

The management of the limb deficient child and its family

Y. SETOGUCHI

Child Amputee Prosthetics Project, Shriners Hospital, Los Angeles, USA.

Abstract

A properly constituted clinic team needs to be involved as soon as possible after the birth of a child with a limb deficiency, to answer the parents' questions, counsel them and the family, and plan the treatment programme for the child so that they can properly assist the child to become a productive, self-sufficient member of society.

The management of the limb deficient child

The birth of a child with congenital anomalies is a traumatic event for parents who have been expecting a normal child. This is compounded when the physical defect is visible such as in the case of a limb deficiency. The obstetrician or paediatrician is often unprepared and the parents and other immediate family members need to be seen as soon as possible to begin the treatment programme. It is this philosophy that physicians like Ernst Marquardt and Milo B. Brooks, emphasised in their concepts of the management of the limb deficient child. They felt that it was not just the physical treatment of the child but the positive bonding of the parents to their child that ultimately led to a healthy, productive member of our society, instead of a "handicapped" person.

The team approach, the involvement of a multi-disciplinary group of professionals focusing on all aspects of the child's needs, was advocated by Marquardt, Brooks and others. The team's emphasis was on the needs of the whole child and his family. The child's medical, genetic, and sometimes surgical needs are all important in the treatment programme as are the prosthetic and therapy requirements. It is most important to co-ordinate all of the above

All correspondence to be addressed to Dr. Y. Setoguchi, Medical Director, Child Amputee Prosthetics Project, Shriners Hospital for Crippled Children, 3160 Geneva Street, Los Angeles, CA 90020 - 1199, USA.

treatment modalities with evaluation and treatment of the psychosocial needs of the patient and his/her family. The team's responsibility is to ensure that all aspects of the child are assessed and appropriate therapy provided.

No parents imagine that their baby will be born with a defect. Therefore, regardless of the severity of the problem, all parents experience shock at the birth of the limb deficient child. They may experience other emotional stresses, such as sadness, anger, embarrassment, guilt, feelings of isolation, feelings of failure as parents, denial and unhappiness. How the parents are helped to accept that these are normal reactions and to resolve these feelings can make a great difference in their response to the child's limb deficiency. The longer the parents are left to experience their feelings without appropriate resolution, the more likely they will develop unhealthy attitudes and reactions. This in turn can have very harmful effects on the parent/child bonding.

The initial evaluation should be made as soon as possible. In fact, the first consultation is often in the newborn nursery. The parents need to have their questions answered as soon as possible and to be given a chance to vent their feelings. If a visit to the hospital by the clinic team, usually physician and social worker, is not possible or necessary, then a clinic appointment is scheduled as soon as possible. As soon as a referral is made, the clinic social worker contacts the family to inform them of the functions and procedures of the clinic. Questions regarding the initial evaluation, as well as the financial aspect of the treatment programme are answered.

A booklet entitled "The Child with a Limb Deficiency: A Guide for Parents" is sent to the family. The subjects covered in this short and concise pamphlet include: the problem at birth;

fears about the future; reactions of others; self-acceptance; your child's questions; school and potential concerns; adolescence; and vocational considerations. It is not intended to cover all of the subjects thoroughly but to answer many of the questions that the new parents may have. The booklet also helps the family prepare for the first appointment and raises other questions that the team will need to address. The acceptance of the "physical difference" and the family's ability to deal with the limb deficiency (ies) is critical to the child's future treatment efforts.

The first visit is a very important part of the treatment programme. The parents have many questions that need to be clarified. It is important that the team address these issues in a simple, clear manner. The first question usually is "What caused this to happen?" Often the parents are looking for someone to blame, other than themselves. They wonder about medicines they may have taken, chemicals or environment substances they may have been exposed to, and in one group, the effects of exposure of the mother to lunar or solar eclipses. They wonder whether the child has other abnormalities. Of particular concern to the family is whether the child will be of normal intelligence.

From a functional standpoint, the parents are concerned whether the child will be able to perform self-care activities and be able to compete effectively in school and later in vocational endeavours.

The initial consultation should be done by a multidisciplinary team familiar with the needs and treatment of children with limb deficiency. The usual team consists of a paediatrician, (usually the team leader), orthopaedic surgeon, physiatrist, medical social worker, occupational therapist, physical therapist, prosthetist, geneticist, and rehabilitation engineer. Not all of these individuals are involved in the clinic assessment at each visit, but are needed to maintain the maximum and most up to date treatment programme for the limb deficient child.

The assessment should include not only the child's medical history and a thorough physical examination, but also the psychosocial status of the parents including the family's financial and emotional ability to support a treatment programme. A careful and complete

explanation of the various prosthetic fittings and components available must be given. They should also be given information about how the child would function if no prosthesis is fitted. It should be emphasised that therapy is available to allow the child to become as independent as possible with and without prosthetic fitting. Some children with limb deficiencies are more functional using the residual limbs or their feet than they can be with prostheses. The acceptance of the prosthesis by the child and family depends on their understanding of its purpose and function as well as their approval of the ultimate fitting.

A complete history and physical examination of the patient is essential. Today, a number of syndromes, some with genetic or hereditary implications are recognised and these must be identified. At times a genetic consultation is important. This is especially true when multiple anomalies, are noted. Although this article is not intended to be specific, two conditions need to be mentioned. Radial deficiencies, both unilateral and bilateral and tibial absence are known to have hereditary implications and so patients with these conditions need to be referred to a geneticist. Other medical problems associated with limb deficiencies include craniofacial anomalies; musculoskeletal anomalies; cardiac and haematopoietic disorders.

Questions frequently asked about treatment include either transplantation or reconstruction of a limb. The ultimate hope of any parent is to be able to provide a "normal" arm or leg for their child. Even in a prosthetic device many parents are seeking a normal "flesh and blood" extremity. These concerns must be addressed by the team and correct and truthful answers must be provided.

The assessment of the "total" child is an absolute necessity in providing the best rehabilitation, including prosthetic treatment for the limb deficient child who is the "core" or central figure in the treatment programme. Initially treatment decisions are made by the parents, but as soon as the child is mature enough to participate in the decision making process he should be allowed to do so, and be actively involved in any decision regarding prosthetic fitting, therapy and other treatment programmes.

The parents are the first to learn about the

birth defect(s). How they cope with this initial shock will have a great deal to do with their abilities to raise their child with a healthy attitude about its self-image and esteem. The team must allow the parents to express their feelings and to develop positive approaches to manage the child's needs as he/she grows. The parents need to know that they are not the only ones with a child with limb deficiencies. Introduction to other families or to support groups is very helpful.

Concern should not be limited only to the immediate family. There are many family members who take part in the child's care and, therefore, need to be involved in the evaluation and subsequent treatment programme. Siblings are often the neglected members of the family. The patient initially requires considerable time and effort from the parents, and other siblings, especially the next older child are affected. Until the patient was born the older sibling was the "baby" of the family and had the attention of the parents. A normal newborn baby requires considerable parental attention but a child with a birth defect demands more. The older child therefore feels left out and may even feel that he or she was to blame for the birth defect. The team's attention to the older sibling and his inclusion in the treatment programme often will provide a valuable ally for the patient in later years.

Relatives too are important in the evaluation process. They may not actually participate in the decision making but their understanding of the rationale and reasons for treatment, such as prosthetic fitting will help ease the child's progress. Members of the family we sometimes call the SOG or "silly old grandparents" are very influential and it is extremely important to include them in the orientation and subsequent treatment planning.

The treatment programme for the limb deficient child must be "home centred". Except for surgery, treatment should be as far as possible on an outpatient basis. Prosthetic fitting and subsequent training in the use of the device need not require hospitalisation. In fact, there are three good reasons why hospitalisation should be avoided. The first is that hospitalisation implies the patient has an illness which requires medical attention in a hospital setting with the attendant hospital gowns, frequent measurement of vital signs,

blood tests, nurses, etc. Our patients are not "sick". Secondly, they are being provided with an artificial limb, followed by therapy. This can be done as an "out-patient". Patients/family coming from a distance can be housed in guest rooms, friend's/relative's homes or motels. The use of outside housing usually means the costs are much less, except that often insurance and governmental agencies will not cover non-hospital expenses. The third and most important reason for out-patient treatment is that carry-over of the treatment programme can be accomplished better. Out-patient prosthetic fitting and treatment requires one or both parents or carers to bring the child to the clinic. They can be included in the fabrication and therapy process and have a better appreciation of the abilities of their child relative to the prosthetic programme. They are then better prepared to encourage the child to use the prosthesis in the home situation. They can explain the functions of the prosthesis and its benefits to other family members, neighbours and school personnel.

In order that the treatment programme be a comprehensive one for the limb deficient child, a co-ordinated effort is required to involve the local physician, local treatment (O.T., P.T., prosthetics) agencies, school, friends, and community programmes such as clubs, churches and employment.

One of the most critical issues in the treatment programme especially in the USA where we do not have some type of socialised medicine or catastrophic health insurance, is the family's abilities to afford the costs of medical care for the limb deficient child.

The cost of prostheses in the past 10 years has increased a great deal because of the number of "high technology" prosthetic devices now available.

In the USA the cost of medical care (including physician, therapists and social worker's fees, x-rays, surgeries and prosthetic costs) are covered in one of four ways. If the family has sufficient resources, they may manage all costs themselves. However, this is rare. Approximately 20-40% of our patients have private insurance (either standard health insurances with deductible payment by the insuree or Health Maintenance Organisations through contracted groups). Government assistance programmes such as Medi-Care

(Medi-Cal in California) and Crippled Children's Services (a programme established by the Federal Government in the 1930's to assist families with orthopaedically and/or physically handicapped children with contributions towards the cost of medical care from the county, state and federal agencies), will provide funds for families who qualify financially (earnings under \$40,000/year) and whose child has a medically eligible condition. The final method of payment for treatment comes from private philanthropic groups such as City of Hope, Shriners Hospital for Crippled Children and Variety Clubs.

The problems with all of these funding programmes is that there is little consistency in the assistance to the families. Factors such as: pre-existing condition, i.e. the condition existed before insurance coverage started; extent and type of coverage, frequency of payment for durable goods are so different that families are never sure that financial coverage of care is available. Even with the same insurance companies, the actual coverage for prosthetic care varies. In some cases externally powered prostheses, and the more expensive lower limb "hi-tech" devices such as Endolite and S-N-S systems are covered for some, but for other families are refused. In cases of infants, some companies only pay for the first prosthesis and not for subsequent replacement even though replacement is necessary due to normal physical growth. Finally, the cost of prostheses, especially the more expensive ones, varies as

much as \$2,000, depending on the location in US and even among shops in the same area.

Therefore in prescribing prostheses the clinic must not only concern itself with the medical condition and the needs of the patient, but also whether the cost of the system or components can be paid for by the family or its third party payer. Often this decision is not up to the clinic but to the payer of the prosthetic or rehabilitation programme.

A major concern in most clinics in the US is who should make the final decision regarding prosthetic prescription. In countries such as the UK, Germany and Japan, the clinic team decides, based on criteria developed by the team. In the US, the family through its insurance or payer can often dictate prosthetic treatment even if the team is *not* convinced that the treatment programme is the best. Hopefully we can come to some objective criteria that will apply to all patients regardless of their financial status.

Summary

The team approach is considered the optimal to the care of the limb deficient child. A co-ordinated programme utilising the expertise of experienced personnel and taking into consideration the developmental needs of the child will allow the child to grow and function as normally as possible. The goal of the team is to assist the patient to become a productive, self-sufficient member of society.