problem for the surgeon. The decision of whether to operate or not must therefore be taken here in the first 24 to 48 hours after birth.

Exstrophy of the bladder is usually considered as a very serious malformation. But here, reconstructive operations on the bladder in combination with urine drainage procedures are relatively successful, and such a child would never cause ethical problems as everyone expects that this child will be treated actively.

Occasional cases with a so-called cloacal exstrophy or vesico-intestinal fissure, where in addition to a bladder exstrophy there is also an anorectal anomaly, represent a much greater problem, for from purely practical aspects such children can only survive with a colostomy on one side and a urine drainage on the other side by means of a colon or ileum conduit. In addition, there arise necessarily considerable doubts as to the potential quality of life of a patient who is condemned from the start to a colostomy and an ileostomy. To make the point once more: without surgical measures, these children are almost always, even if not with a certainty of one hundred percent, condemned to death.

The clinical pictures of myelomeningocele or spina bifida respectively has illuminated most powerfully the entire problem of medical ethics in the neonatal period. Whereas the average myelomeningocele with a certain mobility of the legs and a reasonably normal head is nowadays no doubt always treated by most paediatric surgeons, there has nevertheless been a considerable change in the medical evaluation of this specific problem within the past 20 years. In the 60s, the concept of the emergency closure of this malformation of the back was introduced in England, and as this attitude did not involve any ethical complications, it is not surprising that this procedure became very popular and an enormous number of such spinal fissures were sealed as emergency cases.

It was John Lorber who showed us that this uncritical closure of all myelomeningoceles led to the survival of an immense number of seriously handicapped children. From this arose the entire complex of questions of the so-called selection for treatment. Unfortunately it has become apparent with the spina bifida that Lorber's view, that without surgical or medical treatment all these patients would die, represents a false hope; indeed it became clear that a considerable number of completely untreated myelomeningocele children survive even without the administration of antibiotics, in so far as they receive here a normal hospital treatment and nutrition. The decision as to whether a certain baby with a large spinal fissure should be treated or not is accordingly extremely difficult, even if we talk through the entire problem with the parents of the child. Even if we were always to respect and accept their views and wishes, I believe that in the end the decision of whether to treat or not, in the case of a serious spina bifida, must be taken by the respective specialist, whether he be the registrar or the consultant himself.

There are, as you can see, a small but very im-

pressive number of congenital malformations which can be improved but not completely cured. Thus we are at present in the position of either producing severely handicapped survivors or to hold back with the treatment, which will then with reasonable certainty lead to death. The decision as to which way is to be taken appears to become more difficult, rather than easier, from year to year.

But ethical considerations must also be carried out with children after the neonatal period. In my opinion it is worth concentrating for a moment on two groups of children. In the first place is the group of children with malignant illnesses, which have in the course of recent years developed to be amongst the significant causes of death in childhood, whilst many other illnesses have become accessible to treatment. It is beyond doubt that the progress in modern chemotherapy is enormous, and my own collaboration with the Royal Marsden Hospital and Prof. Tim McElwain has taught me that a considerable number of children with progressive malignant illnesses are completely curable. On the other hand some cases can not be controlled either by extensive surgery, nor by most aggressive cytostatics. And thus one very quickly reaches a point in treatment where the modern chemotherapy is almost worse than the illness, so that the decision must be reached of suspending all treatment, and to let the child die in peace.

The hopeful efforts of the oncologists to try out ever stronger and better medication is understandable. But we have had the experience that the incorporation of a paediatrician into the team for the tumor treatment ensures a certain sober objectivity in the discussion about the overall treatment plan.

The second group of children where ethical considerations play a major role, are some of the accident victims, and moreover in practice mainly the traffic accidents. The child which was run into on the road or injured in the car comes into hospital unconscious, presumably with multiple injuries, and is already or will be automatically intubated, ventilated and given emergency treatment. Most of these patients recover again completely and do not cause any problems. However, with a considerable number of such children it can become apparent after a few days of treatment and observation that they are very seriously injured, mostly in conjunction with a skull-brain trauma, so that a complete recovery appears improbable or must even be negated. The temptation to switch off the respirator or to remove the endotracheal tube is very great and in fact that is also not infrequently done. Of course, the switching off of a respirator comes within the area of responsibility of a specialist, and I have had to subject myself to this particularly unpleasant task in numerous situations already. Nevertheless one always has the extremely unpleasant sensation when taking this measure, that this particular action is so inevitably definitive.

For the doctor who treats a child with very serious skull-brain trauma, the greatest problem is the almost complete impossibility of predicting or estimating the degree of a possible regeneration of the brain functions. This is mostly only possible after days, weeks or even months. The predictability in some few cases makes the entire problem of reserved therapy even more difficult. Accordingly one should turn once more to those persons who are involved in the decision making with regard to the ethical problematic.

By tradition, it is the doctor caring for the patient, who will take all decisions, in particular when it is a matter of a decision of life and death, and here one was sure of his attitude, this being in the view of life in which one was educated and brought up.

In the past 10 years, however, it became apparent that such authoritarian decisions are no longer applicable and are no longer accepted, but that older medical colleagues were included in the responsibility. It is my own conviction that one should always speak with the parents and should listen to their views with regard to any further procedure. But I again and again have the impression that the parents, for their part, do not wish at all to take a definitive decision, and I believe that this is a very reasonable attitude. In my experience over many years it is extremely seldom that one will find parents who will take up a position completely contrary to the opinion of the team of doctors. Admittedly most of the parents would like to be consulted, but they do not wish to have to make any definitive decisions.

Where I work, the social workers emphatically demand to be included in the discussion about the decision, if it is a matter of an ethical problem concerning children. But with the training program as it is at present, most of them are not likely to have sufficient hospital experience or general medical know-

ledge at their command in order to be able to understand and also to process further the complicated medical information. But for the decision with regard to further therapy, this is essential. Unfortunately, however, in Law and in the amendments which have recently been carried out, long term experience is not taken into consideration.

With the present day trend of increasing the number of staff in hospital management and to increase their influence, and at the same time to remove the organisational responsibility from the doctors as far as possible -although they have, up to the present, carried out this task quite satisfactorily- there should be no doubt that it is only a matter of time until the hospital management will want also to exert influence on ethical decisions. I suppose that soon it will have got to the stage where on each occasion a commission will have to meet, if an important surgical decision is to be taken. I personally would doubt, however, that a commission will ever be able to reach the correct decision at the right moment in time. I am convinced that we -and that lies in the nature of our work- will always have ethical conflict situations, as long as we treat our patients. The only thing that will change will be the form and manner in which we approach these problems. Based on my own observations as a paediatric surgeon over the past 20 years, I regret to have to say that as doctors we today have greater difficulty in dealing with a situation which belongs solely into the sphere of the family, the doctors and the nursing staff, and where the inclusion of other people as a rule does nothing but harm.

In past years, already, I have always felt it to be very difficult to discuss ethics in medicine. Even my own colleagues showed surprisingly little interest in these problems. I also had the opportunity to discuss ethical questions with a considerable number of members of the most varied religious groupings. Although I was always listened to with great patience and it was admitted that problems did exist, I can not recall any truely helpful advice, neither from a cleric of the Church of England, nor from a Jewish rabbi.

In the religions that I have encountered, ethics presents neither greater nor lesser problems. The views of those parents who belong to the Church of England are identical to those who belong to the Roman Catholic faith; nor have I been able to observe any difference between Jews and Moslems. Amongst those who have to take the decisions, the adherence to a religious attitude can also be of significance. Almost all those who partnered me in discussions could be described as definitely "religious", yet the adherence to a specific religion (whether Protestant or Catholic, whether Jewish or Moslem) again not playing any part. Someone like me, who, as a result of his past, has never joined any specific religion, will miss the help, which, I assume, grows from a firm faith in God. Therefore, I would like to thank Miss Margaret Atkins, Head of the Social Services in the Hospital for Sick Children, Great Ormond Street, and Siegfried Hofmann-von Kap-herr of the University of Mainz, who have shared my interest in these questions and who have supported me with much useful information and many ideas.

† Editor's Note:

This paper represents one of Herbert Eckstein's final works. The original manuscript in English is missing; the present text is from the proceedings of conference given in German at the "6. Papenburger Pädiatrisches Symposion" (1 September 1984).
A translation has been very kindly provided by
Dr. Peter A. Eckstein and Mr. Klaus E. Eckstein.