MEDICAL PRACTICE

Contemporary Themes

Parental Involvement in the Decision to Treat Spina Bifida Cystica

H. L. ELLIS

British Medical Journal, 1974, 1, 369-372**Summary**

Twenty couples whose newborn baby had an open myelomeningocele were given a detailed account of the baby's clinical state and likely future by the paediatrician. They each said how they wanted their child treated. I believe a high percentage of parents would like to be involved in the decision on how to treat their spina bifida baby. When parents are given all the facts (including an interpretation of the clinical assessment) by an experienced doctor—and who better for the job than the paediatrician—then the chances of reaching the right decision for child and family which that joint consultation offers are greater than when the doctor has to act as adviser and sole adjudicator.

Introduction

Between 1950 and 1960 an increasing number of babies born with an open myelomeningocele had the lesion closed for two main reasons. Firstly, the operation made it easier for mothers to nurse their babies at home, where paediatricians were obliged to send them as there was insufficient accommodation in the local hospitals; and, secondly, the development of the ventriculo-atrial shunt in 1952, which protected many children from hydrocephaly, brought hope where previously there had been little or none.

Early treatment increased during the 'sixties. This appealed to those who considered it the doctor's duty to maintain life at all costs, a philosophy that gained ground as more scientifically

motivated people took up medicine. There was also a body of opinion, previously concerned about the advisability of early operation yet also worried about the outcome when surgery was withheld, that came to regard early treatment more favourably because the surgeons who practised it most advocated it more and more.¹

These comments are not recorded to belittle what have been significant contributions to the treatment of spina bifida but to illustrate some of the factors that have influenced its development. Much had to be learnt the hard way and some centres, notably Sheffield, have performed tasks for which many have cause to be grateful.

With the early 'seventies came Lorber's invaluable contribution. He evaluated the late results of early surgery and drew attention to the high incidence of grave handicap among children in Sheffield, when most of them were receiving active therapy.² In addition, more information also became available about the outlook for children for whom surgery had been considered inadvisable,^{3 4} and there was the encouraging news that alterations in the level of alpha-fetoprotein might point to an open neural defect early enough in pregnancy to permit termination.^{5 6}

The need for selective treatment of babies with open myelomeningocele is now well recognized and the contributions by Lorber; Smith *et al.*, and Hunt *et al.* describing methods by which more accurate assessment of cases can be made should prove immensely helpful.⁷⁻⁹ Nevertheless, selection is still difficult and the extent to which the parents should be involved in the decision to operate requires careful consideration.

It was inevitable and indeed unavoidable that during the past 20 years there would be differences of opinion between one hospital and another, and even between colleagues in the same hospital, on the best way of managing these very difficult cases. The circumstances were not conducive to parental involvement and there was some justification for the comment made in a letter to *The Times* in August 1972 that the fate of the baby with spina bifida seemed to depend on several chance factors.

At present, for different reasons, most doctors think that they should make the decision about treatment. A very few of them do not discuss the situation with the parents largely because of their own limited knowledge of the subject—though this has not always stopped them from expressing an opinion. Then there are those who make their talk deliberately brief because they believe that the combination of mental shock, physical weariness, and increasing confusion as the various complications are explained make purposeful thought by parents impossible, and that a long discussion only adds to the parents' distress. But parents thus advised generally have little idea of the magnitude of the task that lies ahead and as this slowly becomes apparent their apprehension, concern, and even bitterness may increase.

Probably most consultants talk in depth to the parents but for one or more of three good reasons they also think the decision to treat should be made by the doctor.¹⁰⁻¹² They may think that only by making full use of their clinical judgement and expertise can the correct verdict be reached; they may consider it wrong for parents to be held accountable for their babies when the choice before them is that of life with handicap or of eventual death after handicap; or they may believe that parents prefer the doctor to make the decision. Finally, there are those who believe that no baby with an open myelomeningocele should have the lesion closed before all the possible effects have been carefully explained to and discussed with the parents, and the latter have been given an opportunity to express their own views on how they would like the child treated. It was a correspondent to *The Times* who wrote: "It is they, not the doctor, who should have the final say over a child which they and not he have to bring up."¹³

Parents

In this study 17 married couples who had a baby with an open myelomeningocele were interviewed by me within 24 hours of the birth and usually within a few hours of that event. The fathers of three children born 30 or more miles (48 km) from Oxford were also interviewed, and they discussed the interview with their wives. One of these had signed an operation consent form after talking to her family doctor but changed her mind after she and her husband discussed the Oxford interview.

The parents formed an unselected consecutive group whose children had either been delivered in or admitted to the hospital on my admission day. Twelve of the cases were seen in 23 months and the remainder over a longer period. The parents of one baby had separated during the pregnancy, necessitating separate interviews. Of the remaining 16 couples, three fathers asked for a preliminary interview with the consultant before the child was discussed with both parents. Thirteen couples preferred to be together when the first consultation took place. The parents represented a good cross-section of the community.

Four of the mothers were under 21, 14 were between 21 and 30, and two were over 30. The fathers were the same age or one to two years older, with the exception of a father of 29 and a mother of 22.

Pre-interview Procedure

The baby was examined before each interview by me and generally by the paediatric surgeon or his deputy, and an x-ray film taken of the spine to determine the degree of kyphosis. The obstetricians were asked about the health of the mother during pregnancy, details of the delivery, and about the size of the family and about any abortion, miscarriage, or stillbirth. The family doctor was generally but not always consulted.

Interview

One couple and one husband had a previous knowledge of the abnormality, but the event was no less distressing for them.

When the various ramifications were discussed it was thought that their enormity weighed even more heavily on those with prior knowledge. The interviews with the latter were conducted differently while the others followed a pattern, and the subjects were discussed in the following order: spinal lesion; hydrocephaly; urinary tract and colon; skeletal anomalies including kyphosis (when relevant); leg paralyses; attitudes to handicap in childhood, adolescence, and adult life; outlook for the untreated case; expected risk in a subsequent pregnancy; and medical appraisal—given a little while after completion of the talk.

The parents were told that there was no evidence to suggest that what had taken place was the fault of either of them. They were given a simple explanation of the abnormality, which was likened to a hernia with the spinal cord protruding through a hole in the bony part of the back. They were advised that the cord could be covered by skin drawn from around the lesion, that the wound was likely to heal, but that local infection or escaping cerebrospinal fluid could delay or adversely effect the outcome. Hydrocephaly was then defined, and the incidence of the condition, how it could be treated, what the parents would be required to do, and what was likely to happen if the condition was not treated were discussed. In a previous Oxford study it was disclosed that parents sometimes worried unduly about valve maintenance and they were therefore always reassured on this point.¹⁴

Next followed, tailored to whether the baby was a boy or a girl, a brief description of the effect of the spinal cord lesion on bladder and rectum, of the measures that might have to be taken to make good the sphincter deficiencies, and of the likely long-term effects. The parents were told, when relevant, about kyphosis and its long-term effects, about any skeletal deformities present in the legs and how remediable by surgery they were thought to be, and about the leg paralyses and the extent to which it was thought they would hinder the child's mobility.

Attitudes to handicap were discussed. I pointed out that young children were generally happy, in spite of their handicaps, provided they were kept occupied and enjoyed love and security. But adolescents might become acutely aware of their limitations and their happy dispositions change. The adult would often have come to terms with the disabilities but some, particularly those with severe physical handicaps and no mental impairment, might come to regard their existence as purposeless and look on the future with dread. I reminded the parents that the ability to deal with a handicap is influenced partly by the help and encouragement that is provided in the home and by the child's inherent determination to overcome adversity. Parents are generally better able to assess these factors than the doctor.

At this stage parents would be told about the outlook for the child for whom surgery was considered inadvisable, and those seen more recently were given some of the data disclosed by the Oxford Survey. I explained that when an operation was thought unwise the hospital would, with the parents' permission, arrange for the baby's subsequent care as it was thought inadvisable for the child to be looked after at home. I also pointed out that progress would be carefully watched and if this was better than expected there would be further consultations with the parents. Finally, they were informed of the risks of further children being born with the same handicap and were told that the subject would be further discussed with them at a later date. The prognostic appraisal generally followed after the parents had been given an opportunity to express some of their own thoughts.

The interviews lasted an hour and sometimes much longer, and a resident doctor or nurse was always present. They were normally held in the evening, and afterwards the parents could discuss the problem together or with a close relative or friend. There was usually a short break, after which they were asked if they had any further questions and when there was continuing uncertainty they were advised to defer making a decision until the morning.

To try to clarify my own thoughts as the interview proceeded

I gave myself these guide lines: to assess on the basis of the clinical examination the degree of handicap from which the child was likely to suffer; to visualize the effects of these handicaps on the patient in childhood, adolescence, and adult life; to see the problems through the eyes of each particular parent; and to assess the possible effects of physical and mental strain on those most likely to be subjected to it.

Results of Parental Involvement

All the parents said how they wanted their baby treated within 12 hours of the interview. One couple, whose baby had at first looked very bruised after a face presentation, declined surgery, but after 48 hours changed their minds. Their child was not too severely affected and the doctors favoured surgery. Seven other couples requested surgical treatment though I had doubts about the advisability of this decision with three of the babies. Two of these subsequently died, one at 6 months with meningitis and the other at 23 months from renal failure associated with gross hydronephrosis. The third child is making fair progress at a school for the handicapped but is confined to a wheelchair. Of the remaining five cases, two are able to attend normal schools and three have not yet reached school age but are doing well.

Twelve couples did not want surgical treatment and the paediatrician and paediatric surgeon concurred with these requests. Eleven of the babies subsequently died, all before 9 months of age (see table). The twelfth baby, who had been delivered in a service hospital and later transferred to Oxford for possible surgery, was sent by the service hospital to a children's unit in another part of the country. The case was reviewed after two months and treatment started.

Survival Time of Eleven Babies for whom Parents Considered Surgery Inadvisable

	Male	Female	Total
1-7 days	0	1	1
8-28 days	2	1	3
1-3 months	0	2	2
3-6 months	1	2	3
6-9 months	0	2	2
Over 9 months	0	0	0

Discussion

In 1971 the National Association for Mental Health published a working party report, entitled *Telling the Parents*, which dealt with the subject of babies born with congenital abnormalities. Referring to cases of spina bifida, it said that there was "no question about when to tell parents but only how to tell them."¹⁵ But it is not merely a matter of how to tell parents but what to tell them and how much to involve them in the extremely important decision that has to be made so early in the child's life.

It is sometimes implied that telling the parents when their child has some congenital abnormality might be better done by non-medical people. Singular patience, exceptional human understanding, an above average ability to relate to others, and the faculty to explain complex things in easily understood terms are not of course prerogatives of the medical profession, but there is no reason to suppose that other groups in the community are any better endowed. All doctors should try and develop such virtues but must never forget that as credentials for dealing with the spina bifida baby they are, per se, totally inadequate. Sympathetic remarks offered by seemingly knowledgeable people who lack the necessary professional knowledge and clinical acumen can easily lead to a wrong decision, create misgivings, destroy confidence, and sometimes cause considerable distress.

Retrospective studies into the conducting of the spina bifida consultation have their limitations. Few people can remember after several months all they were told at lecture or interview

and fewer still when the interval has been extended to several years and other peoples' ideas have been superimposed. A Survey in 1972 indicated that parents would have preferred to have had more facts given to them.¹⁶ It is undeniable that to talk in depth to parents about their baby with spina bifida within 24 hours of the child's delivery sets them a Herculean task and makes the consultation extremely difficult, yet most people at moments of great crisis will succeed in calling upon hidden reserves of willpower that enable them to think clearly and act wisely, as the following illustrates.

The wife of a physically fit, well-housed couple in their middle twenties, with a healthy daughter aged 2½, gave birth at home to a daughter with spina bifida. The abnormality was briefly explained to the couple and within the hour the father had accompanied his baby to hospital, where he was interviewed by a resident doctor who told him that the lesion on the back could be repaired. The father signed the operation consent form and left instructions that he and his wife wanted everything possible done for the baby. The paediatric surgeon subsequently agreed to operate but also agreed to defer doing so until I had had time to visit the home and talk to the parents. With the practitioner's consent that visit took place later in the day when a discussion was held first with the father and then with both parents. In the course of the first talk the father suddenly said: "doctor, I cannot go on with it," and when asked why it was he had changed his mind when only a few hours earlier he had requested the hospital to do everything possible, he replied with great frankness that he was very much in love with his wife and was devoted, as she was, to their little girl. But there was, he continued, a history of mental illness in the wife's family and twice in their short married life he was aware that his wife had come near to a breakdown. From what had now been told him he realized that if his second daughter were to be operated on the strain on his wife would almost certainly prove too much for her and he would then have a sick wife, his little girl would lack the mother she now knew and loved, while his little handicapped child would be without a home and a mother. "What possible good," he asked, "would this do for any of them?" It was suggested and agreed I should have a talk with both parents and that they should subsequently discuss the matter together before any decision was reached but at the close of the joint consultation the wife made a comment very similar to that of her husband. They were subsequently left to talk things over between themselves but within a short time the paediatrician was called back and told that they were quite sure they did not want their daughter to have an operation. This was a borderline case and had the decision been left entirely to the paediatrician and paediatric surgeon the child would have been treated. As it was I was able to tell the parents with complete sincerity that I would have made the same decision in their place. The baby was not sent home and died some six weeks later.

Conclusions

Given the necessary information I believe that most parents wish to be involved in a decision that is vitally important to their child and themselves. The doctor who advises them should be well informed and of consultant status. A paediatrician or paediatric surgeon should undertake the interview, which should include both parents. The interview should not be hurried and the facts given slowly, systematically, and in language they can understand.

When the prognosis is considered to be very good or very bad the parents should be told explicitly what should be done. Normally, however, cases fall into a borderline group and here the information should be presented without bias so that the doctor can learn something about the parents, and about any special problems they may have, before he advises them.

Years later a son or daughter might ask the parents: "why did you let them treat me when I was a baby?" It will not lessen the handicaps, but it might comfort just a little both the parents and that young man or woman, if they were able to reply: "we had all the facts explained to us, we thought about them carefully, and we discussed them with the consultant. We were truly anxious that only what seemed best for you should be done. If now that you have grown up you think we made a mistake, we are indeed sorry, but we can promise you we tried at the time to

do what we thought, hoped and prayed would be right the thing for you."

For some people and some families a handicap is a challenge that is met by the individual's resolve to overcome and the family's united effort to see he does. For others, who may be equally brave yet in a different way, severe handicap saps away the will to live and such people may become lonely and rudderless in this very competitive world. Only by consultation with the parents are these familial traits likely to be disclosed.

When an operation is considered inadvisable, and arrangements are made for the baby's subsequent care, the consultant should keep in touch with the parents during the child's lifetime. I consider that this was inadequately done in this study.

I am grateful to my colleague Mr. Malcolm Gough for his support and surgical expertise. I also wish to thank the Oxford Regional Hospital Board for its help in promoting research into this condition.

References

- ¹ Zachary, R. B., *Lancet*, 1968, 2, 274.
- ² Lorber, J., *Developmental Medicine and Child Neurology*, 1971, 13, 279.
- ³ Hide, D. W., Williams, H. P., and Ellis, H. L., *Developmental Medicine and Child Neurology*, 1972, 14, 304.
- ⁴ Stack, G. D., and Drummond, Margaret, *Archives of Disease in Childhood*, 1973, 48, 676.
- ⁵ Brock, D. A., and Sutcliffe, R. G., *Lancet*, 1972, 2, 197.
- ⁶ Allan, D. L., Ferguson-Smith, M. A., Donald, I., Sweet, Elizabeth, and Gibson, A. A., *Lancet*, 1973, 2, 252.
- ⁷ Lorber, J., *Archives of Disease in Childhood*, 1972, 47, 851.
- ⁸ Smith, G. K., and Smith, D. E., *British Medical Journal*, 1973, 4, 195.
- ⁹ Hunt, G., Lewin, Walpole, Gleave, J., and Gairdner, D., *British Medical Journal*, 1973, 4, 198.
- ¹⁰ Eckstein, H. B., *British Medical Journal*, 1973, 2, 284.
- ¹¹ Hatcher, G., *British Medical Journal*, 1973, 2, 285.
- ¹² Lorber, J., *British Medical Journal*, 1973, 3, 46.
- ¹³ Reed, N., *The Times*, 14 August 1972.
- ¹⁴ Jones, Hilary, Personal Communication, 1970.
- ¹⁵ Report of Working Party of National Association for Mental Health, *Lancet*, 1971, 2, 1075.
- ¹⁶ Walker, J. H., Thomas, M., and Russell, I. T., *Developmental Medicine and Child Neurology*, 1971, 13, 462.

General Practice Observed

Patients' Attitudes to Medical Students in General Practice

H. J. WRIGHT

British Medical Journal, 1974, 1, 372-376

Summary

259 consecutive adult patients were interviewed regarding their attitudes to the presence of medical students at consultation, at examination, and at home visits. Few patients declared reluctance to discussing physical illness and smoking or drinking problems in the student's presence, but many had appreciable inhibitions about discussing almost every other common component of consultation. Over half of the younger women interviewed would prefer students not to be present at physical or pelvic examination.

Neither age nor social class showed significant association with declared preference, but previous contact with students did not decrease inhibitions among patients. Only 15% of respondents said that they would be more upset by the presence of two students rather than one.

Introduction

The teaching of British undergraduate medical students in the setting of general practice has increased considerably in the past 20 years: in 1969 Harris¹ reviewed in some detail the arrangements for such teaching at 14 of the (then) 26 British medical schools. The situation was further reviewed by Byrne² in 1972, who detailed some of the rapid changes which had occurred in the intervening four years. While the momentum for such change has sometimes arisen in the past from objectives more appropriate to postgraduate training than to undergraduate

education (Wright, 1973³) undoubtedly the next decade will see a considerable further increase and the distinctive contribution of general practice to the student's training will become more clearly formulated.

Such learning must be built on an experience of consultation and patient care. But there are two inherent difficulties: firstly, ideally the student's clerkship should be over an extended period of time; secondly, the presence of a student converts a duo activity into a trio one.

Thus an already complex interaction between patient and doctor⁴ becomes further complicated by the presence of a third party. Because of this, many general-practitioner teachers insist on a one-to-one relationship of student and doctor, and are reluctant to consider the presence of more than one student at consultation. Such teaching is naturally expensive in terms of professional time, of money, and of the number of teachers.

The objectives of the present study were:

- (1) To devise a feasible method by which a practitioner could assess the attitude of his patients to the presence of students at consultation.
- (2) To define some of these attitudes in my practice.
- (3) To define some of the factors influencing these attitudes.
- (4) To determine the extent to which patients thought that their attitudes would be modified by the presence of two (rather than one) students.

Method

259 consecutive adult British patients were personally interviewed—in the absence of any student—when they attended for consultation. A standardized interview was used, which took 6-7 minutes to complete. The data were then transferred to I.B.M. punch cards and sorted in the usual way. The proportion of patients who declared a preference *not* to discuss, *not* to be examined, or *not* to be visited at home in the presence of a student was then taken as an index of reluctance.