

Ethical Problems in the Management of Myelomeningocele and Hydrocephalus

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Within the last generation the application of major advances in drug therapy, intensive care, transfusion techniques, surgery, anaesthesia, and radiotherapy, together with a vast expansion of knowledge due to increased investigative facilities, have led to an unprecedented, dramatic and beneficial increase in the number of persons who would previously have died, or lived with severe handicaps, but can now be cured. Techniques have also been developed to prolong the lives of many people who are now able to enjoy several extra years of productive and meaningful existence, and to alleviate and improve the quality of life of many seriously handicapped persons, enabling them to become integrated as useful and contented members of the community.

Choosing from numerous examples of paediatric experience, it is notable that many more extremely premature infants now survive without physical or intellectual damage; infection can almost always be cured, including neonatal and all other forms of pyogenic meningitis and the now rare cases of tuberculous meningitis and miliary tuberculosis. The few remaining new cases of Rhaemolytic disease are also readily cured. There are outstanding successes in the treatment of childhood malignancy. Paediatric surgery has made great strides. The prognosis of congenital heart disease, of obstructions of the alimentary canal and many other conditions has improved beyond recognition.

Unfortunately, the indiscriminate use of advanced techniques of all types has also kept alive those who would have died but now live with distressing physical or mental handicaps or both, often for many years, without hope of ever having an independent existence compatible with human dignity. There are many examples, including those who have sustained major brain or spinal cord injuries.

SPINA BIFIDA AND HYDROCEPHALUS

These modern techniques have been used on a massive scale for the treatment of infants born with spina bifida and hydrocephalus. There are many who have benefited greatly and more will continue to benefit in the future but, unfortunately, there are also large numbers who have suffered from the uncritical application of technological advances. It is to be hoped that with the knowledge of this experience, further unnecessary disasters will be avoided.

Spina bifida has existed throughout human history. Ferembach (1963) showed that malformations of the lumbo-sacral vertebrae were common in 12,000-year-

old skeletons. Hippocrates was aware of the condition. It was Tulpius, the teacher in Rembrandt's *The Anatomy Lesson*, who described and illustrated it in 1652, and who first called the condition spina bifida. In 1714, von Ruysch distinguished between the paralytic and non-paralytic forms and, later, Morgagni (1761) first associated hydrocephalus with spina bifida, and described hydrocephalus which was not associated with spina bifida. It was in 1883 that Cleland first described the almost constant anatomical malformation of the hind brain, now called Arnold-Chiari malformation (Chiari, 1891, 1895; Arnold, 1894), as well as the now well-recognised associated lacunar skull.

TREATMENT OF MYELOMENINGOCELE

The treatment of simple meningocele, without neurological involvement, will not be discussed here because the indications and techniques are not controversial, the results are good, and the subject raises no ethical or moral issues. An infant born with myelomeningocele, however, is very different because treatment raises complex surgical, medical and ethical problems.

There are five phases in the history of the treatment of myelomeningocele. The first phase lasted from the beginning of mankind until the late nineteenth century. No treatment was possible, and the majority of the sufferers died early in infancy although a few less severely affected may have survived with variable degrees of handicap.

The second phase was a brief period in the late nineteenth century, when Morton (1877), a Glasgow surgeon, injected a solution of iodine in glycerine into the spina bifida sac and claimed success. Others followed him, but the method was soon forgotten, no doubt because it was impossible to treat the many other aspects of spina bifida. At about the same time Mayo-Robson (1885) attempted surgical excision and closure of the lesion, but his technique gained no acceptance and was abandoned. Nothing further happened until the middle of the twentieth century.

The third phase lasted some 20 years, up to 1958. There was more interest in treatment and an appreciable minority of patients were operated on at some centres. Treatment was highly selective. By now there was no difficulty in closing the spinal lesion, but there was little enthusiasm for such surgery because there was no adequate treatment for the associated hydrocephalus. Most infants were still left untreated and allowed to die, including some who might have had a reasonable prognosis. Even in the most advanced neurosurgical centre in Boston, Ingraham and his colleagues (1944) operated on infants only if they had no serious neurological lesions and had survived for at least a year or 18 months from birth, and if their general condition was then good. Most infants died of meningitis or of hydrocephalus or of other illnesses long before then. Matson (1969) adhered to a highly selective policy throughout his career.

In England more and more infants were treated during the early 1950s. Zachary, in Sheffield, and McNab, in London, were among the more active and

Naish (1956), also in London, was one of the first to carry out ileocutaneous ureterostomy on children with neurogenic incontinence of the bladder, with the object of reducing their handicap. During this third phase very few were operated on early in infancy, and those who were selected themselves as milder cases, often without significant hydrocephalus, by the fact that they had survived long enough to be treated. The results were nevertheless disappointing and far less satisfactory than might have been achieved in the same children had they had the total care known to be necessary and available for them today.

In Sheffield a more aggressive surgical policy was adopted in the early 1950s (Zachary, 1968) and, though the mortality was high, in 1974 it was possible to review the condition of 100 young survivors who were born before 1959. Although few of those born before 1957 had significant hydrocephalus, the condition of this initially favourable group was disappointing. About half were retarded, most had major physical sequelae and very few were able to obtain or hold a job (Parsons, 1972; Lorber and Schloss, 1973).

The fourth phase lasted from the late 1950s to the early 1970s. It was characterised by the vast increase in the number of infants treated and was brought about by a new shunt system developed by Holter, an American engineer. It was used by Spitz, for the first time, on Holter's own child. This shunt incorporated two unidirectional valves which opened at a predetermined pressure. With it, for the first time, it was possible to treat hydrocephalus adequately (Nulsen and Spitz, 1952). There had been many other forms of surgical treatment before this development (Scarff, 1963; Matson, 1969) but none was satisfactory for this purpose. A little later, Pudenz introduced a slightly different shunt, using only one valve (Pudenz *et al.*, 1957). Since then there have been many modifications and different types have been introduced in an attempt to avoid the many late complications of shunt therapy.

As hydrocephalus is present in over 80 per cent of cases of myelomeningocele, and as untreated hydrocephalus is an important cause of mortality and morbidity, it is easy to see that a new technique that makes it possible for the child's head to grow at a normal rate and allows him a chance of developing with normal intelligence could lead to uncritical enthusiasm to treat all infants with myelomeningocele, irrespective of the severity of their condition at birth. This was the policy adopted in Sheffield (Sharrard *et al.*, 1963), Carshalton (Forrest, 1967), and Liverpool (Rickham and Mawdsley, 1966), and later, largely through moral pressure from these units, all over the western world. By the 1960s it was difficult for any doctor not to refer babies for surgery and for a surgeon not to operate, for fear of adverse criticism. The parents were hardly ever adequately consulted or informed. They usually understood that their baby had to be operated on and that they had to sign a document signifying their agreement, although most had very little idea what this signature meant for the future of their infant or for their family life (Freeston, 1971; Walker *et al.*, 1971; Richards and McIntosh, 1973).

Untreated Severe Cases

Nevertheless, not all units followed this pattern of treating all infants, even during this period. In Oxford (Hide *et al.*, 1972), Edinburgh (Stark and Drummond, 1973), and Melbourne (Smith and Smith, 1973) the more severely affected newborn infants were not treated, though exact criteria for selective treatment were not laid down. In these series (Table 1) 2 to 10 per cent survived for two years and the survivors were not necessarily in a worse condition than they would have been had they been treated. Every patient who was referred to the Liverpool unit was treated, but in 1960-62 56 infants born in Liverpool were not referred to hospital; presumably they were the more severe cases. None survived for six months (Rickham and Mawdsley, 1966).

Table 1. Survival rate in severe, untreated cases.

	Number	Survived to	
		6/12	2 yr
Rickham and Mawdsley (1966)	55	0%	0%
Hide <i>et al.</i> (1972)	99	21%	4%
Stark and Drummond (1973)	85	15%	10%
Smith and Smith (1973)	79	?	2%

These results fit in with Laurence's experience (1974) in South Wales where between 1956 and 1962 all infants were left largely untreated. By 1972, 11 per cent of 272 myelomeningocele cases were still alive. These must have included many initially mild cases, as 9 of the 31 survivors walked unaided and were continent. This series does not show that 11 per cent of unoperated severe cases would have survived in the absence of early operation and full treatment.

Long-Term Results in Sheffield

In Sheffield, treatment was carried out on a wide scale. No patient was refused admission or full treatment and we accepted all the most difficult cases from a wide area. A combined team of paediatric and orthopaedic surgeons, paediatricians and all supporting services was set up in 1959. It was soon established that the best results were obtained if the infant's spina bifida was closed on the first day (Sharrard *et al.*, 1963) and more and more of well over 1,000 patients treated during a 10-year period were admitted on the first day of life. During this time we carried out much basic research and several therapeutic trials that would not have been possible without such large numbers. A sound neurological basis was established for the orthopaedic care of our patients and many ingenious orthopaedic procedures were developed. The urological aspects received increasing attention. We were supported magnificently by the laboratory and our radiological colleagues (for references see Lorber, 1972a), not to mention the parents and the parents' associations. We established a thriving research fund.

Between 1959 and 1968 we treated 848 infants with myelomeningocele from the first day of life (Lorber, 1974) (Table 2). In spite of all the care, all the innumerable operations and medical treatment, only 50 per cent survived. Most of the deaths occurred during the first year, but a quarter occurred later and there is a steady annual mortality of 2 per cent. The commonest causes of these later deaths were shunt complications and progressive renal disease. Twenty per cent of our shunt-treated children died as a direct result of shunt complications. It was much harder for parents to lose their child after several years of devoted care and after many operations than it would have been had they lost their child soon after birth.

Table 2. Infants treated from first day of life, Sheffield 1959-1968.

Number treated	848	
Alive 4-14 years	424	(50%)
No physical handicap	6	(1.4% of survivors)
Moderate physical handicap	73	(17.2% of survivors)
Severe physical handicap	345	(81.4% of survivors)

Only six survivors (1.4 per cent) have no handicaps, and a further 73 (17.2 per cent) have what might be termed moderate handicap in a spina bifida context, though the combination of incontinence with partial paraplegic deformities and a well-controlled hydrocephalus may not be considered moderate by the patients or their parents.

Of the survivors, 345 or over 80 per cent have severe multi-system physical defects consisting of at least two but usually many more, of the following, in combination—

1. Incontinence of urine, or a urinary by-pass, with frequent infections, hydronephrosis, or hypertension or impending renal failure. Incontinence of the bowel.
2. (a) Considerable paraplegia, often with gross deformities of the legs and feet. They require calipers, elbow sticks, or rollators and wheelchair. Many can only take a few laborious steps and others are fully chair-bound.
 (b) Gross kyphosis, scoliosis or lordosis, alone or in combination. A lot of these have undergone heroic surgery with improvement, but the relapse rate is very high.
 (c) Repeated fractures, unreduced or recurrent dislocated hip joints. Many children had had well over 10 orthopaedic operations by the time they reached secondary school.
 (d) Recurrent trophic ulcers that may take months to heal.
3. Shunt-treated hydrocephalus requiring several revisions. The child with the largest number of revisions has had 17, so far.
4. Blindness, fits, sexual precocity, gross obesity and other less common defects.

Intellectual Development: Employment

Almost all the moderately handicapped and 59 per cent of the physically severely handicapped children are of normal intelligence with an IQ of 80 or more. There are, however, 144, or 41 per cent of the physically handicapped who are retarded, and 51 of these (14 per cent) are profoundly retarded, chair-bound or bedridden, and a few even have an abnormally large head (Table 3). If we had a similar number of severely handicapped children who had not been treated, we would rightly be horrified and justifiably be criticised by others. Yet, for every such untreated child who was referred to us in later life, we have at least 30 such children in spite of all the effort we have made on their behalf.

Table 3. Intellectual level in 345 children with severe physical handicap

Normal	IQ 80 or over	201	(59%)
Moderate retardation.	IQ 60-79	93	(27%)
Gross retardation	IQ below 60	51	(14%)

No person with severe handicaps is likely to be able to earn his living in competitive employment, unless his IQ is at least 100. This statement is borne out by the experience of our patients in the earlier series who have now left school. Yet we have very few with an IQ of over 100. It is unlikely that more than 5 per cent of the 848 admitted during this 10-year period will be able to earn their living: fewer will have a chance to get married.

Lessons of the Fourth Phase

It became more and more obvious that the pendulum, which was at one extreme in the first three phases in the history of the treatment of myelomeningocele, had swung to the other extreme in the fourth. In spite of a progressively increasing survival rate to some 60 per cent, the problems we created were greater than those we solved. With increasing technical experience we could save more and more badly handicapped children, without increasing the proportion of the less severely affected. Treating all babies, without selection, resulted in much suffering for large numbers, in spite of the massive effort of large and devoted teams. The cost of the medical care and of the special education of each severely handicapped child exceeded £50,000 by the time they had reached 16 years of age.

The problems created by a severely affected child often have disastrous effects on family life (Tew and Lawrence, 1973; Tew *et al.*, 1974). A large proportion of the mothers are on tranquillising drugs and more need them (Dorner, 1974). Young parents age prematurely through constant anxiety and recurrent crises. The up-bringing of brothers and sisters suffers. Some families break up. Perhaps worst of all, because severely affected infants were 'saved', many more potentially normal lives never started because their parents did not dare to have other children.

SELECTION FOR TREATMENT

Five years ago a detailed analysis of a group of 524 patients (Lorber, 1971) was presented to the Society for Research in Hydrocephalus and Spina Bifida in Freiburg. In this analysis an attempt was made to find, if possible, suitable criteria for selective treatment. It was essential to find such criteria so that no infant should be denied good treatment if he had a chance of surviving with only moderate handicaps. This meant that some infants who would end up with severe handicaps would still be treated because, after a complete neurological examination (Stark, 1971), it is easy to forecast, on the first day of life, the minimum handicap any patient will have later on, but not what complications or deterioration will occur later, and the actual eventual handicap is often more severe than anticipated.

Fortunately, it was possible to find criteria that could be readily detected by an expert in this field, without wasting time and without recourse to elaborate or costly investigations.

No child who had any one or a combination of the following physical signs survived with less than severe handicaps—

1. A large thoraco-lumbar or thoraco-lumbo-sacral lesion.
2. Severe paraplegia with no innervation below the L3 segment.
3. Kyphosis or scoliosis clinically evident at birth.
4. Gross hydrocephalus, as shown by a head circumference exceeding the 90th centile by at least 2 cm.
5. Other gross congenital defects, for example, congenital heart disease, and
6. Severe cerebral birth injury or intracranial haemorrhage.

In addition, if an infant whose spinal lesion is closed and who already has hydrocephalus develops meningitis, this infant should only be treated with analgesics.

Finally, the infant's social condition should be considered in detail. The fate of an abandoned or unwanted child is very grave, even if his physical condition is a little better than those with major adverse criteria. These criteria were subsequently adopted as a basis for selection.

The main object of selection is not to avoid treating those who would die early in spite of treatment, but to avoid treating those who would survive with severe handicaps. Therefore it is essential that the criteria against treatment should not be any less severe than those suggested above.

Admittedly, it is difficult to forecast future intelligence for any individual baby with certainty, though the presence and the degree of hydrocephalus are important pointers. Stein and his colleagues (1974) in Philadelphia claim that there is close correlation between the presence of lacunar skull in early infancy and later intellectual development. The mean IQ of 85 survivors who had lacunar skull was 63.8 in contrast with 95.8 in those 71 who did not have lacunar skull. They propose that babies with craniolacunia should not be treated. Un-

fortunately, our experience on a similar number born between 1967 and 1969 did not confirm these findings (Lorber *et al.*, 1975). Using our criteria, some children who would have survived with normal intelligence will be excluded from treatment and will die. Nevertheless, it is my experience, as it is that of psychologists, social workers, teachers, and parents, that those young people who are severely handicapped by multi-system defects suffer far more if they have normal intelligence than if they are retarded. Only the intelligent realise fully what they have been through, what they have missed and will miss. Only the intelligent will worry about the frustrations of employment, loneliness, lack of opportunity and of normal family life. Only they will worry about their future and who will look after them when their parents are too old or are no longer alive.

Had we not treated any infant who had adverse criteria at birth we would not have lost a single child who now survives with only moderate handicaps. In other words, all those who had one of these criteria and survive are permanently and severely handicapped.

The case and indications for selective treatment were overwhelming. Such a conclusion could not have been reached without the vast experience gathered during the non-selective approach in the preceding 10 years.

In Sheffield, selective treatment began in 1971 and with it the fifth phase in the history of the treatment of myelomeningocele had started. The policy of selection is fully supported by all the paediatricians in our Region, by the junior medical staff and by the nurses. It is fully supported by the teachers in the special schools for spina bifida children, by social workers and by careers officers. It is whole-heartedly supported by all the branches of the Parents' Associations in the areas from which children regularly come to Sheffield for treatment. It is fully supported by the parents of newborn infants with myelomeningocele. No parent has ever wished for operation if after full explanation about their baby's condition the advice was against active treatment. The right to a second opinion is always offered: it has never been taken up. On the contrary, most parents ask whether something could be done quickly to bring the infant's life to an end. They ask for this because they care for their baby and do not wish him to suffer and to live a life with severe handicaps.

A few parents disagreed with the advice that their infant should be treated. If the infant's condition was near the borderline for selective treatment, no attempt was made to persuade or force the parents against their judgement.

It is essential, once the decision not to operate has been reached, that nothing should be done which might prolong the infant's survival, but every infant should be given normal nursing care and should be protected against suffering. They should be fed on demand. Analgesics, sedatives or anti-convulsants may be given, as needed. They should be nursed in an ordinary cot with a simple dressing on the spina bifida. Tube-feeding, the administration of oxygen or resuscitation is forbidden. Infections are not treated with antibiotic drugs. The greatest temptation for the surgeon is to operate on the hydrocephalus if the infant's head

is growing rapidly. Such a temptation must be resisted, because progressive hydrocephalus is an important cause of early death (Lorber, 1973a; Laurence, 1974). Once an operation is performed a succession of others is bound to follow. The end result is worse than either total treatment from the beginning or no treatment at all.

After the publication of these results and views (Lorber, 1971) from Sheffield, others who already practised selection (see above) published their results, adding their support to the principle of selective approach. Other units, who in the past believed that all patients had to be treated, have altered their views and practice. Selective treatment is now widespread, and is the rule in Carshalton (Collis, 1972), Great Ormond Street (Eckstein, 1973), Cambridge (Hunt *et al.*, 1973), and Cardiff (Laurence, 1974), and many other recent bastions of the non-selective approach. Nevertheless, there remain a few thoughtful doctors who are concerned about the ethical implications of a policy of selection (de Lange, 1974; Zachary, 1968).

Of the first 41 untreated infants in Sheffield none survived beyond eight months and 60 per cent were dead before they reached one month of age (Lorber, 1973a). The fact that all the untreated infants have so far died should allay fears that many untreated infants may survive with greater handicaps than they would have had had they been treated from the beginning. The fear of those who still doubt the wisdom of selection is not that the infant will die, but that he may survive with severe handicaps. This should rarely happen if non-treatment is strictly adhered to. There is nothing worse than half-treatment and it is such half-treatment that accounts for the relatively high short-term survival rates in some centres.

Nevertheless, a few truly untreated infants will survive. If the criteria for selection were correctly adhered to, these infants should not be worse off than if they had been treated from the beginning. They already have gross paralysis, they already have no sphincter control and they already have hydrocephalus. Their spinal lesion will epithelialise. As the spinal lesion has not been closed, their hydrocephalus is likely to be less rapidly progressive or may arrest spontaneously. If an infant is still alive at six months of age, and is in such a good general condition that he is likely to survive for some time, then whatever treatment is necessary can be started (Smith and Smith, 1973). A decision not to treat is not necessarily a final one, as long as interruption of therapeutic inactivity is to enhance good health rather than to interfere with failing health. The decision whether to interfere or when to interfere requires great experience and a firm purpose. The parents' agreement to any change in policy must be secured on a basis of fully informed consent.

The results in those now selected for treatment is far more satisfactory. The incidence of hydrocephalus is naturally less and its degree is less severe. Since the introduction of isosorbide for the medical treatment of hydrocephalus (Lorber, 1972b, 1973b, 1975) far fewer have required surgical treatment. As one treats

fewer cases, more individual attention can be given to them, thus improving their prognosis.

It is not pretended that this policy of selection is a good solution of the problem. In certain desperate situations there is no good solution. What selection offers is merely less unsatisfactory than treating every baby. It does not matter what proportion is treated. What matters is that all the babies who can truly benefit should be given prompt comprehensive care.

Decision Making

Who should make the decision to treat or not to treat? Most consider that it is the doctor's duty. The doctor should be a consultant and an expert in this field of medicine (Ellis, 1974). Without such a proviso disastrous mistakes may be committed. One cannot leave the decision to junior staff. One cannot leave it to the parents because they are hardly ever sufficiently informed and because they are under severe emotional strain at the time. Further, whatever happens, they may later feel guilty for the decision they took if events turn out unexpectedly or if they forget the issues on which the decision was made. Of course, the parents' wishes must be taken into account, though usually they will ask the doctor's advice, even if the doctor appears to leave the decision to them.

ANTENATAL DIAGNOSIS

In spite of the logic and the practical aspects of selection, no doctor can be satisfied with condemning babies to death by inaction, however essential it may be for the babies and for their families' benefit.

The situation in this fifth phase in the history of the care of babies born with myelomeningocele would still be far from satisfactory if it were not for the development of techniques for antenatal diagnosis and the first promise of prevention.

It is therefore of the utmost importance that antenatal diagnosis of at least the more severely affected became possible in 1972. Brock and Sutcliffe (1972) in Edinburgh discovered that alpha-fetoprotein is present in excessive quantities in the amniotic fluid if the fetus has anencephaly or serious spina bifida. Amniocentesis is carried out at about 16 to 18 weeks of pregnancy. The result is available within a few days and, if abnormal, pregnancy can be terminated at once. Their findings have been amply confirmed by many other groups since (Allan *et al.*, 1973; Harris *et al.*, 1974; Milunsky and Alpert, 1974; Nevin *et al.*, 1974; Stewart *et al.*, 1975). This advance led to the birth of many normal infants who would not have been conceived, and has already prevented the birth of many antenatally diagnosed cases of spina bifida. Some less severe cases are missed, but so far no false positive findings have been reported.

Amniocentesis is now universally available in this country. Nevertheless, its use in high risk cases alone will only prevent the birth of some 5 per cent of all spina bifida babies.

The next step is to develop mass techniques to detect alpha-fetoprotein in maternal serum. It has been shown already that excessive quantities are present in the serum during the middle trimester of pregnancy (Brock *et al.*, 1973, 1974; Seller *et al.*, 1974; Wald *et al.*, 1974), though the results are not so reliable as the amniotic alpha-fetoprotein levels (Harris *et al.*, 1974). This technique is still new and not available on a large scale, though major trials are in progress in various centres, including Sheffield, to develop facilities for routine screening of all pregnancies. This should be possible within the next few years. Infants born with severe myelomeningocele should become a rarity and the painful decision whether to treat or not treat should no longer be necessary. This will be the end of the fifth stage.

OLDER CHILDREN

There is still the problem of the several thousand older children alive today. Many are gravely handicapped. What is the correct policy in their management? The universal opinion seems to be that, once treatment has started, there is no moral or practical justification for withholding further treatment, except among the most severely handicapped when a life-threatening situation occurs. In all patients the doctor's aim must be to 'add life to their years, rather than years to their lives'. It is not necessary to revise blocked shunts or to treat septicaemia if this will lead to a speedy death for those whose life is intolerably difficult.

ETHICAL CONSIDERATIONS

So far only practical aspects have been considered. There are, however, serious ethical considerations when a doctor, or a parent, faces the problem of making a responsible decision whether to treat or not to treat.

Today very few people in the medical profession, in the general public, or among religious leaders have ethical doubts about the propriety of terminating a pregnancy before the fetus is viable, if it is known for certain that it will be severely defective. Most people would agree that it is ethical to terminate pregnancy even if the fetus is likely to be abnormal, and this is legal. But it is illegal, and probably most people consider it unethical, to kill a newborn baby, when one knows that it is grossly abnormal. There is a major inconsistency and perhaps hypocrisy here, yet I, for one, uphold this principle. It may also be inconsistent or hypocritical to oppose active euthanasia, yet support non-treatment, or what is often called passive euthanasia. However, active euthanasia may brutalise the persons who carry it out (Bok, 1974; Fletcher, 1975). It would be wrong for a doctor to order his junior or his nurses to carry out such a task if he cannot bring himself to do it. I strongly disagree with active euthanasia, especially for babies and children, who cannot possibly ask for it or give their considered consent. It would be impossible to formulate legislation, however humane are the intentions, that could not be abused by the unscrupulous. There have been plenty of horrific examples of this in the past, especially in Hitler's

Germany. Few just or compassionate persons would wish to give such a dangerous legal power to any individual or group of people.

Yet for some severely handicapped spina bifida babies or others who are equally severely handicapped it would be the most humane way to deal with a desperate situation (Freeman, 1972). It is painful to see such infants gradually fading away over a number of weeks or months, when everybody hopes for a speedy end. It is this consideration of lingering death that still compels some doctors to treat, reluctantly, all babies, in spite of the suffering such a policy will entail (Freeman, 1974).

Nevertheless, no treatment is not necessarily equivalent to passive euthanasia. No treatment with normal nursing care is a safeguard against wrong diagnosis and against deliberate mis-diagnosis for an evil purpose. If an infant's condition is not as grave as was thought, he will live, and he can then be given optimal care if he has any handicaps.

There are ethicists and moralists, as well as doctors, who consider that life must be maintained at any cost, because any life is better than no life. It may be legitimate to adhere to such principles within their own family, but it is not right to enforce such a philosophy on others who do not hold with it. To my knowledge none of the world's great religions or religious leaders believe that a severely defective innocent newborn infant would be worse off in heaven or wherever they believe their souls will go after death. Is it therefore humane to inflict an immense amount of suffering on such infants and on their families to ensure that they reach this heaven or haven in the end?

De Lange, a neurosurgeon, is one who is rightly worried about some implications of deliberate non-treatment. Nevertheless, he writes: 'Large numbers of spina bifida children kept alive by early closure of the defect and more efficient treatment of the hydrocephalus are now adolescents, most of them painfully aware of their deficiencies. Some of us feel their presence not as a tribute to a medical achievement, but as an accusation against misuse of medical power' (de Lange, 1974).

CONCLUSION

Doctors and the public today have to consider whether the vast resources of learning, skill, manpower, time and money needed to keep some extremely handicapped persons alive, maybe against their will, are wisely spent. Is it right to allow technique to triumph over reason and compassion? The doctor's primary duty is to do his best for his patient. Normally, this means saving his life, but saving or prolonging life is not necessarily the best for all patients and may be actively harmful.

If, therefore, today a surgeon is faced with a newborn baby with an extensive myelomeningocele, he should not consider this as an immediate tactical problem, but should think of the life that lies ahead for the baby. If he would not like such a child of his own to survive, he should take the logical long-term strategic view and resist the temptation to operate.

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THE MAN FOR ALL SEASONS

'These hospitals are so well run, and so well supplied with all types of medical equipment, the nurses are so sympathetic and conscientious, and there are so many experienced doctors constantly available, that, though nobody's forced to go there, practically everyone would rather be ill in hospitals than at home.' No, it's not your friendly District Hospital. It's from Thomas More's *Utopia*, racily translated by Paul Turner. Utopian, says the dictionary, ideally perfect but unpractical.

The favourite pleasure of More's Utopians was health, 'because it's the basis of all the others. It's enough by itself to make you enjoy life, and unless you have it, no other pleasure is possible. A sensible person they say prefers keeping well to taking medicine, and would rather feel cheerful than have people trying to comfort him'. Because of this, More said, 'they would never dream of despising their own beauty, overtaxing their strength, converting their agility into inertia, ruining their physique by going without food, damaging their health, or spurning any other of Nature's gifts, unless they were doing it for the benefit of other people or of society'. Tudor health must have been such a transient asset that it was perhaps more highly prized than now. But few of us would share with More, that witty urbane man, his secret discipline of a hair-shirt.