

Orthotic Maintenance Program for the Myodysplastic Child

by Terry J. Supan, C.P.O.*

The faculty of the Southern Illinois University School of Medicine has been actively involved in a comprehensive, multidisciplinary approach to the management of the myelodysplastic child. Since the establishment of the orthotic clinic in July of 1982, a systematic approach to the orthotic-physical therapy needs has proven successful in providing a higher degree of function and fewer complications for these patients. The purpose of this article is to inform the reader of the appropriate orthotic involvement and the high degree of orthotic maintenance which is necessary for this type of patient. By describing the experiences of Southern Illinois University School of Medicine, it is hoped that the reader will gain a more realistic understanding of the orthotist's role in this situation.

The types of orthoses run the full gambit from a simple UCB foot orthosis to a complex reciprocal gait orthosis. A consistency with these patients is that as children they develop at a normal rate. A second point with these children is the fact that without orthotic management, effective ambulation would not be possible. Higher levels of lesion necessitate a greater amount of orthotic management. When you combine an intimate fitting plastic orthosis with growth, you can understand the necessity for continuous maintenance and adjustments of their orthotic devices. A regular system of return visits is necessary.

The relationship of the myodysplastic child to the orthotist is similar to that of a patient to their general practitioner. They are seen on a routine basis, unlike the medical specialists who only

see a patient a limited number of times. This should be kept in mind if an orthotist is considering the possibilities of becoming involved in myodysplastic patient management. An orthotist involved with a clinical practice of scoliosis can associate the nature of their spinal practice with the ambulatory myelomeningocele practice that we have developed at SIU School of Medicine. The repetition of clinic visits is very similar to that involved with scoliosis. However, there is an increase of time involvement with the child to make growth adjustments and maintain proper fitting plastic orthoses necessitated by the insensate skin in these children. If a CTLSO is improperly adjusted, it may affect the outcome of the scoliosis treatment, but it will not effect the activities of daily living of the individual. An improperly fitting RGO severely decreases function.

Orthopaedic involvement with the myodysplastic child starts within the child's first few days of life. There is a high incidence of associated scoliosis, kyphosis, hip dysplasia and clubfoot deformities. Therefore, the infant must be continuously monitored. If any of these conditions exist, early orthotic intervention may be used effectively. Maintenance devices such as the Pavlik harnesses, thermoplastic TLSOs, and serial casting for clubfeet have all been used effectively.

When the child reaches nine months of age, plans for ambulation are considered. If a resistant clubfoot exists, it is dealt with by surgical intervention at this time. A one stage Turco¹ procedure is accomplished with post surgical maintenance in an ankle-foot orthosis.² During this time period, if a dysplastic hip is also prevalent, bilateral molded knee orthoses connected with a spreader bar to maintain the hip in abduction and internal rotation are used. Since the ninth month is the milestone period for

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standing in the normal child, use of a parapodium³ is considered. Because of the growth spurts which normally occur during this same time period, consistent monitoring of applied devices is necessary. The ankle-foot orthoses must not impinge on either the calcaneus, navicular or metatarsal heads. Proper knee and hip locations in both the knee orthoses and the parapodium must be checked. Children in these devices should return to the clinic or the orthotist every three months.

Since the development of the reciprocal gait orthoses,^{4,5} children with a thoracic level myelomeningocele are now candidates for ambulation. This is only possible with aggressive orthopaedic and physical therapy management. Full range of motion of the paralyzed extremities and prevention of flexion contractures of the hip, knee, and ankle is necessary if effective use of the reciprocal gait orthosis is expected. If a dislocated hip exists unilaterally, which would impede the function of the orthosis, surgical intervention would be necessary prior to use of the RGO.

Our experience has shown that twenty-four months of cognitive development is the ideal time frame for training of the reciprocal gait orthosis and fitting thereof. Prior to this milestone, communication with the child and the necessity of multiple adjustments to the orthosis limits the effectiveness of the RGO. Once it is determined that a child is a candidate for reciprocal gait ambulation, an extensive physical therapy program is initiated to improve upper extremity strength and increase standing balance.

When the child is initially fitted with an orthosis, it is left in the adjustable state as recommended by the development team at Louisiana State University. Extensive post-fitting physical therapy is necessary. During the first week of physical therapy the orthotist repeatedly checks the device so that optimum orthotic ambulation can be achieved. Subtle adjustments of the cable housing length and hip joint locations can mean a difference between an ambulator and a nonambulator.

After one month's use of the reciprocal gait orthosis, the correct location of the hip joints and cable should become evident. At that time the hip joints and knee joints can be attached on a more permanent basis. Because of the necessity of numerous adjustments on a growing

child, screws instead of rivets are used. High strength Loctite® is used to prevent loosening of the screws.

The child returns to the orthotic clinic one month after permanent attachment of the side bars to the RGO. Subsequent to that visit the child is seen every two months for the first five months. Thereafter return visits are decreased to four times a year.

The physical therapy routine also diminishes as independence in use of assistance devices is decreased. Initially the child is seen on a daily basis for two weeks. Thereafter, a weekly therapy program is established. As the child progresses from parallel bars, to walker, to forearm crutches, it is no longer necessary to maintain a continuing outpatient physical therapy treatment. Parents and teachers have successfully been taught to monitor the fit of the devices and the ambulatory status of the patient. Periodic physical therapy evaluation for gait deviation prevention is all that is necessary.

Growth adjustments and routine maintenance of both the reciprocal gait orthosis and parapodium are accomplished at approximately four month intervals. The use of the pop rivets on the parapodium, make it a relatively easy task to increase the distance between the floor and knee and hip centers. Increases up to one inch between each joint center can be accomplished before the tubular structures of the parapodium must be replaced. Since children are removed from the parapodium at age two, it is only necessary to maintain one size in stock. Because of the presence of static hip and knee joints in the parapodium, the exact alignment of anatomical/mechanical joint centers is not critical for standing. However, if the joint assemblies are extremely malaligned, they will cause impingement during seating.

Because of the relative newness of the program, the first child fitted with the RGO has not had to have a replacement of any major component of the orthosis. However, since we are approaching the twenty-month time period, it appears that future replacement of the plastic sections of the KAFOs will be necessary. A review of the adjustments made for growth indicates that the first length corrections were between the knee centers and the ankles. Subsequent growth adjustments were made between the hips and the knees to improve seating comfort. Seating discomfort seems to be the first indi-

cator of improper positioning of the hip joints.

Maintenance of the devices have included replacement of Velcro® straps because of wear, replacement of the anterior cable due to breakage at the point of connection between the cable and connector to the hip joint, and the replacement of two thrust bearings in one hip joint. One child also has had the metal pelvic band increased in diameter secondary to pelvic growth. Although the metal pelvic band makes the orthosis heavier and cannot be as form-fitted as the thermoplastic pelvic section, it does have allowance for pelvic widening. In cases of pelvic obliquity, lumbar scoliosis, or lumbar kyphosis, a thermoplastic pelvic section is mandatory. There have been no increases in the maintenance of the thermoplastic versus the metal pelvic band. Because of longitudinal growth between the calcaneus and the malleoli, several of the children needed adjustments in the orthosis. This is accomplished by localized heating and expansion of the carbon inserts and the polypropylene material. Care should be taken not to overheat the materials.

Initial assessment of the ambulatory program for thoracic level myelomeningocele children at SIU has been favorable. All parties concerned—the clinic team, the parents, the funding agencies and the children themselves—seem to have accepted the program quite readily. Objective data cannot be determined on such a short range program. Only until such time as multiple years of experience has been gained in several centers will the determination of the cost/benefit ratio prove the worthiness of this program. Subjectively, however, the children seem to be much better off than they would be otherwise.

In our own program, four children with spina bifida are in the pre-parapodium stage (younger than nine months). Seven children are in the preambulatory, parapodium stage of growth development. Two children are awaiting fitting of their orthoses pending authorization from state funding agencies. Eight children have been fitted with the reciprocal gait orthoses with wearing time ranging from twenty months to one month duration. Each of these children are followed on a three-month basis by the clinic team with subsequent visits to the orthotist for

adjustments. No major deformities or pressure sores have developed on the children who are in the program during this time period. Urinary tract infections and stress fractures have been reduced in the patients fitted with the reciprocal gait orthoses, although every child in the program has had at least one long bone stress fracture prior to being fitted with the reciprocal gait orthoses.

In summary, we have shown at SIU School of Medicine that a comprehensive team approach to myelomeningocele should include a program of ambulation for the thoracic level myodysplastic child. With a routine return visit program and follow-up adjustments on the orthotic devices, no major complications have arisen in the system. The use of pop rivets on the parapodiums, and screws for attachment of side bars on the reciprocal gait orthoses, have contributed to the ready availability of adjustments to the devices. Although there are increases in time constraints involved in dealing with this severe level of disability, the program has subjectively proven to all concerned that this present technique for spina bifida management has proven successful.

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