Clinical Topics

The young adult with spina bifida

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Although the management of infants with congenital defects remains controversial,[1] the adoption of a policy of selective surgery for the neonate with meningomyelocele has had the effect, predicted by Weatherall and White,[2] of reducing the number of survivors with this condition and diminishing their degree of disability. The policy of careful selection for surgery practised in most centres followed an evaluation of the results of a period of more liberal intervention during the late 1950s and early 1960s when most infants were treated. Examination of the survivors of that period showed a group of children suffering from complex physical and intellectual handicaps,[3 4] and complementary studies of their families measured the social and emotional costs of their care.[5 6] Although in future the numbers of children and young adults heavily handicapped by the effects of spina bifida and meningomyelocele may be considerably reduced, it is important to remember that a cohort of those treated during the earlier years of active optimistic intervention remain and are in danger of being forgotten by all but those concerned in their day-to-day care.

During their school years most children in this group benefited from a high standard of special education, often in newly built schools for the physically handicapped or in special units attached to normal schools. This care had been provided because the Department of Education, becoming aware of the optimism of the surgeons, had anticipated the increased survival of children with meningomyelocele and their ultimate arrival in School and had encouraged local education authorities to make special provision. In many areas the special school co-ordinated educational, social, and medical care and provided a high degree of physical and emotional security for both the child and the parents.

As the children grew, became adolescent, and approached school-leaving age, it was increasingly apparent that security of this type would not continue and that many of the basic requirements for an independent early adult life might be lacking.

A leading article in the *BMJ* identified four hurdles awaiting each young adult with spina bifida. The first, on the assumption that the youngster would be capable of coping alone, was the withdrawal from the cosseting care of parents; the second, the problem of finding suitable accommodation where he could live, if necessary in a wheelchair; the third, the problems of mobility; and the fourth, a job in a world where work even for the able-bodied may be difficult to find.

The ability of young adults with spina bifida to surmount these hurdles could be regarded as a measure of the adequacy of health and social services. In the Northern Region one exception to the generalisation that services for the young physically handicapped are less than satisfactory are those for the cerebral palsied, where the Percy Hedley School and Centre in Newcastle upon Tyne has provided and co-ordinated educational, social, medical, and occupational services for those with cerebral palsy for many years. In assessing the needs of young adults with spina bifida and the extent to which they had been met a group of young people with cerebral palsy provided a suitable control.

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Population

In the Northern Region all the school leavers with spina bifida known to the nine regional specialists in community medicine (child health) and the regional spina bifida clinic were approached: 45 of the 67 people identified in this way collaborated in the study. Forty-five young adults with cerebral palsy who had attended the Percy Hedley School during the same period were identified and 31 collaborated. All were interviewed by one of us (BJC) using a semi-structured open-ended questionnaire.

AGE, SEX, AND DISABILITY

In each group the sexes were equally represented. Ages ranged from 16 to 23 (mean 20·5). Disability in each group was classified as follows:

Mild—Some orthopaedic problems—for instance, needing a stick or caliper.

Intermediate—Occasional use of wheelchair or a well-functioning urinary diversion or appliance.

Severe—Substantial reliance on wheelchair plus other problems—for example, urinary or bowel problems or athetosis.

Very severe—Totally dependent on wheelchair plus major urinary, bowel, or other problems.

Table I illustrates the degree of disability for candidates in each category. With the exception of those who were chairbound with urinary and bowel problems the groups were comparable in terms of disability.

TABLE I—*Degree of disability for candidates in each category*

Condition	Mild	Intermediate	Severe	Very severe	Total
Spina bifida	9 (20%)	15 (33%)	11 (24%)	10 (22%)	45 (100%)
Cerebral palsy	4 (13%)	13 (42%)	14 (45%)	0	31 (100%)
Total	13	28	25	10	76

INTELLIGENCE

Formal testing of intelligence was not undertaken, although academic performance allowed some inferences to be drawn. Of the school leavers with spina bifida, 49% achieved at least one certificate of secondary education and 22% five or more. In comparison 29% of the patients with cerebral palsy achieved at least one CSE, and one (3%) achieved over five. The method of selecting young adults with

cerebral palsy inevitably biased the sample towards those whose disabilities required them to be educated in a special school (table II), although 71% of those with spina bifida were educated in similar institutions.

Preparations for school leaving and current placement

Thirty-four (76%) of the young people with spina bifida and 28 (93%) of those with cerebral palsy had received career advice, and 44% of those with spina bifida and 60% of those with cerebral palsy had visited factories while at school and were aware of some job opportunities and occupations. About 50% and 70% respectively thought that the advice on careers that they had received had been helpful, although a further 40% and 20% thought that it had been insufficient.

TABLE IV—*Number of subjects who experienced delay in placement after leaving school*

	Cerebral palsy	Meningomyelocele
Before entering employment	5	11
Before entering a day centre	2	6
Before entering further education		3
Other	1	
Total	8 (26%)	20 (44%)

either alone or accompanied and a further 10 (22%) could travel by train if helped. Only 22% of those with meningomyelocele compared with 32% of those with cerebral palsy were unable to use public transport at all.

TABLE II—*Numbers (percentage) attending various types of school*

Condition	Ordinary day school	Day school for physically handicapped	Boarding school for physically handicapped	Junior training centre	Tuition	Total
Spina bifida	11 (24%)	18 (40%)	14 (31%)	1 (2%)	1 (2%)	45 (100%)
Cerebral palsy	1 (3%)	18 (58%)	12 (39%)	0	0	31 (100%)
Total	12	36	26	1	1	76

TABLE III—*Number (percentage) of those in various occupations*

Condition	Open employment	Remploy	Further education	Day centre	Unemployed	Total
Spina bifida	15 (33%)	0	4 (9%)	12 (27%)	14 (31%)	45 (100%)
Cerebral palsy	5 (16%)	2 (7%)	2 (7%)	20 (65%)	2 (7%)	31 (100%)
Total	20	2	6	32	16	76

$\chi^2 = 24{\cdot}04$; df = 4; $p < 0{\cdot}001$.

The major difference between the groups was in their current placement and in the speed with which this had been achieved. Over 90% of the young adults with cerebral palsy were in employment, and the two who were not at the time of interview had good prospects of a job. In comparison almost a third of those with spina bifida were unemployed.

Twelve of those with cerebral palsy and 20 of those with spina bifida attended day centres, although the character of the centres differed considerably for each. Those for the patients with cerebral palsy were usually run by local voluntary organisations and had often been initially sponsored by the Spastics Society. The work they undertook was usually of a commercial nature and created an impression of productivity. Centres attended by young people with spina bifida, on the other hand, were run by local authority social service departments and provided care for a wide range of ages and handicaps. Almost half of those with spina bifida attending these centres did so on a part-time basis, which reinforced the impression that the centre provided occupational therapy rather than employment. In contrast to the Spastics Society, the Association for Spina Bifida and Hydrocephalus has worked through small local groups providing personal and family support. The provision of day centres and workshops has been discussed but has not yet proved possible. Although table III implies that young people with meningomyelocele had been successful in gaining posts in open employment, six of the group of 15 were in job-creation posts and were concerned about their future when these posts terminated. Only nine (20%) of the group with meningomyelocele were therefore in secure, permanent jobs.

Even when a post had been achieved this was often after considerable delay. Some 44% of those with meningomyelocele had spent periods of several months unemployed compared with 26% of those with cerebral palsy (table IV).

A major factor influencing employment was the ability to travel. Of the six (20%) with cerebral palsy who owned a car, five were in open employment. Only five (11%) of those with meningomyelocele owned a car, although 25 (58%) were capable of travelling on buses

Social life

SOCIAL ISOLATION

Late adolescence and early adult life are normally periods of maximum social contact, and absence of friends or the inability to see friends at least once a week might therefore be regarded as relative isolation. Seventeen (38%) of those with meningomyelocele and 10 (32%) with cerebral palsy fell into this category. No single reason explains this phenomenon, which appears to be a feature of the handicapped life. Similarly, only 22% of those with meningomyelocele and 21% of those with cerebral palsy had boy or girlfriends. Both groups were nevertheless concerned about their attractiveness to the opposite sex; those with meningomyelocele being particularly concerned about the impact of their urinary appliance on others. There was, however, no evidence that those with a urinary appliance were any more isolated than those without. The less severely disabled were in fact more conscious of their image than those with more obvious handicaps. Despite these problems, 75% of those with meningomyelocele and 59% of those with cerebral palsy hoped to marry, and two of the cerebral palsied group were already married. Of those with meningomyelocele, 70% hoped to have children, although many were concerned as to whether they were capable, whether they could look after them, and whether the children themselves would be handicapped.

ACCOMMODATION

With the exception of the two married individuals with cerebral palsy and one young man with meningomyelocele who lived in a home for the handicapped, all the subjects in the study lived with parents or grandparents. Over one-third of those with meningomyelocele and half of those with cerebral palsy were in accommodation unsuitable for the physically handicapped, with bathroom, bedroom, and lavatory upstairs. In two instances the only lavatory was outside the

house. At the other extreme, 20% of each group lived at home in purpose-built or especially adapted single-storey accommodation. In whatever type of accommodation they lived 58% of those with cerebral palsy and 40% of those with meningomyelocele required help with the process of daily living—bathing, dressing, and, in the case of those with meningomyelocele, care of incontinence appliances. Almost invariably care of this type was provided by the mother, often with increasing difficulty.

MEDICAL AND SOCIAL CARE

Although during their school years many of the subjects had had multiple admissions to hospital or frequent attendances at outpatient clinics, advice about most day-to-day problems was usually provided at school. An important consequence of leaving school was therefore the severing of the link with this type of support.

At the same time the continuity of care provided in the hospital, usually by the paediatrician, ceased as the young adult moved out of the appropriate age group. Leaving school was therefore associated with a substantial diminution in the quantity of care. Only 25% of the group with meningomyelocele and 20% of those with cerebral palsy had at the time of interview any regular contact with a member of any of the caring professions. Seventy per cent of each group welcomed the suggestion that a special clinic or service for physically handicapped youngsters should be established.

Discussion

If the characteristics of an acceptable quality of adult life include independence, occupation, and the opportunity for social contact with peers, the young adults in this study are considerably handicapped. Although the disabilities produced by meningomyelocele and cerebral palsy differ, functional impairment in each group was similar. If performance in school examinations can be accepted as a criterion those with meningomyelocele were less handicapped intellectually than those with cerebral palsy.

For the group with spina bifida as a whole the four final hurdles remain. Few are independent of parents and for some the dependence increases with age. Almost all live at home, some in purpose-built accommodation, but over a third in quite unsuitable surroundings. Most are mobile and are capable of travelling on buses or trains if helped. Despite their mobility most are unemployed or are passing time in inappropriate occupational therapy. In addition a third live in relative social isolation.

One conclusion of this study must be that young people with spina bifida require more help to surmount the hurdles of transition to an independent adult life. The Warnock Committee recommended that each handicapped child should have a named person to whom they could turn for continued advice and support. During childhood this was usually provided by a paediatrician or a team in a special school. Similar support must be provided during the early vulnerable adult years. In the group interviewed 70% welcomed the suggestion of a special service for physically handicapped young people. Such a service could identify need, provide support, co-ordinate medical, social, and occupational care, and act as an advocate for individuals and for the group as a whole. Financial constraints in the health service may well inhibit the development of such a service and the medical profession may suggest that it should be provided by the social services or the Department of Employment. The reality is that most young people with spina bifida and meningomyelocele will remain the patients of an orthopaedic surgeon, a urologist, and certainly a general practitioner. The health service is inevitably involved.

If the outcome of managing disabling disease in childhood is measured by the achievement of an independent and fulfilling life as an adult success with sufferers from meningomyelocele and spina bifida must be regarded as strictly limited. As the aetiology of the condition is increasingly understood and prevention becomes possible the problem may diminish. In the meantime more needs to be done to ensure that those who have survived are provided with the social and occupational support they require. Although this may primarily be social, the medical profession in general and the doctor of each patient with this condition in particular must share the responsibility.

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MATERIA NON MEDICA

Contributions to this column are always welcome.

The geck

The word "geck" means one who is cheated, a dupe or an object of scorn; also, it is an old country name for the cuckoo, apparently used mainly in Cornwall. Yet the cuckoo, surely, is the one which deceives, and, although it may be disliked, it is hardly regarded with scorn. When it flies, the cuckoo often confuses. With its long tail, even though white-spotted and graduated, it is frequently taken for a male sparrowhawk. Sparrowhawks have broad, blunt wings while cuckoos' wings are pointed and thin and are depressed well below the body horizontal when the bird flies. However, the cuckoo will occasionally broaden its wings by feather spreading and its flight then resembles that of a sparrowhawk remarkably closely and, moreover, both birds have barred underparts. Immature cuckoos are often rufous and adult females have an unusual red colour phase; under these circumstances, cuckoos can look like kestrels, with their pointed wings and chestnut shading.

That adult cuckoos are unwelcome may be deduced by the protesting crowd of small birds that will follow one in springtime. One day in May I saw a pair of agitated, alarming great tits in a bush while a cuckoo was perched nearby. Yet great or blue tits, nesting deep in holes in trees, are not parasitised by cuckoos and are, presumably, wasting their energies in mobbing them. It is understandable, of course, when the common cuckoo fosterers show aggression; indeed, if a cuckoo's egg is found in a nest, it is not unusual to see a scattering of the cuckoo's blue-grey feathers in the herbage, suggesting a conflict. The general mobbing which a cuckoo experiences indicates that it is mistaken for a bird of prey, although it has no hooked bill. In fact, cuckoos feed largely on caterpillars and are thus no threat to other birds from this aspect.

When a nestling cuckoo thrusts its meadow pipit nest-mates in turn over the nest rim, however, one realises the cunning of the species. The outcome of this deceit becomes more obvious as the foster parents slave to feed this sole, cherished and demanding fledgling not only for three weeks in the nest but for some time after it has flown. It is not surprising that few people nowadays look on a cuckoo as a geck: few birds can be more artful and skilled in deceit.—PHILIP RADFORD (retired general practitioner, Taunton, Somerset).