TREATMENT OF SPINA BIFIDA CYSTICA AS USED AT THE QUEEN ELIZABETH HOSPITAL FOR CHILDREN LONDON E2

JANICE BEHR (nee Green)
Dip. Physio. (U.C.T.)

INTRODUCTION

The aim of this article is to present some of our theories and practice in the treatment of children with Spina Bifida. Various different methods are used in other hospitals treating this type of handicap and overlap in many respects. I hope to be of help to the physiotherapist handling these children for the first time.

We are fortunate in our hospital in that the medical and nursing staff, medical social worker, physiotherapist and occupational therapist all work in close co-operation to the best advantage of the child and the family group.

It is very likely that these families will present a disturbed pattern due to the trauma of initial separation of mother and child at birth, plus the added physical defects of the child. This will all naturally affect all members of the family. We find, therefore, that the most important early factor in the treatment of these children is the thorough preparatory care-work provided by our medical social worker to help these parents to accept their handicapped baby. Continued support is provided for these families by the hospital medical social worker so long as the child continues to attend this hospital.

Apart from the obvious physical difficulties presented by these children, factors often overlooked are the associated problems, the major one at an early stage being hydrocephalus with recurrent urinary problems due to the paralyzed bladder. The child requiring frequent hospital admissions because of blocked valves and urinary infection will be delayed in all phases of development at this stage. The gross family problems which may arise due to the uncertainty of the outcome of this condition. The anxiety of the parent will lead to over-protection of the child, which may delay development.

The role of the physiotherapist in treatment is now described:

TREATMENT PROGRAMME

The first stage of treatment covers the newborn baby to the pre-moving phase.

Admission and Initial Referral

The children are admitted to our hospital within a short time of birth from a number of maternity units in North-East London, Essex, Hertfordshire and Kent regions. The reason for this early and urgent admission is the surgical necessity of early closure of the myelomeningocele or meningocele. This requires a paediatric surgeon who specializes in this procedure.

Muscle Charts

The baby is usually referred to the physiotherapy department for initial muscle charting prior to surgery. This is the first muscle chart and often the most difficult to produce accurately due to the following:—

(1) The baby may still be sluggish from birth trauma.
(2) Primary reflex activity will interfere with actual muscle power.
(3) Leg deformities may mask true muscle power, though these do often indicate the presence of muscle activity.

The muscles are charted in basic groups as accurately as possible, care being taken to differentiate, where possible, between reflex activity and actual muscle power. Example: skin stimulation of the plantar surface of the foot may elicit a flexor withdrawal pattern of the leg.

A second muscle chart is completed post-operatively, observing the same procedure as before. Whenever possible a third and final initial in-patient chart is completed between 14 and 28 days, depending upon the degree of hydrocephalus and the time the surgeons select to insert the valve. Once the baby has settled from this procedure, the chart is completed and it appears that this is the most accurate assessment.

TREATMENT OF ASSOCIATED DEFORMITIES

Many of these children present with congenital paralytic deformities which require correction.

Talipes Equino Varus

(1) Robert Jones strapping with passive manipulations. Felt and zinc oxide strapping or Elastoplast alone are used depending upon skin reactions and ease of manipulation.
(2) Modified Robert Jones strapping to below the knee.
(3) Foam-backed Zimmer finger splintage ½ in. to 1 in. width, bent to the required angle and strapped on to the foot to hold the corrected position.
(4) Dennis-Brown bootees on a bar for the older baby and child.
(5) Surgical intervention with the older child.
(6) Minimal deformities are corrected with daily manipulations and passive movements.

Calcaneo Feet Deformities

Corrected by passive stretching, or the third method as above.

Hip and Knee Contractures

(1) Passive movements.
(2) Prone lying for hip flexion contractures.

Dislocated hips will be corrected surgically, depending on the general condition of the child. This is usually performed between the ages of one year and three years.

In some children (pre- or post-operatively) a passive, full range of movement is never obtained.

Spinal Deformities

Scoliosis and lumbar/thoracic kyphosis too may have to be corrected surgically at a later date.

Physiotherapy contact with the parents is established at a suitable stage, this will usually be prior to the first discharge. It is essential that, during these early stages, a constructive and friendly rapport is established with the child's family. Home instruction is normally the only necessary physiotherapy and, if needed, weekly visits for restrapping of foot deformities are arranged. We feel that the minimum instruction should be given at this early stage, and that the parents should be encouraged to visit the department with their child on normal outpatient appointments. Further details of treatment programmes are given when the family next attend, and have become cognisant with the child's special difficulties. It may be necessary to repeat muscle charts throughout these early stages.

From the very first, all disciplines must emphasize to the whole family the necessity of allowing the baby to be as normal as possible and to put him on the floor at the usual time. Foam wedge pillows, etc. are sometimes found help-

ful for the children to lie over, with toys placed on the ground in front. These parents need alerting to the necessity of bringing different experiences to the baby to compensate for its loss of natural movement.

SECOND PHASE OF TREATMENT

Assessment of Movement

Observation by the therapist is made, wherever possible, of the child's ability to move, pivot, sit, crawl and show alertness in personal and social situations.

Comparison with the normal milestones is difficult, for even the child with minimal paralysis may be retarded in his early stages, owing to hospitalization and often over-protection by the family.

If, at 9-12 months it is apparent that further active treatment and help are necessary, then in some cases we have found that further advice to parents has proved adequate, but in some cases it is found necessary to institute regular attendances in the department to stimulate both intellect and movement.

Care must be taken by the therapist in interpreting reports given by the parents of the child's progress at home. Parents cannot be expected to function as trained observers, e.g. misinterpretation of pivoting for a definite backwards or forwards movement of the child. A guide of actual movement for parents to report upon is a six-foot directional crawl in any form. Thus the non-movers will fall into the next treatment group.

Treatment Programme

In this department we feel strongly that these children should establish each stage of development, i.e. floor mobility, pre-walking training, standing, through to calipered walking in sequence.

The occupational therapist is also concerned with the establishment of programmes for intellectual and emotional stimulation, which will run parallel to the movement ones. We feel that the child needs to be encouraged in all disciplines for any one of these to be established successfully. The child who has no interest in play will not have the motivation for moving.

Floor Mobility

(1) *Prone lying* — lifting head and pushing up on arms. Some children with hydrocephalic heads have difficulty with this movement. A larger wedge may be used to elicit the above response. We have had the occasional child who starts to move principally to remove himself from the wedge!

(2) Rolling to sitting from supine through side flexion is taught but the child with a high paralytic lesion may be unable to achieve this movement. Rolling may be unobtainable for the same reason until the child is older.

(3) *Independent sitting* is delayed and is at first achieved with a forward lean and until the child can balance his own body weight, he cannot achieve a good sitting position. Falling play in this position is important for the child to gain self confidence in independent sitting.

(4) *Mermaid crawl:* We teach the child to pull on his forearms in prone to stimulate forward movement on the floor, but first the idea of head lifting in prone must be acquired. This activity will take time to achieve, especially with the poorly motivated child. Parents should be encouraged to give the child plenty of opportunity to practise this at home — a shiny surface, such as lino, should be used at first and all forms of play incorporated. Some children do not manage the mermaid crawl and develop a "bottom shuffle" in the sitting position. Any movement in any form is a great achievement, especially with the slow starters.

(5) *Spina Bifida Trolleys:* This gives the child an idea of speed of movement and a means of joining in play with other children. A trolley is a means of reducing frustration in the irritable child. Some children will not yet be moving on the floor, although mobile in the trolley, and this may lead to the "trollev bound" child which is not a desired result.

Pre-Walking Training

(1) The child is taught falling from standing in all directions. This will overcome his fear of falling from this strange and high position of standing. There are many games and much fun from this form of exercise.

(2) The back extensors are strengthened with specific exercises in the standing position, incorporating the aims of the above. Both this and above activities will need to be carried out with support from the therapist to the child to maintain knee extension and a standing balance.

(3) When the child can move on the floor — our minimum of six feet — Queen Elizabeth Hospital standing splints are fitted. These should be worn as much as possible during the day, as with calipers, and play in the upright position can now be more easily supervised by the parent. At this stage it is not felt that a pelvic band for the additional support will be needed but, at the time of writing, these splints are on trial and are proving very successful. It is helpful to suggest to the parents that play surfaces, e.g. sandpits, water-play, etc., be on a level with the child's best standing position.

(4) For arm strengthening and development of a down thrust the children play various games. One that we find most helpful is "pushing off" from various objects placed on either side of the child in a sitting position. This will lead to the required action for crutch walking. Secondly, this same action is used in the forward, lean-standing position in some falling games. Thirdly, throughout all phases the parent and therapist support the child's arms with extended elbows and a palmar grasp to enable the child to thrust down when walking.

Calipers and Walking

Throughout our series and from experience with many Spina Bifidas treated at this hospital, we have found that a child is not ready for walking training until he has achieved a good form of floor mobility and has overcome the fear of falling and must show the desire to walk as well as being mature enough to concentrate. This stage may not be reached until the child is nearly four years old. When the child is ready, we start walking-training in standing splints while awaiting the supply of calipers. We prefer not to use hip locks on full calipers to allow more freedom and security in falling.

The child with frequent admissions to hospital and the added difficulty of over-protection from disturbed parents, will invariably be late in all developmental stages and may not be ready for walking training at the arbitrary age of three. Each case must be considered on its own merits, but we do not push walking before this age. Most of these children require time to achieve a walking pattern and have a limited concentration span for such a difficult task. In our survey group we have found that the older children who, for various reasons, could not be calipered until 4½-5, have all been able to walk within a couple of months on quadripod sticks.

In the early stages either a swing through or a reciprocal gait is taught so that the child can appreciate and enjoy movement in the vertical position. A swing through gait may lead to the realization of a reciprocal gait. The older child or adult usually reverts to a swing through gait for speed when using crutches.

Walking Aids

Rollators and quadripod sticks are used as walking aids in conjunction with parallel bars, in the initial stages of training, progressing later to crutches.

Rollators have the advantage of moveable wheels which allow the child to appreciate movement. We find the square framed rollator the preferable model, as the child is able to place his arms in the correct position later needed for crutch gaits.

PHYSIOTHERAPY ASSOCIATED WITH ORTHOPAEDIC MANAGEMENT

Reduction of Dislocated Hips

Modified tummy trolleys have been used most successfully while the child is in a uni- or bilateral plaster hip spica. This maintains mobility while in plaster and helps to have a happier child. A wide rear end on the trolley is necessary to accommodate the abducted position of the legs.

When the plaster is removed, the child is admitted to hospital for mobilisation — approximately two weeks. Great caution must be exercised at this stage because fractures, due to osteoporosis, are likely to occur with the slightest stress. The children are at present put into standing splints following removal of plaster. These help to prevent fractures by maintaining a straight leg. The lower end of the femur fractures when the child pushes up in prone and a fracture may occur at the lower end of the plate in the femur when the child rolls, leaving part of the leg to one side. It is hoped that the standing splint will be a help in reducing the fracture risk, as already the number of post-surgery mobilisation fractures has dropped since these were first applied after the removal of plaster. The mobilisation programme is carried out with these splints, which are worn continually except for short periods, a few days after removal of plaster when knee flexion is required.

1. Passive movements are found to be unnecessary and may be traumatic. The child will manage the majority of his mobilization with positioning by the therapist and from instruction to the nursing staff and parents.
2. A programme of graduated sitting is commenced to flex the hips until approximately 90° is reached. Until this stage, the child is limited to bed — usually two days. (Discretion must be used with the child who sits on his lumbar spine and does not require the same degree of flexion to obtain a good sitting position.)
3. When the child has achieved this required sitting position, he will be allowed up in his standard trolley and to sit at the table to play. While in this chair sitting position splints are removed and, with the thigh fully supported, gravity will act as an aid to knee flexion. The upper leg must be supported to the knee when the knee is flexed. Fractures have occurred when a child has slid forward and the femur protruded over the edge of the chair. Feet must be adequately supported. At all times care must be taken in handling the limbs of the child when lifting, carrying and moving in bed.
4. After ten days the child recommences standing with support and floor mobility in creeping and sitting, graduating stresses and strains to continue programme as above.

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SUMMARY

In this paper we have shown how, in our hospital, Queen Elizabeth Hospital for Children, London, E.2, we treat spina bifida cystica during the neonatal, pre-walking mobilization and early walking calipered life. The aims of the whole treatment team — doctor, therapists and medical social worker — being to help the total family unit with the management of this child.

Our hope is that, by the time the child reaches five, he will only require minimal supervisory physiotherapy and be able to concentrate on his school activities.

Mrs. Behr, who trained at the Physiotherapy School, University of Cape Town, spent several years at the Queen Elizabeth Hospital for Children, London, E.2. She recently returned to Cape Town, South Africa.

OCCUPATIONAL THERAPY FOR THE SPINA BIFIDA CHILD

R. BARNITT

Occupational Therapist
Queen Elizabeth Hospital for Children, London, E.2

There are four areas in which the occupational therapist should combine with the physiotherapist to provide a co-ordinated programme for the Spina Bifida child.

(1) Activities to encourage or distract the spina bifida child during his specific physiotherapy treatment. This may take the form of using a teddy bear or a doll to do exercises at the same time, or providing music to which group exercises are performed. Many variations can be provided if some imagination is used.

(2) When the baby first comes to the department the mother will often ask for advice on handling and play. The suggestions given are directed to promoting maturity of eye/hand skills and increasing the range of stimulation that is provided in the home. The parents are advised to place toys and visually stimulating objects within the baby's focal range, and to encourage eye following; to interest the child in his hands by attaching bell bracelets, to provide as much tactile stimulation as possible by carrying the child around the house and garden touching things. When the child is old enough to sit, a soft foam floor chair may be made and bags of textured material, blocks and other toys suitable to the age, placed on the floor near the child. From a year onwards great emphasis is placed on handling different materials and messy play as these children will not be prepared for saving, propping and pushing until they have experienced the relevant preparatory play.

(3) With the older nursery age children group situations are provided. Many of these children will have little opportunity for mixing with other children of this age, and an ability to socialize will make the start of school easier. In these groups a common type of play is provided such as pretend cooking or painting. The children encourage each other and the physiotherapist will be able to use the group for standing practice and as an incentive for play after treatment.

(4) Some spina bifida children have perceptual difficulties; the most common that we have found is a faulty body image. To prevent this the parents are encouraged to play with the child from an early age, games of touching and naming parts of the body, especially the lower limbs. Later activities can include mirror painting, dressing dolls and cardboard cut-out figures.