MANAGEMENT OF FIBULAR HEMIMELIA

AMPUTATION OR LIMB LENGTHENING

DOUGLAS NAUDIE, REGGIE C. HAMDY, FRANCOIS FASSIER, BENOIT MORIN, MORRIS DUHAIME

From Shriners Hospital for Crippled Children, Montreal, Canada

We reviewed retrospectively 22 patients (23 limb segments) with fibular hemimelia treated by amputation or limb lengthening to evaluate these methods of treatment. There were 12 boys and 10 girls, all with associated anomalies in the lower limbs. Twelve patients (13 limb segments) had early amputation and prosthetic fitting and ten had tibial lengthening using the Ilizarov technique.

At the latest follow-up, the twelve patients who had amputation were functioning well and had few complications. The ten patients who had lengthening had suffered numerous complications, and all had needed either further corrective surgery or to wear braces or shoe-raises. Two of the ten lengthened limbs required late amputation for poor function or cosmesis. There were fewer hospital admissions, clinic visits, and periods of absence from school in the amputation group.

Our findings suggest that amputation is a more effective method of management than limb-lengthening in severe fibular hemimelia. The Ilizarov method is an attractive alternative for selected patients, but its exact role is not yet established. One problem is that families often have unrealistic expectations of the surgical and prosthetic technology available and may refuse amputation when this has been recommended.

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D. Naudie, BSc, Medical Student
R. C. Hamdy, MD, FRCS C, Assistant Professor of Orthopaedic Surgery
F. Fassier, MD, FRCS C, Associate Professor of Orthopaedic Surgery
B. Morin, MD, FRCS C, Associate Professor of Orthopaedic Surgery, Assistant Chief of Staff
M. Duhaime, MD, FRCS C, Professor of Orthopaedic Surgery, Chief of Staff
Shriners Hospital for Crippled Children, 1529 Avenue Cedar, Montreal, Quebec, Canada H3G 1A6.

Correspondence should be sent to Dr R. C. Hamdy.

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Fibular hemimelia is a congenital disorder characterised by partial or complete absence of the fibula. It is the most common deficiency of long bones, and consists of a spectrum of anomalies ranging from mild fibular shortening to bilateral involvement with associated defects of the femur, tibia, ankle and foot.[1-3] The usual clinical presentation involves limb-length discrepancy, anteromedial bowing of the tibia, valgus deformity of the knee, equinovalgus deformities of the foot, and ankle instability with absence of the lateral rays of the foot.[4]

Successful management aims to restore normal weight-bearing and normal limb length so that the patient can walk with as normal a gait as possible. In mild cases, treatment includes shoe-raises, step-in prostheses, epiphysiodeses or limb-lengthening procedures, and correction of foot deformities. For more severe deformities, the management is controversial. Many authors recommend early amputation of the foot and prosthetic rehabilitation.[5-9] The advantages of this approach are a single surgical procedure, a short hospital stay, and immediate walking and equalisation of limb length so that the child can adapt quickly and lead a normal life. The major disadvantages are that amputation is irreversible and that prosthetic limbs require periodic replacement and cannot provide normal sensation and proprioception.

The introduction of the Ilizarov method of limb lengthening to the Western world has provided an attractive alternative to amputation. Some surgeons prefer this method because it preserves the foot and can provide simultaneous correction of limb-length discrepancy and ankle or foot deformities.[10-12] The major disadvantages are the multiple and unpredictable operations needed, often including two or three separate lengthenings during growth, and the very long periods in hospital and in rehabilitation which may have a considerable psychosocial impact on the patient and family. Moreover, these procedures sometimes fail to achieve satisfactory or cosmetically acceptable results and may end in amputation.[7]

The treatment of fibular hemimelia by amputation, the Ilizarov method, and a variety of other techniques has been well described,[5,8,9, 1,12-17] but we could find only two studies which compared the results of limb lengthening with amputation.[6, 10] We reviewed our total experience of Ilizarov lengthening and amputation in patients with fibular hemimelia

PATIENTS AND METHODS

We reviewed 22 consecutive patients (23 limb segments) with fibular hemimelia treated at our institution between August 1988 and November 1994. Details of the patients are given in Tables I to III. There were 12 boys and 10 girls of mean age 4.0 years (6 months to 16 years). The right side was affected in 16 limb segments, the left in seven. Two patients (cases 12 and 22) had bilateral involvement, but one was treated only on the right side.

Table I. Details of patients who had amputation or limb lengthening

	Amputation	**Lengthening**
Number	12 (13 limb segments)	10 (10 tibiae)
Mean age at surgery (range)	13.3 mth (6 to 24)	7.9 yr (1 to 16)
Male:female	8:4	4:6
Right:left	8:5	8:2
Associated anomalies		
Absent lateral rays	11	6
Proximal femoral focal deficiency	1	2
Classification		
Coventry and Johnson[1]	10 type II, 2 type III	1 type I, 5 type II, 4 type III
Achterman and Kalamchi[18]	1 type IB, 11 type II	1 type IA, 3 type IB, 6 type II
Mean length of follow-up in months (range)	39.0 (6.0 to 77.9)	20.2 (0.7 to 58.5)
Mean number of hospital admissions (range)	2.3 (1 to 10)	4.1 (2 to 9)
Mean length of hospital stay in days (range)	19.3 (3 to 78)	49.0 (16 to 131)

Table II. Details of the 12 patients who had amputation

Case	**Age at surgery (mth)**	**Gender**	**Type CJ, AK***	**Procedure**	**Follow-up (mth)**	**Number of admissions, length of stay (days)**	**Complications or additional procedures**	**Latest follow-up**
1	6	F	II, IB	R Boyd	77.9	2, 28	Fitting problems Adjustments	Possible conversion to Syme
2	12	M	II, II	R Boyd	8.6	1, 8	Dressing changes	Ambulating well No complaints
3	7	M	II, II	L Syme	19.4	2, 19	Metal removal Adjustments Misplaced heel pad	Ambulating well No revisions Expense concerns
4	17	M	II, II	R Boyd	37.0	1, 13	Adjustments Stump deformity Refusal to wear prosthesis	Running Climbing
5	24	M	II, II	L Syme	67.3	1, 5	Stump irritation Adjustments	Doing well Good ROM† Swimming
6	11	M	II, II	L Syme	29.7	1, 5	Adjustments	Ambulating well Good ROM
7	14	F	II, II	R Boyd	53.2	1, 14	Hardware removal Foot eversion	Possible conversion to Syme, femoral lengthening
8	7	M	II, II	R Boyd	30.9	2, 30	Adjustments	No complaints
9	7.5	F	II, II	R Syme	77.6	1, 7	Adjustments Bowing of tibia Unequal knees	Possible femoral lengthening
10	14	M	II, II	R Syme	6.0	1, 3	Post-op rash Wound breakdown	Ambulating well
11	24	F	III, II	L Boyd	36.3	4, 21	Metal removal Adjustments	Ambulating well Good ROM
12	9	M	III, II	L Syme	23.9	10, 78	Adjustments Gait training	Ambulating well No functional impairment
	20			R Syme			Metal removal R genu valgum	

* CJ = Coventry and Johnson[1] classification; AK = Achterman and Kalamchi[18] classification
† range of movement

Table III. Details of the 10 patients who had limb lengthening

Case	Age at surgery (yr)	Gender	Type CJ, AK*	Procedure and length attained (cm)	Follow-up (mth)	Number of admissions, length of stay (days)	Complications or additional procedures	Latest follow-up
13	3.5	F	I, IA	Ilizarov L tibia 3.8	5.6	3, 24	Knee flexion contracture Knee subluxation L genu valgum	Residual LLD† 3 to 4 cm Possible osteotomy Possible 2nd lengthening
14	13	F	II, IB	Ilizarov R tibia 3.0	15.9	2, 19	Pin-site infection Paraesthesiae Knee flexion contracture Aesthetic concerns	Residual LLD 1 to 2 cm Walks with limp Possible plastic surgery
15	10	F	II, IB	Ilizarov R tibia 5.0	21.2	2, 16	Pin-site infection Knee flexion contracture R genu valgum	Wears brace Doing sports Possible osteotomy
16	11.5	M	II, IB	Ilizarov R tibia 6.0	17.5	4, 84	Pin-site infection Knee flexion contracture R genu valgum	Possible osteotomy
17	1	F	II, II	Ilizarov R tibia 3.0	19.8	4, 28	Pin-site infection Emergency pin removal Bowing tibia	Recent tendon release Recent osteotomy 2nd Ilizarov in place Pin-site infection
18	16	F	II, II	Ilizarov R tibia 11.1	0.7	3, 19	Mild paraesthesiae Depression	Valgus deformity foot Wears brace
19	7	M	III, II	Ilizarov R femur and R tibia 11.4	25.3	2, 131	Pin-site infection Bowing femur Refracture of femur Stopped prematurely	Residual LLD 3 to 4 cm Wears shoe-raise
20	5	M	III, II	Ilizarov L tibia 5.5	8.5	5, 37	Pin-site infection Prolonged physiotherapy Decreased ROM‡	Residual LLD 3 to 4 cm Wears shoe-raise Wears brace for sports
21	3.5	F	III, II	Ilizarov R tibia 11.0	58.5	9, 75	Wound debridement Knee subluxation Fracture of femur Residual LLD 9 cm	R Syme at age 8 Osteotomy
22	8	M	III, II	Ilizarov R tibia 5.0	29.5	7, 20	Residual LLD 10 cm Persistent genu valgum	Wears braces and lifts Recent osteotomy Planned R Syme Possible L Syme

* CJ = Coventry and Johnson [1] classification; AK = Achterman and Kalamchi [18] classification
† limb length discrepancy
‡ range of movement

The patients were classified by two systems. According to Coventry and Johnson[1] one patient had type I, 15 had type II, and six had type III. On the classification of Achterman and Kalamchi,[18] one patient had type IA, four had type IB, and 17 had type II. We considered our patients in two groups: 12 had an early amputation with prosthetic rehabilitation and 10 had tibial lengthening by the Ilizarov technique (Table I).

Amputation group (Table II)**.** Of the 12 patients who had early amputation, one patient (case 12) had bilateral involvement. All patients had other associated anomalies in the lower limbs, 11 lacking one or more lateral rays of the foot. One patient (case 11) had an associated focal deficiency of the proximal femur. Ten patients were type II and two were type III by the Coventry and Johnson[1] classification. On the Achterman and Kalamchi classification,[18] one had incomplete fibular deficiency (type IB); the others were type II. Six limbs were treated by Boyd amputations and seven by Syme procedures. Five patients (cases 3, 4, 8, 10 and 12) had wedge osteotomies to correct tibial bowing.

Lengthening group (Table III)**.** Of the ten patients who had Ilizarov lengthening, one (case 22) had bilateral involvement and had lengthening only on the right side. Six had associated deformities of the lower limbs: six (cases 15 to 17, 19, 21 and 22) lacked one or more lateral rays of the foot and two of these (cases 19 and 22) also had an associated focal deficiency of the proximal femur. One was type I, five were type II, and four were type III on the Coventry and Johnson classification.[1] On the Achterman and Kalamchi classification[18] one patient was type IA, three were type IB, and six were type II. In six (cases 17 to 22) amputation had been recommended first, but the patients' families refused this and opted for Ilizarov lengthening. All patients had tibial lengthening, and one (case 19) required simultaneous ipsilateral femoral lengthening. Foot deformities were treated by transcalcaneotibial pins after

soft-tissue release (cases 13, 17 and 21), tendon release and lengthening(s) (cases 17, 18, 20 and 22), wedge osteotomy (case 14), or an Ilizarov foot extension (case 17).

RESULTS

The results were assessed by the number and duration of subsequent hospital admissions, the occurrence of complications, any additional operations performed or planned, the satisfaction of patients and families, the functional outcome in terms of daily activities, and clinical examination of the patient.

Results of amputation. The mean age at operation of the 12 patients who had amputation was 13.3 months (6 to 24) (Tables I and II). Two had other operations before amputation; one (case 5) had lengthening of tendo Achillis and the other (case 4) a tibial wedge osteotomy to correct tibial bowing. Mean follow-up was 39.0 months (6.0 to 77.9), but one patient (case 3) was followed only by correspondence.

At the latest follow-up, the mean number of hospital admissions for these patients was 2.3 (1 to 10) and the mean number of days spent in hospital was 19.3 (3 to 78). Outpatient follow-up attendances included those for prosthetic adjustments, changes in wound dressing, gait training, and physiotherapy. Subsequent hospital admissions were for removal of internal fixation, extensive prosthetic adjustments, or secondary surgery. Minor postoperative complications ranged from problems with prosthetic fitting to temporary refusal to wear the prosthesis. More serious complications included persistent angular deformities, tibial bowing, stump irritation or wound breakdown.

Only one patient (case 12) required additional major surgery, which was a Syme amputation on the second leg because of bilateral involvement. Three patients may require surgery in the future. One (case 9) may need femoral lengthening to correct a residual limb-length inequality of 3.5 cm. One (case 1) may require a stump revision, from a Boyd to a Syme amputation, to facilitate prosthetic fitting. The third (case 7) may require both lengthening and stump revision. The outcome was regarded as satisfactory in all but two patients. One family (case 9)

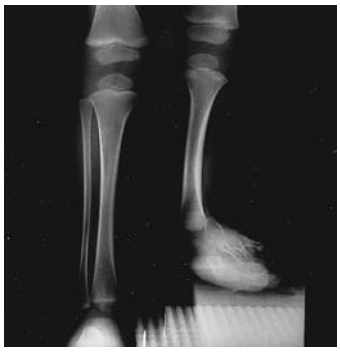

Fig. 1a

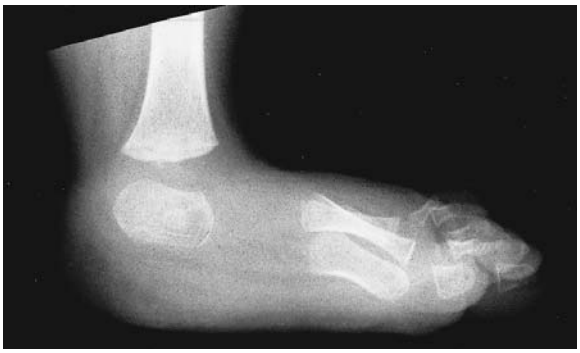

Fig. 1b

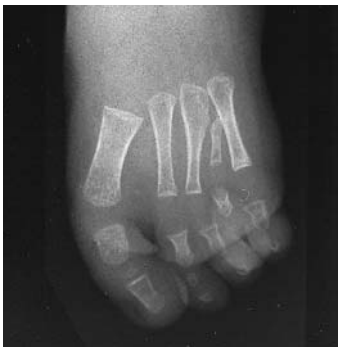

Fig. 1c

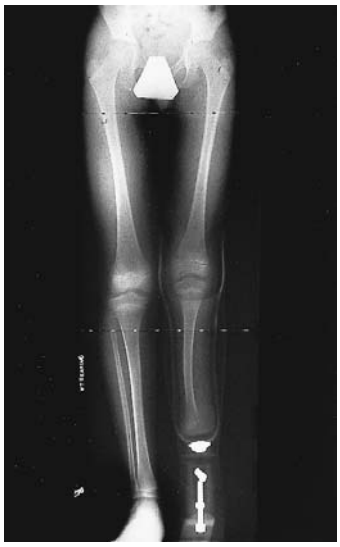

Fig. 1d

Fig. 1e

Case 5. Figure 1a – Preoperative standing radiograph of a two-year old boy showing complete (type II) absence of the left fibula with a limb-length discrepancy of 3 cm. Figure 1b – Preoperative lateral radiograph showing absence of the talus and tarsal bones in the left foot. Figure 1c – Preoperative AP radiograph showing partial absence of the fourth ray of the left foot. Figure 1d – Postoperative standing radiograph six years after a left Syme amputation showing equalisation of limb length with a fitted prosthesis in place. Figure 1e – Postoperative photograph showing a functional prosthesis.

was unhappy because of the need for a future surgical procedure, and another (case 3) complained that prosthetic equipment and maintenance were expensive and not available to them locally. All patients were functioning well with their prostheses at the latest follow-up.

Figure 1 shows an example of a Syme amputation with a good result.

Results of lengthening. The ten patients who had lengthening (Tables I and III) were much older at the time of surgery (mean age 7.9 years; 1 to 16). Two had had previous lengthenings elsewhere: one (case 14) had lengthening of 5.5 cm and the other (case 18) of 11.0 cm in addition to multiple tendon lengthenings. The mean follow-up was 20.2 months (0.7 to 58.5). Two patients (cases 16 and 19) were followed by correspondence.

All ten patients had lengthening of the tibia and one (case 19) of the ipsilateral femur. The mean lengthening achieved was 6.5 cm (3 to 11.4). Limbs were equalised to within 1 cm in five of the ten (50%) patients (cases 14 to 16, 20 and 21). The mean duration of application of the external fixator was 7.8 months (3.8 to 19.5) and the mean lengthening index (total treatment time in months per centimetre of lengthening) was 1.23 (0.62 to 1.80).

At the latest follow-up, the mean number of hospital admissions for these patients was 4.1 (2 to 9) and the mean length of stay in hospital was 49.0 days (16 to 131). Outpatient care included attendances for physiotherapy, periodic evaluation of bone consolidation, and nursing care of pin-site infections. Reasons for subsequent hospital admissions included adjustments to the fixator device, treatment of pin-site infections, and removal of the fixator. Minor postoperative complications were numerous and included flexion contractures, persistent valgus deformities, stiff joints, pin-site infections, aesthetic concerns, transient paraesthesiae, depression, and temporary refusal to wear the prosthesis. Major complications included subluxation of the knee, a pressure sore which required wound debridement, emergency removal of a dislodged pin, and two pathological fractures in the involved limb after removal of the fixator.

Three patients have had or will need a second major operation. One (case 17) recently began a second lengthening procedure to correct residual leg-length discrepancy, and one (case 21) recently had a late Syme amputation. A third patient (case 22) will need a late Syme amputation of a functionless and poorly cosmetic limb. Four patients from this group may also require future corrective surgery. One (case 13) will probably require a second lengthening and possibly a tibial osteotomy to correct genu valgum. Two (cases 15 and 16) may require tibial osteotomies to correct similar deformities. The fourth (case 14) will require scar revision to improve the appearance of a cosmetically unacceptable limb. The outcome was considered to be generally satisfactory in only four (cases 15, 16, 18 and 20) of the ten patients. The three patients (cases 18 to 20) who are unlikely to require additional surgery were still wearing braces or shoe-raises for daily activities at their latest follow-up.

Figures 2 and 3 show some examples of lengthening.

DISCUSSION

The management of severe fibular hemimelia remains controversial. Treatment by early amputation and prosthetic fitting gives excellent long-term results and has many advantages, but is an irreversible procedure. The Ilizarov method can salvage the limb by simultaneous correction of limb-length discrepancies and foot deformities, but has many complications. Refusal of amputation by some families, even when this is strongly recommended, can add to the difficulty in management.

In this series of 22 patients, we found that those treated by amputation were much younger and also more severely affected than those treated by lengthening. The groups cannot therefore be directly compared. In addition, follow-up was relatively short: most of the children are still growing and some will need further surgery. The assessments and conclusions of our study therefore can only be provisional because they result from a comparison of dissimilar series.

Our results do indicate, however, that the 12 patients who had amputation had considerably fewer hospital admissions (means 2.3 *v* 4.1) and less than half the hospital stay (means 19.3 *v* 49.0 days) than those who had lengthening. Moreover, the patients who had lengthening spent on average an additional 7.8 months in a fixation device. There were fewer clinic visits and missed school days for those who had amputation. We believe that repeated hospitalisation and absence from school can have a considerable impact on the normal psychosocial development of these children. Manifest psychopathology has been reported in some of these patients.[9]

There were very few complications after amputation. Of the lengthened group, seven of the ten patients had or are likely to need more corrective surgery, including two late amputations, compared with four of the 12 patients who had amputation. All our patients were able to function well after amputation and were participating in a wide range of sports and daily activities. All ten who had lengthening either needed further corrective surgery or continued to wear braces or shoe-raises for daily activities. No family reported regretting an amputation and all were happy with the rapid rehabilitation of the child.

Of 22 patients whom we report, 18 (19 limbs) had been recommended for early amputation as the first line of treatment. All but one of these were type II of Achterman and Kalamchi.[18] Twelve patients agreed to the amputation and six refused and opted for Ilizarov lengthening. All six who refused had severe complications and two needed late amputation.

Parental refusal of early amputation is a major problem, especially when the child's foot is stiff and severely

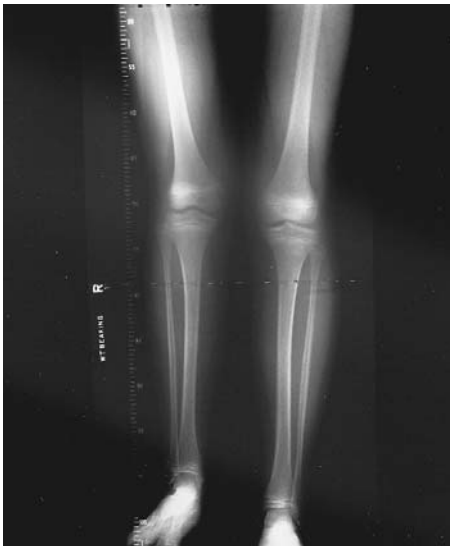

Fig. 2a

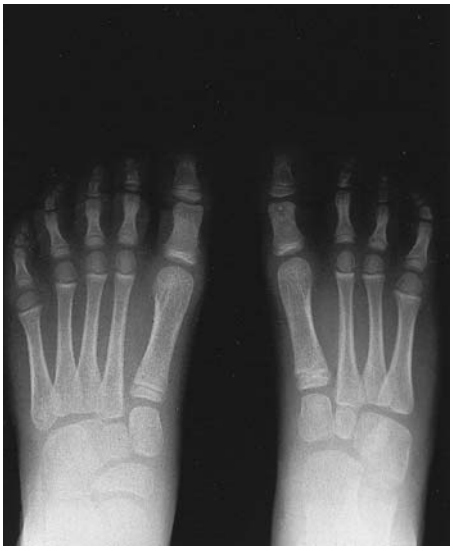

Fig. 2b

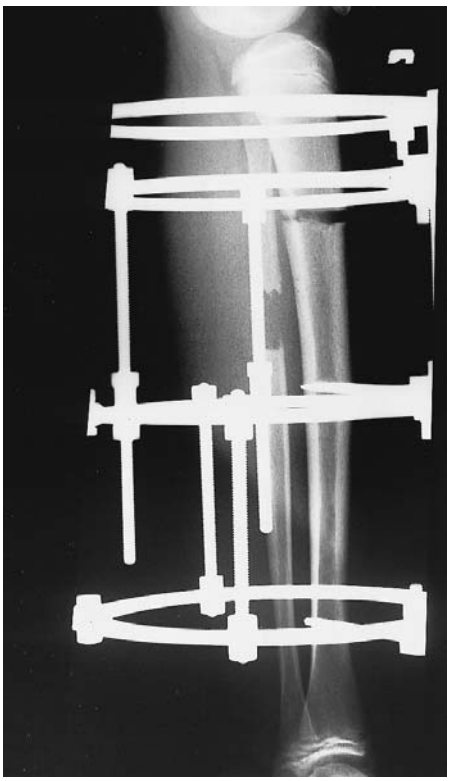

Fig. 2c

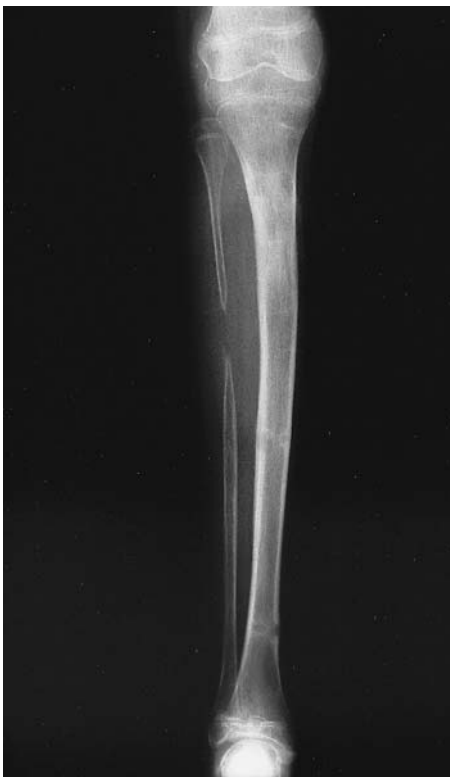

Fig. 2d

Case 15. Figure 2a – Preoperative standing radiograph of a ten year-old girl showing a mild degree of fibular hemimelia, a ball-and-socket ankle, and a limb-length discrepancy of 4 cm. Figure 2b – Preoperative AP radiograph showing complete absence of the fifth ray (right side) in a relatively normal foot. Figure 2c – AP radiograph with an Ilizarov apparatus showing the proximal corticotomy sites. Figure 2d – AP radiograph eight months after surgery showing good consolidation of the lengthened bone.

deformed and a major discrepancy in limb length is expected. Letts and Vincent[17] describe some of the reasons for this parental refusal including a denial of the natural history of the condition, a near-normal appearance of the affected foot, a gait that is functional at the time of decision, and a wish to allow the child to participate in the decision-making process. Decision-making is also harder for some parents because limb-length inequality and foot deformities in the first two years of life do not appear to be as severe as they would be in later years. Furthermore, some children

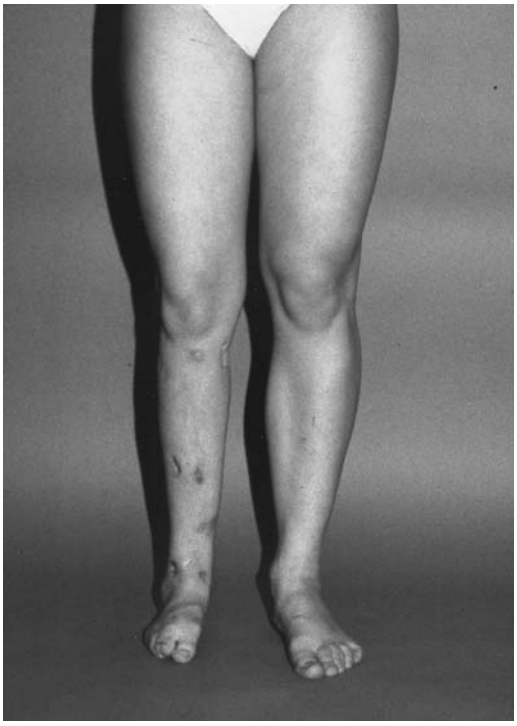

Fig 3

Case 14. Postoperative photograph of a 13-year-old girl with partial (type IB) absence of the right fibula, showing a severely deformed foot after Ilizarov lengthening.

with severe deformities have a remarkably functional gait (with walking aids) in the early years and it is only in adolescence that they start to develop problems. This makes it difficult to convince some parents that amputation is the best method of management.

We have developed a special programme which aims to help parents of children with severe fibular hemimelia to make such decisions. This includes a second opinion from another surgeon in the limb-length discrepancy clinic and possibly a third opinion from an experienced specialist in physical medicine in the paediatric amputee clinic at another institution. We also arrange for the parents to visit the amputee clinic to see for themselves how children with the same condition function with their prosthesis after amputation. If the parents still refuse amputation after this, we respect that decision and make every effort to improve the function of the affected limb.

Review of the English and French literature has shown consistency in the opinions of many other authors. Choi et al[6] reported 88% satisfaction in patients who had amputation as against 55% in patients who had Wagner lengthening. Epps and Schneider[5] reported excellent short- and long-term results in 11 of 12 patients with fibular hemimelia after early amputation and prosthetic rehabilitation. Although Dutoit et al[7] reported that socioprofessional integration was satisfactory in 26 patients after surgical lengthening, they did report that 22 of these patients were unhappy with the appearance of their limbs and that at the latest follow-up 20 had problems putting on shoes. Oppenheim,[8] Herring[9] and Letts and Vincent[17] do not recommend lengthening except in carefully selected cases.

Nevertheless, a number of authors have obtained good results with repeated lengthenings. In a retrospective comparative study, Jawish and Carlioz[10] reported good correction of the foot in 60% of cases of fibular hemimelia treated by lengthening. Miller and Bell[11] and Calagni[12] also preferred to preserve the foot and use repeated lengthenings for limb-length discrepancies, angular and rotational deformities, and foot and ankle deformities. These authors all agreed, however, that there are many potential problems and complications associated with repeated lengthenings.

Our results and a review of the literature show that there is a place for preservation of the foot and repeated lengthenings in carefully selected cases with mild foot deformities and small limb-length discrepancies. We believe, however, that amputation remains the treatment of choice for most cases of type-II (complete) fibular hemimelia. We support the recommendations of Oppenheim[8] that amputation is indicated for a leg-length discrepancy of 7.5 cm or more by the time of skeletal maturity, and for foot deformities severe enough to indicate that any surgery to make the foot plantigrade and functional is likely to fail. We also suggest that amputations are performed before the age of one year, when most children begin to walk. The child can then adapt quickly to the prosthesis, before the foot has become fully incorporated into the child's body image.[9,17]

We recommend also that it should be clearly explained to the families that amputation is a reconstructive procedure and should not be considered as a failure of treatment. When families refuse amputation, however, we must always respect their decision, but the short- and long-term complications of repeated lengthening must be clearly explained.

No benefits in any form have been received or will be received from a commercial party related directly or indirectly to the subject of this article.

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