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SPINA BIFIDA AND THE PARAPLEGIC SERVICE

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THE estimated incidence of meningocele and meningomyelocele in Southern Ireland is over 3 cases per 1000 live births. One survey returned a figure of 4 per 1000. With a population of 2,750,000 and a birth rate of 62,000 per annum, this gives a figure of between 180 and 250 such cases. Not all of these are at present referred to centres for immediate operation.

The incidence in Liverpool of meningomyelocele and/or hydrocephalus taken from the Congenital Abnormalities Registry between 1960 and 1964 was 3.1 live born per 1000 births. In Birmingham the registry from 1955 to 1959 showed 2.5 per 1000. Rates in different parts of Britain vary from 1.3 to 3 per 1000 (General Register Office).

Up to 12 years ago 94 per cent. of babies born with spina bifida cystica died of meningitis and 4 per cent. remained as wheelchair cases. Immediate operation within 24 hours of birth dramatically alters this outlook and prevents increase in paralysis. Ventriculo-cardiac drainage to control hydrocephalus has also completely altered the prognosis. Sharrard's results show 70 per cent. of these post-operative children surviving to school-going age. Of these, one-third have little or no paralysis, one-third with coincident myelodysplasia have moderate paralysis, but with corrective orthopaedic procedure can walk with minimal or no splintage. One-third, however, have severe flaccid or upper motor neurone paraplegia of varying degree, many being wheelchair cases.

There is an increasing number of these children being operated on early in Ireland, and it is possible that this figure will increase to 180/200 per annum. If we have similar success to Sheffield, it means that we can expect up to 40 or possibly more paraplegic cases of different severity surviving per annum from this cause alone. If we were to include all those with some lower limb paralysis and some bladder disturbance the figure would be higher.

We get about 40 traumatic paraplegic cases per annum, the majority of them incomplete. We also admit about 20 other cases of non-traumatic paraplegia, not including cases of multiple sclerosis.

It must be appreciated, therefore, that the progress in treatment of spina bifida cystica may possibly provide as many paraplegics, complete or incomplete, in the community as those resulting from trauma—it certainly will provide a very significant number. The initial stages of treatment are different, and I will come back to this point. The resultant paraplegic is a rehabilitation problem, differing little from the post-traumatic case, and in my opinion requiring the long-term follow-up during life and guidance, for which the paraplegic unit is designed.

Either the doctors interested in paraplegia accept this as in effect a new and considerable area of work, or alternative follow-up services, including in effect another paraplegic service for treatment of these problems, will evolve. It seems absurd to contemplate this possible reduplication.

I have mentioned the difference in the first stage. The traumatic case is best treated in the spinal unit from the start. With present organisation this is not so for the spina bifida case. The early closure is carried out in a paediatric hospital or neurosurgical centre. Possibly 60 per cent. or more may require the ventriculo-cardiac shunt, and this may have to be replaced perhaps two or three times in the average case over years. Many require orthopaedic surgery and estimates of an average of seven such procedures, mainly in the first four years, have been given. There are other general complications requiring the attention of the paediatric team. The neurosurgical, orthopaedic and urological supervision appears to dominate the first few years. After this, however, the general physical rehabilitation together with the care of skin, bowel and bladder is the main problem. Problems arise in reference to schools, housing and work at a later stage. These rehabilitation problems are, I believe, best based with the paraplegic services.

It is natural and right for the paediatric consultants engaged in the earlier aspects to keep contact with their patients, and it is in the child's interest to provide continuity. The consultants should be introduced to, or be associated with, the paraplegic section dealing with these children. The problem is so large that they will welcome sharing some of the load and later, as the paraplegic child passes to adolescence their interest will be less immediate. Continuity of urological care throughout life is of great importance. Here again the long-term follow-up by the team in the spinal unit will be of great value to the patient. I believe the conservative approach of the urologist with experience over many years in these units will be reflected in a reduction of the number of urinary diversionary procedures so frequently carried out in these children. Many of them are done for social reasons and I would hope that research, possibly along the lines of the 'Urovac', may reduce the pressure to operate.

In Ireland there are two centres, in Dublin, which do the bulk of the early operations in these cases. Each was developing its own follow-up system with reduplication of much medical staff. The Department of Health, following consultations, agreed that the main long-term problem was one of rehabilitation, and that it was desirable that the two main operating centres (one is the neurosurgical unit and the other is the main children's hospital) should work towards a common follow-up system. It was agreed also that it would be absurd to develop another paraplegic centre apart from that at the National Centre. At the request of the Minister a Committee was set up, of which I am Chairman, with representatives, from the consultants of these hospitals. We have employed a senior medical officer for research work, a whole-time social worker and secretary. There is agreement on common records and follow-up and further areas of unity are being

explored. This Committee is to advise the Minister on the need for special schools and other facilities.

We have opened a 16-bed unit for these children, as part of the paraplegic unit in the National Centre, and have introduced some of the consultants from the paediatric hospital to provide a link. This has been welcomed by the doctors and it is welcomed by the staff of the spinal unit. I think it is desirable to have a separate physiotherapy and occupational therapy section for the children, and we propose to build this. The work with the children is rewarding, and in their own way they bring a fresh breath of life to the paraplegic unit. Early operation is still fairly recent in Ireland and the children are young. I would not claim that we have achieved much in the bladder training and other aspects as yet. Our aim is to keep the children at home as much as possible, and if possible to get them to attend the local school. We have two psychologists and a number of Youth Educational Advisory Officers able to visit homes and schools and advise. Basically we are providing a link and continuity between the early operation procedures and the long-term medical rehabilitation follow-up and care required for life, and also linking the social and educational programme.

I believe it is important for members of this society to recognise that these children will provide a significant percentage of paraplegic cases in future, and to be willing to take on this work. This recognition should be made known to the appropriate Ministry for Health.

Some formula for co-operation and co-ordination with the consultants responsible for the earlier operative stages should be worked out and this may differ from area to area.

The paraplegic team has much to offer these children and adults, and the work is rewarding.

Discussion

CHAIRMAN—Mr. J. COSBIE ROSS. Thank you very much, Dr. Gregg, for this paper. It might be summed up by, as somebody said, no man is an island and we must develop continuity and correlation. I will just give you a simple example of that from my own experience. Until recently, the patients treated at the Alder Hey Children's Hospital for spina bifida, when they reached the age of 14, were no longer able to attend that hospital and for urological follow-up were handed over to me. But, we have altered this now, we have one of our younger urologists who has taken over paediatric urology alone, and he not only looks after them from a urological point of view at Alder Hey Hospital but he follows them up in our department at the Sefton Hospital with a colleague, so that he will be able to continue this urological follow-up indefinitely. That's only one aspect of this, and it's obvious that we must develop the whole subject in a similar sort of way.

J. SILVER (*G.B.*). I am grateful to Dr. Gregg for his very interesting presentation. He has drawn the similarities, as we are all well aware of, between the spina bifida and other forms of paraplegia. I think it is the differences which worry us all, the question, really, of mental defects amongst children. Working in Liverpool, I have seen a small number of spina bifidas, as Mr. Ross has explained, when reaching the age of 14 they are referred from the Alder Hey Hospital to one of the consultant urologists, either Mr. Gibbon or himself, and then they come to my spinal unit for appropriate treatment, if necessary. What worries me with these unfortunate children are the mentally defective ones, where one has the utmost difficulty in getting them to work. Paraplegics most

often, as we all know, have been working before they are injured, and if they have the will and the intelligence can be got back to work. But, many of these spina bifida children have been taken from their parents at birth, operated on and kept in hospital for many, many years. I know that at Alder Hey they are opening up ward after ward of the hospital to care for these children who cannot be discharged home. I am sincerely asking, how we can fit into our existing framework not only the fit spina bifida children who require the odd urological operation but the mentally defective ones who cannot be made fit to work and require custodial care. And, there has recently been a most valuable leading article in the *B.M.J.* which gave the actual figures of the unoperated series—those that would require special schooling, and these were rather horrifying. I can't remember the exact figures, but very few of them could be accepted at normal schools without operations, and with operations presumably many of the worst ones were being saved. So I would like to know what Dr. Gregg's and other members of the Society's views are, not on those spina bifidas without mental defect, but on the more severely affected ones.

T. GREGG (*Ireland*). The actual figures quoted again in *Surgery for the New Born*, Her Majesty's Stationery Office publication, the figures are Sharrard's figures and he quotes 5 out of a 100 of those are operated on or about 8 or 9 per cent. in effect are ineducable. But that is not the problem of this Society—the provision of special schooling, the provision of hostels or residential accommodation. There are factors in this in which our members could advise, but that is not our province. Our province is the medical aspect of this particular work—the medical follow-up of these children, the medical guidance—trying to get them going if they are intelligent enough to co-operate. And because the child is dull or because the child is backward—if the child is a paraplegic and can benefit from the skills of the doctors who are interested in paraplegia, surely the child should have that benefit. It's a different problem, it's someone else's problem, and I think this should be made clear: it is not our problem to turn all the paraplegic centres into residential centres for the people who come from anywhere else. The problem is: can the paraplegic centres be of benefit to these children with the facilities that they have, bringing them in for courses of treatment or for review, and this sort of thing? This they probably can. I think there is a case for doctors with this particular interest also to go out and visit these institutions and perhaps help and advise and perhaps visit them on a consultant basis occasionally. But, I think the fear of being swamped by these children just landing on you and not going away again—this is possibly a real danger but it is a danger that can be overcome by just decisions on policy before it's done. I don't think that because there are a lot of disabled children actually left, we should ignore them because we are afraid of being dumped with them.

Sir LUDWIG GUTTMANN. I would like to congratulate Dr. Gregg on this excellent paper on his experience with this problem of spina bifida already made in one year, and this is indeed in accordance with Dr. Paeslack's experience. However, I would like to make one point that we should not distinguish between medical rehabilitation and further education. Rehabilitation in these children, or more precisely termed 'habilitation', is one entity. Division between the so-called medical rehabilitation and social education is an artificial thing, to which we doctors should not subscribe. And that applies as much to the spina bifida children as it applies to the grown-ups. I think there are three problems with these children as there are in the grown-ups: first, the clinical assessment and the physical adaptation including the development of compensatory mechanisms; secondly the education of the children which has to start immediately. When we took these children in at Stoke Mandeville during the 1950s, we set up a school for these children where we had the opportunity to divide the children into various groups according to their mental state. The third aspect is the administrative problem, to organise the future of the child which, of course, can be done in co-operation with various medical consultants, the parents and welfare authorities. No doubt there are quite a number of

these children who are mentally as normal as you or I and any other paraplegic. They can be developed into excellent people, can go to universities and can be developed in a normal way. Then we have the other extreme, the mentally defective children for whom special arrangements in special schools have to be made. When we talk about education it is not just education of the child, it is education of the parents in the first place, in particular the mother. We must prevent mothers to become overprotective of these people, that they don't care, for instance, about their incontinence. I was amazed to find intelligent adult spina bifida cases who couldn't care less whether they were urinary incontinent or not and, of course, were socially unacceptable. The mistake which had been made was that these children have not been made conscious that to be incontinent of faeces or urine makes them socially unacceptable. That can be done, as we proved even in young adults who came to us at the age of 16. It takes sometimes a long time to develop that sense of shame of being smelly—an interesting psychological point which I have met with these spina bifidas. I agree with Gregg that with a certain group we should try as we do with the able-bodied to get as many as possible home and into society, but there will always be a group, as we also know about traumatic paraplegics and tetraplegics, who cannot return into society, and for these we have to make special arrangements. Here I think this Society can do a lot of good work. Dr. Gregg is in a relatively fortunate situation: Eire is a country of 2½ million people. He is an excellent organiser and has really taken the opportunity to centralise these spina bifida cases now in his unit. You can do that in a small population, but it is more difficult, of course, in a greater community. But it is an excellent beginning and I do congratulate Dr. Gregg.

CHAIRMAN. Thank you, Sir Ludwig. Now, I know that a number of people would have liked to discuss this subject, but time is getting on and we have a number of papers still to hear. Perhaps, indeed, this might be one of the main subjects of discussion at some future date.

OUR EXPERIENCES ABOUT PREGNANCY AND DELIVERY OF THE PARAPLEGIC WOMAN

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WITH the increasing number of paraplegic women, the study of pregnancy and delivery of these patients gains considerable significance, theoretically as well as practically.

In the past three years we followed six gestation periods in our Spinal Unit in Heidelberg. The patients' ages ranged between 24 and 32 years. All patients had complete lesions of the thoracic cord as a result of trauma of the spine. In the following the case histories of three patients are given which seem to be worth while discussing.

Case 1. Sch. G., 28.2.39, 27 years. Complete spastic paraplegia below Th8 due to compression fracture-dislocation of the 9th thoracic vertebra, as the result of a road accident. At the time of accident pregnancy had lasted 5 to 6 months, being the second gravidity. A healthy boy was born two years ago without complications. In the second month of pregnancy, i.e. three months previous to her accident, the patient had a long-lasting, moderately strong vaginal haemorrhage, the cause of which could not be determined.