The orthotic management of spina bifida children present status—future goals

N. C. CARROLL

Hospital for Sick Children, Toronto

All spina bifida children should have functional goals established for them. These goals will vary with the severity of the motor and sensory deficit, and with the child's developmental threshold. In establishing such goals it is convenient to group the children according to neurosegmental level: thoracic, upper lumbar, lower lumbar, and sacral.

Children with spina bifida tend to be delayed in their developmental landmarks: (a) head control, (b) creeping, and (c) ambulation (National Academy of Sciences, 1973). They should be reared in a milieu which is intellectually and physically challenging. Every effort should be made to "normalize" their lifestyle. These children benefit from a sense of achievement. Mobility is essential if the child is going to attain social maturation and educational, vocational and avocational goals. Goalorientated programming requires a co-ordinated team effort, with the patient the most important member of the team.

From birth to head control, the goals are to correct deformities, avoid contractures, encourage development through mobility and protect anaesthetic skin.

The goals from the time of head control to creeping are to achieve a sitting balance, prevent deformities, protect anaesthetic skin, encourage the use of hands bilaterally, improve eye-hand co-ordination, improve upper-limb strength, improve interaction with a broadened environment and improve mobility.

As regards ambulation, spina bifida children can be classified by functional level into nonambulators, nonfunctional ambulators, household ambulators and community ambulators (Hoffer *et al.*, 1973). "Nonambulators—These patients are wheelchair-bound but usually can transfer from chair to bed.

"Nonfunctional ambulators—Walking for these patients is a therapy session at home, in school or in the hospital. Afterwards they use their wheelchairs to get from place to place to satisfy all their needs for transportation.

"Household ambulators—These patients walk only indoors and with apparatus. They are able to get in and out of their chair and bed with little if any assistance. They may use the wheelchair for some indoor activities at home and school, and for all activities in the community.

"Community ambulators—These patients walk indoors and outdoors for most of their activities and may need crutches or braces, or both. They use a wheelchair only for long trips out of the community."

In a study of 68 spina bifida children aged 12 and over, De Souza and Carroll (1974), found that the eventual ambulatory status was primarily dependent on (1) the neurosegmental level of the lesion, (2) the motor power within a given neurosegmental level, (3) the extent and degree of the orthopaedic deformities, (4) age and stature, (5) the design and effectiveness of the orthosis, (6) intelligence, (7) motivation, (8) spasticity, (9) obesity, and (10) possibly sex.

The goals for a child with a thoracic neurosegmental level who has progressed to the point where he is ready to ambulate are (1) good sitting balance, (2) ambulation at least during first decade, (3) ability to do transfers, (4) wheelchair propulsion, (5) self-care, (6) social acceptability, (7) schooling, (8) access to environment. As an adult, the patient should learn to drive an automobile.

All correspondence to be addressed to N. C. Carroll, Hospital for Sick Children, 555 University Avenue, Toronto, Ontario, Canada.

The goals for a child with an upper, lumbar, neurosegmental level who has progressed to the point where he is ready to ambulate are similar to the goals for a child with a thoracic neurosegmental level. However, one would hope that the child with the upper, lumbar, neurosegmental level would learn to be a household ambulator.

One of the goals for a child with a lower, lumbar, neurosegmental level is to make him a community ambulator. He should be capable of crutchless standing and self-care; he should be able to go to a regular school; and he should be motivated to be self-reliant.

The child with a sacral level, neurosegmental lesion should become a community walker with minimal bracing.

The spina bifida programme at the Ontario Centre for Crippled Children includes an information class for the parents of preschoolers, a multidisciplinary clinic, and an orthotic clinic. In the information group parents are taught how to avoid contractures, to encourage development through mobility, and to protect anaesthetic skin. The spina bifida clinic is conducted with a neurosurgeon, an orthopaedist, and a urologist in attendance. The orthotic clinic is attended by an orthopaedic surgeon, an orthotist, orthotic technicians, physiotherapist, occupational therapists, nurses, and social workers. A child is presented at the orthotic clinic when he requires orthoses to help him achieve the next developmental threshold. Most of the children are 10 to 18 months old. The child's specific functional loss is determined, goals are established for the present and future, and decisions are made as to the role of physiotherapy, surgery and orthoses in his programme.



Fig. 1. Caster Cart.

A child with a thoracic or upper lumbar lesion may have difficulty in dragging himself from point A to point B. We frequently prescribe a prebracing mobility aid called a Caster Cart (Fig. 1) for such a child (Carroll, 1974). The Caster Cart makes it easy for the child to move about and explore his environment. He learns to use his hands to manipulate the wheels. His skin is protected.

When a child with a thoracic or upper, lumbar, neurosegmental level demonstrates that he is frustrated with sitting and that he wants to stand, we prescribe a Standing Brace as shown in Figure 2 (Carroll, 1974). This is an



Fig. 2. Standing Brace.

inexpensive prefabricated orthosis which gets a patient upright without delay. It is made of a tubular frame to which parts are riveted. The fitting can be completed in under two hours and the patient can stand without crutches. He can move without crutches by pivoting. He can use crutches to achieve a swing-to or swing-through gait. As a preliminary device it enables the clinic team to assess the child in standing.

We believe that these children should stand and walk even if later in life they will give up their orthoses for wheelchairs. When they stand, their horizons are broadened, their lower limbs are less osteoporotic and they have fewer fractures, their bladders drain better, bowel function is improved and their cardiovascular system is stimulated by the increased physical activity. Upper-limb strength is increased.

Some of the children with an upper, lumbar, neurosegmental level have been fitted with a Reciprocating Gait Brace (Carroll, 1974). This device, by means of a gearbox, harnesses the power of hip flexors on one side to produce hip extension on the opposite side. With the assistance of crutches, a reciprocal gait is possible by activating one hip flexor at a time. Swing-through gait is achieved by activating both hip flexors at the same time to keep the legs rigid. This orthosis is aligned so that it allows crutchless standing. It is hoped that dynamic stretching of the hip flexors will prevent progressive hip-flexion contractures. We have experienced gearbox maintenance problems with this orthosis.

Children with a total paraplegia, i.e. thoracic neurosegmental level, progress from the standing brace to a Parapodium (Fig. 3), (Carroll, 1974).



Fig. 3. Parapodium.

This device supports the spine during both sitting and standing and is aligned so that the child can stand without crutches. A swing-to or swing-through gait can be achieved by the use of crutches. The Parapodium is constructed from a prefabricated kit which has the following design features: stability, low weight, adjustability for growth, quickness of assembly, ease of alignment, ease of maintenance. With the Parapodium the shoe is "part of the child," not part of the brace. Crutchless walking can be facilitated by attaching a pivot-walker or swivelwalker platform to the footplate. Specialpurpose attachments can be designed and mounted easily. Crutchless standing makes it easier for the paraplegic child to engage in activities such as tossing a ball, dialing a telephone, reading from a book in front of a class, opening a bottle, or pounding a nail at a workbench.

In the last couple of years we have been making more and more use of polypropylene.

Practically all our children with instability of the ankle-foot complex are fitted with a vacuumformed polypropylene insert (Carroll, 1974). If knee stability is a problem, a polypropylene insert can be attached to a polypropylene thigh support by means of side hinges.

Orthoses in the research and development stage at the Ontario Centre for Crippled Children are as follows:-

Plastazote shoes—to protect deformed insensitive feet.

Trunk-suspension systems—to prevent scoliosis, pelvic obliquity, and ischial pressure sores.

Curb-climbing wheelchairs—to broaden the nonambulator's environment.

Stand-up wheelchairs—to enable a nonambulator to assume and maintain a standing position.

Early in this paper, goals were listed for children with varying neurosegmental levels. How often are these goals attained? De Souza and Carroll (1974) found that in the second and third decades, community ambulation was achieved by 53 per cent of children with a sacral neurosegmental level, 30 per cent of children with a lower lumbar level, 10 per cent of children with an upper lumbar level, and no children with a thoracic level. Our great challenge for the future is to have these children continue to ambulate when adult, not just during the first decade.

The third most important factor in determining ambulatory status is the extent and degree of the orthopaedic deformities (De Souza and Carroll, 1974). It is incumbent on the orthopaedic surgeon, therefore, to ensure that the spina bifida child under his care has the spine balanced over the pelvis and hip, the hip balanced over the knee, and the knee balanced over a plantigrade foot. Our orthoses must have the following design characteristics: they must be effective, comfortable, lightweight, low in cost, durable, cosmetically acceptable, easy to manufacture, easy to maintain and adjust for growth, easy to apply and remove, and they must uot impede any of the activities of daily living (Carroll, 1974).

Through research we must develop a means of avoiding abduction, flexion and external rotation contractures of the hip, while still maintaining a position favouring hip stability. We need better trunk supports. As yet we do not have good multiaxial hip joints. We must develop a means of maintaining directional stability for limbs that are in below-knee braces.

The fourth most important factor in determining ambulatory status is the age and stature of the patient. As yet we do not have a satisfactory means of getting a tall, heavy paraplegic from a sitting to a standing position. We need urinary-collecting devices for both males and females. We must assess the feasibility of externally powered braces for ambulation. We need suitable stair-climbing aids. Our architects need to be educated so that environmental barriers are removed from the community. We need total mobilisation of medical, paramedical, engineering and community resources to meet these challenges.

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