The Acceptance and Rejection of Prostheses by Children With Multiple Congenital Limb Deformities

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CHILDREN with severe multiple congenital limb deformities associated with thalidomide are numerically few (*22,48*). Because of the severity of this disability, the associated deformities, and the psychological trauma to both parents and child, the thalidomide tragedy has served as a catalyst to study the congenital amputee in depth. There is still controversy concerning the appropriate prosthetic and rehabilitation program for these children, but the attention this tragedy has focused on other less-involved children perhaps will reap benefits far beyond our expectations *(1,13,18,23,26,36,39,42).*

The possible factors associated with acceptance or rejection of appliances may be inherent in the appliance, or they may arise from the child's own frustration, the parental reaction *(15,20,43),* or other environmental factors. Retrospective studies of children who attend the Nuffield Orthopaedic Centre for prosthetic management and a review of the relevant literature have been carried out in an effort to establish a pattern of management and to delineate topics for future research.

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SCOPE OF THE STUDY

During the past four years, 50 children with congenital amputations and limb deformities have attended the Disabled Living Research Unit at the Nuffield Orthopaedic Centre. Approximately half were deemed not to need prostheses or appliances at this time.

This article reviews 21 children with multiple congenital limb deformities who have been under continuous care for prosthetic management and general rehabilitation for four years. All the deformities were presumed to be due to thalidomide, and the lesions were characteristically bilateral (Table 1). Thirteen of the children have been fitted with upper-limb prostheses only, four with lower-limb appliances only, and four with both upper- and lower-limb appliances (Table 2). Henkel's classification *(21)* was used; other classifications are used in various parts of the world *(4,10,16,30,47,51).*

Each child has been fitted with appliances on more than one occasion. In considering acceptance or rejection of prostheses, attention has been focused on the type of prosthesis provided rather than actual numbers. A satisfactory design may well be repeated in different sizes or, after rejection of

TABLE 1. CLINICAL LESIONS OF CHILDREN IN SURVEY

Upper limbs only involved	
Amelia	3
Short dysmelia	4
Long dysmelia	7
Total	14
Lower limbs only involved	
Short dysmelia	2
Upper and lower limbs involved:	
Upper amelia; lower, short dysmelia	1
Short dysmelia of all four limbs	3
Upper short dysmelia with lower amelia	1
Total	5

TABLE 2. APPLIANCES FITTED

Appliances Fitted	No. of Children	No. of Different Stages of Prosthetic Management
Conventional upper-limb prostheses only	3	3
Powered upper-limb prostheses only	2	8
Conventional and powered upper-limb prostheses	8	30
Lower-limb prostheses only	4	10
Upper- and lower-limb prostheses	4	19
	Total 21	Total 70

one type, a different pattern may be tried. On average, each child has passed through three stages of prosthetic management, but the number of prostheses made and supplied is in considerable excess of this (Table 2). The classification of type of prosthesis fitted is given in Table 3.

Some children had only conventional prostheses, and others only powered upper-limb appliances. The majority, however, started with conventional appliances and then "graduated" to the powered ones.

CRITERIA FOR PROSTHETIC MANAGEMENT

UPPER-LIMB APPLIANCES

The fitting of upper-limb prostheses at the Disabled Living Research Unit was governed by various factors. In the early stages, the demands of the parents and the availability of materials and appliances were the most dominant factors. As this was a disability incurred by a man-made drug, the parents felt that they had the right to have the best treatment available. For the first year or so the Unit was dependent upon the availability of material and parts from within the United Kingdom, those imported from Germany, or what could be made locally.

When the children's rudimentary arms were long enough to grasp objects bilaterally, to reach the mouth, and to be within the child's vision, then an appliance was not considered appropriate *(22)*. But when both arms were absent, or the rudimentary arms were so short that they could not achieve the basic function of feeding, artificial arms were fitted. However, these children were also deliberately encouraged to use their feet to enable them to acquire sensory perception of texture, temperature, etc., as well as dexterity in movement and achievement of toilet management *(31)*.

The fitting of the upper-limb appliances attempted to follow the normal behavioral patterns. A cosmetic appliance fitted during the first few months of life helped them to get used to wearing such appliances and learn sitting balance.

TABLE 3. CLASSIFICATION OF ARTIFICIAL LIMBS FITTED

Conventional Upper Limbs

- C.1. Conventional cosmetic upper limb
- C.2. Conventional upper limb with cable-operated hook
- C.3. Conventional upper limb with cable-operated hook and elbow flexion

Powered Upper Limbs

- P.1. Simple "pat-a-cake"
- P.2. Gas-powered hook and single-acting wrist unit
- P.3. As P.2. but with added cable elbow flexion
- P.4. Oxford Metal Jacket, double-acting wrist unit, and powered hook
- P.5. As P.4. but with Otto Bock hand instead of hook

Lower-Limb Appliances

- L.1. Caliper-type with rocker foot pieces
- L.2. Caliper-type with ski foot pieces
- L.3. Caliper-type with shoes
- L.4. Swivel walkers

Fig. 1. The first powered upper-limb appliances known as "pat-a-cakes" were fitted at the age of about one year. These are no longer issued.

Fig. 2. Child with bilateral amelia who was issued an appliance giving powered prehension and wrist rotation with passive elbow and shoulder movements.

In order to give the child some form of bilateral grasp, "pat-a-cake" appliances were fitted when the child was approximately one year old. These were the first type of appliances to be powered by compressed carbon dioxide, and were actuated bv body movement (Fig. 1).

The next stage was the introduction of wrist rotation and externally powered hooks or hands, fitted as the materials became available and the needs of the child demanded (Fig. *2)(34).*

LOWER-LIMB APPLIANCES

A child's development is directly dependent on the vertical positioning of spine. Sitting,

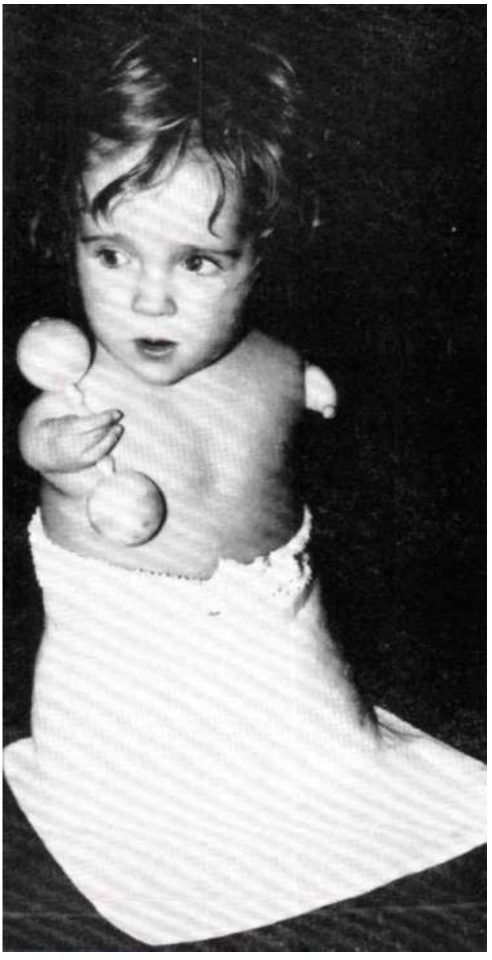

Fig. 3. Child with lower-extremity amelias placed in a "flower-pot" at the normal age of sitting.

standing, and walking at the normal age are important for the child's normal development. Therefore, it is important that babies with amelia or short dysmelia of the lower extremity sit up at the normal age of sitting; that is, at the age of six months in a "flowerpot" (Fig. 3), and at about one year they should be given some form of legs for mobility (Fig. 4) *(22).*

The type and height of the lower-limb appliances issued to the children depended on the degree of competence and confidence in balance (Fig. 5). The children were supplied appliances with "shoes" as soon as was practicable; in any case, before they commenced formal schooling.

Fig. 4. Some form of mobility should be provided during the child's second year.

Fig. 5. The type and height of a lower-limb appliance depend upon the child's competence and balance. Whenever possible, the height should be kept within the lower limits of normal growth.

Coping with appliances for all four limbs imposes a considerable physical and intellectual strain on small children. The physical maneuvers necessary to walk with bilateral lower-limb appliances are often considerably restricted by the presence of upper-limb appliances. The children's activities and needs should be balanced and the training program phased to allow the children to obtain practice with both sets of appliances separately and together. For some children, upper-limb appliances are an aid to balance, whereas for others these appliances are an impediment.

METHOD

The children and parents were interviewed, schools were visited, and all available records and reports were reviewed. These records include functional activities of daily living, simple objective tests of skill, and school reports. The extent of the activities covered included those featured in other simple follow-up studies *(32).* All children were seen by a clinical psychologist.

In the analysis, notation was made of:

1. The children's preferences.
2. The parents' preferences.
3. The amount of cooperation from the child.
4. The amount of cooperation from the parent.
5. The amount of cooperation from the school and teachers.

Concerning mechanical aspects, comments were recorded concerning:

1. The weight of the appliance.
2. Delay in supply of the appliance.
3. Delay in supply of spare parts.
4. Speed of response of the appliance.
5. Limitation of reach.
6. Limitation of other movements.

Physical reactions noted included heavy perspiration (associated with the weight of the appliance), skin rashes, soreness from the harness, and restriction of the child's body movement.

DEFINITIONS

APPLIANCES

The appliances have been grouped into: conventional upper limbs; powered upper limbs; lower limbs; and then classified according to their functional features (Tables 2 and 3).

ACCEPTANCE AND REJECTION

"Acceptance" of prostheses by children is often more passive than active. "Acceptance" of an appliance in this study means that the child uses the appliance for most of the day for various activities; for example, feeding, writing, or playing. "Acceptance" in this context does not necessarily indicate that the child prefers the appliance to his own limbs. Almost invariably, the children prefer to use their own body and residual limbs for most manipulative activities.

"Total rejection" implies complete refusal to wear the appliance. Some children have to be persuaded to wear the appliances even for short periods each day, but will do so with encouragement; this usually means periods of half an hour. This condition is termed "partial rejection"; it could equally well be termed "partial acceptance."

RESULTS

ACCEPTANCE AND REJECTION OF CONVENTIONAL UPPER-LIMB APPLIANCES

Undoubtedly, conventional appliances for this group of children have a poor record of acceptance. Of those fitted before the age of two years, 14 children fitted with 14 bilateral appliances rejected the appliances on nine occasions (64 per cent), whereas acceptance was recorded in five cases (36 per cent) (Table 4). But it is difficult to assess correctly whether a child of this age has accepted or rejected an appliance, as the observer's judgment is likely to be very subjective.

It was noted, however, that after the age of two years conventional appliances were totally rejected.

TABLE 4. ACCEPTANCE AND REJECTION OF 14 CONVENTIONAL UPPER LIMBS ON 14 CHILDREN

Type	Age Range (years)	Accepted	Rejected		Totals
			Partial	*Total*	
C.1.	1–2	5	4	3	12
C.2.	2–3	0	0	1	1
C.3.	3–4	0	0	1	1
		5 (36%)	4 (28%)	5 (36%)	14 (100%)

TABLE 5. ACCEPTANCE AND REJECTION OF 39 POWERED UPPER-LIMB PROSTHESES ON 13 CHILDREN

Type	Age Range (years)	Accepted	Rejected		Totals
			Partial	*Total*	
P.1.	1–2	1	1	2	4
P.2.	2–3	3	5	3	11
P.3.	3–4	2	4	2	8
P.4.	4–5	2	7	0	9
P.5.	5½	4	3	0	7
		12 (31%)	20 (50%)	7 (18%)	39 (100%)

ACCEPTANCE AND REJECTION OF POWERED UPPER LIMBS

Thirty-nine powered upper-limb appliances were fitted on 13 children, and were rejected on 27 occasions.

The acceptance of the powered upper-limb appliances in this series is 25 per cent in children under four years of age and 38 per cent in those over four years (Table 5). Acceptance increased considerably when the powered hand was introduced.

However, partial rejection (or partial acceptance) occurs for 50 per cent of appliances, and total rejection of powered appliances has not occurred in children over four years of age.

ACCEPTANCE AND REJECTION OF LOWER-LIMB APPLIANCES

Seventeen lower-limb prosthetic appliances have been fitted on eight children; 13 of these were accepted, one partially rejected, and only three totally rejected. Ultimately, *all* lower-extremity prostheses were accepted.

One child rejected appliances during her second year, because any type of appliance restricted her mobility and she was able to progress well by crawling. One child rejected, when, at the age of five years, he was fitted with appliances and he found them cumbersome and restrictive. This child has now accepted caliper appliances. Another child preferred the ski-type of appliance rather than those with shoes, because the latter kept on breaking and she had little confidence in them.

Fig. 6. Swivel walkers are a distinct improvement over previous lower-limb appliances.

The swivel walkers were made according to the design principles described by Motloch and Elliott (33) (Fig. 6).

None of the swivel walkers fitted has been rejected. They arc a distinct improvement over any previous appliance. The full details are given in Table 6.

ACCEPTANCE AND REJECTION OP APPLIANCES ACCORDING TO AGE

Acceptance and partial acceptance are clearly related to increasing age (Tables 7 and 8).

TABLE 6. ACCEPTANCE AND REJECTION OF LOWER-LIMB APPLIANCES

Type	Age Range (years)	Accepted	Rejected		Totals
			Partial	*Total*	
L.1.	1–2	1	0	1	2
L.2.	3–4	5	0	1	6
L.3.	4–5	4	1	1	6
L.4.	5–6	3	0	0	3
		13 (76%)	1 (6%)	3 (18%)	17 (100%)

TABLE 7. ACCEPTANCE AND REJECTION OF ALL UPPER-LIMB APPLIANCES ACCORDING TO AGE

Age Range (years)	Accepted	Rejected		Totals
		Partial	*Total*	
1–2	6	5	5	16
2–3	3	5	4	12
3–4	2	4	3	9
4–5	2	7	0	9
5–6	4	3	0	7
	17 (32%)	24 (45%)	12 (23%)	53 (100%)

TABLE 8. ACCEPTANCE AND REJECTION OF ALL LOWER-LIMB APPLIANCES ACCORDING TO AGE

Age Range (years)	Accepted	Rejected		Totals
		Partial	*Total*	
1–2	1	0	1	2
2–3	1	0	0	1
3–4	5	0	0	5
4–5	3	0	2	5
5–6	2	1	0	3
6–7	1	0	0	1
	13 (77%)	1 (6%)	3 (17%)	17 (100%)

MAJOR REASONS FOR REJECTION OF UPPER-LIMB APPLIANCES

There were many recorded reasons for rejection or partial rejection, and for each child there were usually several contributory reasons.

When these were grouped together and all the different appliances were considered, it was found that the commonest cause for rejection was the mechanical inefficiency of the prostheses (76 per cent); the next most common cause of rejection was the child's preference for using his or her own residual limbs. In a relatively few cases, the lack of cooperation of parents or child was a major reason for rejection (Table 9).

CHANGE FROM REJECTION TO ACCEPTANCE

It is even more interesting to analyze the major factors that lead from a rejection to an acceptance (Table 10).

FAMILY ENVIRONMENT

The problem of parental cooperation is partly reflected in the families' general environmental background. Although the numbers are small, the review indicates that the better-educated, middle-class families are more likely to help their children accept appliances (Table 11).

TABLE 9. MAJOR REASONS FOR REJECTION OF UPPER-LIMB PROSTHESES*

Prosthesis inefficient for various reasons	38 (72%)
Child prefers own limbs	22 (41%)
Parents uncooperative	9 (53%)
Child uncooperative	7 (41%)

* This table refers to all rejections for all the children of all the appliances supplied; that is, it refers to 17 children, 17 parents, and 53 appliances.

TABLE 10. MAJOR REASONS FOR CHANGE FROM REJECTION TO ACCEPTANCE OF UPPER-LIMB PROSTHESES*

Hand fitted instead of hook	4
Parental cooperation improved	4
Increased understanding with increasing age	3
Increased function available from appliance	2
Hook fitted instead of hand	1
School cooperation particularly improved	1

* This table refers to seven children and 28 appliances.

TABLE 11. ACCEPTANCE AND REJECTION OF THE CURRENT POWERED UPPER-LIMB PROSTHESES BY 17 CHILDREN ACCORDING TO FAMILY BACKGROUND

Background	Acceptance	Rejection		Totals
		Partial	*Total*	
Middle class—urban	3	2	1	6
Working class—urban	0	2	3	5
Working class—rural	2	1	1	4
Adopted	0	2	0	2
	5 (29%)	7 (42%)	5 (29%)	17 (100%)

CLINICAL PSYCHOLOGISTS' ASSESSMENT

All the children in this series were of at least average intelligence, with three being distinctly above average. Two children of average intelligence developed aggressive tendencies and for a period would use their artificial arms almost entirely as weapons. Their aggression finally diminished after starting at normal primary schools.

Psychological testing was unable to delineate specific features helpful in predicting acceptance or rejection of appliances. Perhaps if the testing had been more comprehensive and more frequent, trends might have been exposed. However, the simple clinical psychological appraisal reflected the acknowledged situation rather than helping to elucidate the underlying motivation toward acceptance or rejection of prostheses (7).

SCHOOL

In this series, 13 children attended normal state schools, five attended day schools for the physically handicapped, and two were at residential schools for the physically disabled. One child was undergoing orthopaedic treatment during the period covered by this survey. From this small series, acceptance for upper-limb appliances was higher for children attending normal state schools than for children at special schools for the physically handicapped (Table 12).

DISCUSSION

The birth of a child with a congenital limb deformity is a domestic crisis and the parents need urgent help and advice on the total management of the child. The crisis intervention *(2)* is a critical function of the management team, but the personal approach and careful handling are also essential (5).

That there should be complex factors interacting to produce acceptance or rejection of the appliances is understandable. Goldner and Titus *(14)* noted that they have been uniformly unsuccessful in the upper-extremity amelia and phocomelia, particularly when the condition occurred bilaterally. It was only when external power was added that they were able to make significant progress. This experience has been true of other authors *(5,19,27,36,44)*.

The outstanding findings in this study are that therapists, parents, and children partake in a mutual learning process, and very close cooperation between all concerned is essential for good rehabilitation *(29,37)*. Brooks *(2)* emphasizes the importance of recognizing

TABLE 12. ACCEPTANCE AND REJECTION OF PROSTHESES RELATED TO TYPE OF SCHOOL*

Type of School	Acceptance	Rejection		Totals
		Partial	*Total*	
Normal state schools				
Upper-limb appliances	6	3	3	12
Lower-limb appliances	2	0	0	2
				14
Schools for physically handicapped				
Upper-limb appliances	0	4	1	5
Lower-limb appliances	5	0	0	5
				10

* This table is based upon an analysis of 20 children wearing 24 appliances, as follows: 11 children with bilateral upper-limb appliances, four children with bilateral lower-limb appliances, four children with bilateral upper-limb and lower-limb appliances, and one child with bilateral upper-limb appliances who was also deaf.

situations which are known to produce adverse reaction and aptly refers to this as "crisis intervention." Each stage of the child's development must be watched *(12,40),* and the value of the appliances should be frequently reassessed.

Many children have deformities which at first do not seem to need surgical or prosthetic intervention. However, as the child develops, function and environmental features change, and there is a need for continuity of supervision and repeated clinical and functional reappraisal. The need for aids to daily living, special aids, or, indeed, surgical management may become relevant at any stage of the child's development *(11,17,35,45,46).* Although surgery of the upper limbs should be approached with caution during infancy, arteriograms indicate that the blood supply, even in single-digit phocomelia, is likely to be adequate for major reconstructive surgery to be contemplated in later life *(30).*

Objective records of activity, writing, and performing other prearranged tasks which can be timed, or for which some degree of accuracy can be charted, are of more value than a "clinical impression" or answers to a questionnaire *(25).* This study has employed simple tests which can be timed, and from which "learning curves" can be constructed *(24,38).*

The assessment of a child's function is more than simple assessment of activities of daily living in a therapeutic environment. Assessment must be in "real life" terms, and the children, the teachers, and the parents need to be integrated into the assessment and therapeutic team. This is well illustrated by the comprehensive evaluation of a functional cosmetic hand carried out by New York University *(9).*

The teacher does not need to be particularly orientated toward the physically handicapped. The children in this study often appear to do better at normal schools than at special schools for the physically handicapped, unless they have all four limbs severely involved; and very often a normal school near home would seem to be more appropriate than a school for the physically handicapped that is located further away. Estimation of intelligence should be an accepted method of evaluation of all children prior to entrance into school, and psychological evaluation may be of significant help *(6,41).*

However, it may be necessary to adapt the child's physical environment, so that he is not penalized by unsuitable classroom furniture or unduly physically fatigued. This can usually be overcome by relatively simple devices.

Gouin-Decarie *(15)* compared thalidomide children to the average population and found the mean I.Q. to be 98. Along with a delay in speech, there was retardation in development of the child's perceptual concept of space and movement.

The design and fitting of prosthetic devices for children with multiple limb deformities and the subsequent training and resettlement of the children at home and school are complex activities involving engineers, technicians, prosthetists, therapists, school teachers, social workers, and, not the least, the children and their parents. The establishment of objective and valid criteria for evaluating patient performance in the very young is difficult. The fact that the children are constantly changing as they grow and develop should emphasize the importance of reassessing goals of achievement as well as anticipated attainment.

There are three major factors of influence: the personality of the child, the parental influences, and the therapeutic unit managing the child *(8).*

Brooks and Shaperman *(3)* devised a "Prosthesis Adjustment Scale" based on the child's use of the prosthesis—the applied use, maintenance, and acceptance. In their experience with the below-elbow congenital amputee, acceptance was interrelated with wearing, use, and skill of applied use. Although they emphasize that the fitting of a unilateral congenital below-elbow amputee before the age of two tends to result in full-time wearing and good acceptance of the prostheses, they also note that the category most closely related to early fitting is full-time wearing. Although indoctrination for full-time wearing is possible for single amputees, it is much more difficult to accomplish for multiple amputees.

The almost complete acceptance of lower-limb appliances from an early age reflects the point that if the appliance fulfills a real need, even if inefficiently, the appliance will be accepted.

In the case of upper-extremity appliances, there is a definite improvement in partial acceptance and a dramatic improvement with the development of more reliable appliances, less subject to mechanical failure (note the change from P.3. to P.4. in Table 5).

In this review, no differentiation has been made between mechanical failure, troubles with control mechanisms, or power packs. Interestingly enough, in this series there was no particular problem relating to the supply and recharging of the gas cylinders. As more function is derived from gas-powered appliances, the supply problem will increase and probably limit the use of this type of appliance *(28).*

Brooks and Shaperman *(3)* also note that the acceptance of a prosthesis is closely related to the ability to communicate, and that good communication between parents and child (that is, good family relationships) is probably the major factor in establishing acceptance of appropriate prostheses. Thus the home environment is critical, and in certain circumstances this may be the determining factor *(50).* In this series, the age of four appeared to be the "watershed." At this age, children can begin to understand the reasons for continuing to use appliances and become at least partially cooperative. They also tend to start to attend nursery school at this age. Children with severe multiple limb deformities may be educated in normal schools or special schools for the physically handicapped, depending upon their clinical or their social needs *(39).*

The decision to remove the child to a residential school for the physically handicapped is a major one, and not necessarily associated with improvement in physical function or acceptance of suitable appliances. In this study, it has been noted that normal state schools have accepted these severely disabled children as a personal challenge and have usually gone to great lengths to encourage the children in their rehabilitation, collaborating closely with the hospital therapists and prosthetics departments. By treating the children in this way, they have been permitted, indeed encouraged, to face up to many of the normal challenges and experiences of school life. This seems to have helped the children to be integrated into community living.

In this series, a small number of children with limb deformities in special schools for the physically handicapped are not so adapted to their disability as those at normal schools, and prosthesis acceptance is relatively poor. The atmosphere of the schools for the physically handicapped is often more protective and necessarily geared to the most incapacitated. Furthermore, some of these schools have many children who are on the borderline of being educationally subnormal. Appliance training in these schools is usually the responsibility of the physical therapist and not the teachers, and the teachers are reluctant to divert individual attention to appliance training in the presence of more disabled children who are unable to use appliances, for example, victims of cerebral palsy. However, children with severe mobility problems, as well as severe upper-limb dysmelia, may find the special equipment, adapted environment, slower tempo, and special staff of particular help.

As a group, these children achieve remarkable levels of manipulative skills using their residual upper limbs, chin, shoulder tips, feet, and mouth. The wearing of an upper-limb prosthesis frequently hampers these skills while only providing a much cruder form of function. However, there has been no experience here in fitting a single multi-functional arm balanced with a cosmetic prosthesis, and there are certain advantages in this approach *(42).* For children with absent or deformed legs, almost any form of lower-limb appliance gives them an immediate advantage in standing, achieving reasonable height, and—as a bonus—walking short distances.

As a general experience, it can be said that patients must obtain an immediate advantage from the appliance for it to be accepted. It is the immediate postfitting phase which appears to be of greatest importance. If the appliance looks unfinished, if the technicians have to make numerous adjustments in the fittings, if it is uncomfortable or scratchy, if mother's face registers horror at the appearance—all these factors have a long-term effect out of proportion to their immediate import. If the antagonistic features even slightly outweigh the advantages, then acceptance is unlikely, or at best partial, and becomes more a matter of deference to authority, or, for children, part of a game rather than a true integration of the appliance into the body image. The immediate advantage gained must outweigh all the antagonistic factors. If this occurs, the patient will persist through further stages of fitting, training, and redevelopment.

The swivel walkers are a striking example. These appliances were used experimentally at first because earlier caliper-type lower-limb appliances were breaking so frequently that the children were continually frustrated. The swivel walkers were both more reliable and more immediately efficient, and acceptance was immediate and universal.

Cosmesis is often a motivating force in acceptance of any appliance *(9,49).* In this series, there was a marked improvement in acceptance on the introduction of a powered hand in preference to a hook (Table 5) even though function might be less. The change from 25 per cent to 75 per cent acceptance associated with the use of a powered hand accentuates the urgent need for a sophisticated, cosmetically acceptable, functional terminal device. This confirms the experience of New York University *(9).* Children were also pleased when ordinary shoes could be fitted to their lower-limb appliances.

Frequently, however, it is the mothers' dominant influences which lead to cosmetic acceptance overriding function, whereas fathers are often more likely to be interested in function. In one instance, a powered prosthesis was frequently returned nonoperational because a father repeatedly attempted to improve its functions. Another father, often at home because of shift work or lack of work, spent many hours training his son to use his upper-limb prostheses.

However, acceptance associated with cosmesis might occasionally extend to a pathological acceptance, and there is one child with bilateral upper-limb, unequal-length phocomelia, who insists on wearing a single upper-limb prosthesis in spite of the fact that it prevents him from undertaking many functions he could perform with his two phocomelic limbs. The initial supply was largely at the insistence of the parents, and in retrospect probably should have been refused.

One problem that was very unsettling for both child and parents was the involvement of more than one clinical center. Usually, this was due to geographical circumstances. The clinicians near the child's home were unable to provide certain facilities; for example, experienced training, or appropriate surgery or prosthetic devices. Furthermore, in some instances, there was a separation between the provision of upper-limb appliances and lower-limb appliances. In all instances, this diversification of clinical control and lack of unified approach led to difficulties in management and was, not infrequently, a contributory factor in rejection of appliances.

CONCLUSIONS

The object of any critical reappraisal of clinical management is to improve the treatment of patients in the future. On the basis of this study, it is possible to lay down some broad general principles for the management of children with congenital limb deformities.

In the initial stages, the parents' attitudes are dominant; therefore, early confident collaboration is essential. The parents should have faith in the doctors and should have a clear understanding of the individual responsibilities of the members of the pediatric and prosthetics team, which may vary according to local facilities. The child should be under frequent review by the same clinical team. Each member of the team—pediatrician, prosthetics consultant, therapist, technician, social worker, and psychologist—has contributions to make at all stages.

For severely disabled children, introduction to adapted clothing, aids to daily living, and training activities must be tailored to fit the individual child's expected development, and independent activities should, wherever possible, match the accepted "stepping stones" of child development.

Lower-limb deformities should be treated by appropriate surgery and prosthetics so that independent mobility is achieved as early and as efficiently as can be matched with normal progress. The size of the appliance should match natural growth as nearly as possible.

Upper-limb appliances present a more complex problem. Most children will alternate between accepting and rejecting appliances, depending on their development and needs.

Early fitting, at perhaps 12 to 18 months (or even earlier), has some relevance in that it accustoms the child to a somewhat uncomfortable appliance. But the child is unlikely to accept formal training in the use of a sophisticated appliance until more than four years of age. Once schooling starts, training in the use of an appropriate appliance should be part of formalized education, and this demands close collaboration between therapists and teachers, particularly in the school surroundings.

The prosthetists and technicians must be prepared to adapt and redesign frequently as the child's needs change. They must accept the need for adequate cosmesis even at an early age. Rejection of appliances must never be regarded as "naughty" or "ungrateful," but as part of natural development. Gentle insistence on regular training sessions may well tide a child over until in later years he understands and appreciates the need for the appliance and can make a reasonable personal decision regarding design and use.

There is an urgent need for the development of mechanically reliable, cosmetically acceptable, and functionally sophisticated upper-limb appliances.

This development of an awareness of the most suitable design and the appropriate uses of upper-limb prostheses should be the outcome of close understanding between the child, parents, doctors, teachers, and therapists.

SUMMARY

A group of 21 children with multiple limb deformities associated with thalidomide who have been supplied with various upper- and lower-limb prostheses is described. The acceptance and rejection of the appliances are analyzed according to age, family background, and the type of appliance.

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