Amputation Versus Staged Reconstruction for Severe Fibular Hemimelia
Assessment of Psychosocial and Quality-of-Life Status and Physical Functioning in Childhood

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Background: Fibular hemimelia, a congenital disorder characterized by the partial or complete absence of the fibula, tibial growth inhibition, and foot and ankle deformity and deficiency, is the most common deficiency of long bones. The purpose of the present study of children with congenital fibular hemimelia was to examine the functional and psychosocial outcomes at a minimum of 2 years after treatment either with amputation and a prosthesis or with reconstruction and lengthening.

Methods: Twenty children who were managed with primary amputation were compared with 22 children who were managed with staged limb reconstruction. The average age of the patients at the time of evaluation was 9 years (range, 5 to 15 years). Patients and parents completed psychosocial, quality-of-life, and satisfaction surveys. Patients underwent instrumented gait analysis and a timed 25 or 50-yard dash. The number and nature of surgical procedures were recorded from a retrospective chart review.

Results: Families of children managed with amputation had lower economic and educational levels and were more ethnically diverse compared with the families of children managed with limb reconstruction. Scores on psychosocial and quality-of-life surveys were comparable with those from healthy patient populations. Parents of males treated with amputation perceived a lower school-related quality of life for their child; socioeconomic and ethnic differences between groups might account for this finding. Statistically but not clinically significant differences were measured during instrumented gait analysis at a self-selected walking speed and during a timed 25 or 50-yard dash. The majority of patients and parents reported satisfaction with the treatment method selected and would select the same treatment method again.

Conclusions: At this interim stage of growth, there were no significant functional or psychological differences between groups. Both groups were satisfied with the outcome in mid-childhood, irrespective of the selection of amputation or limb reconstruction.

Level of Evidence: Therapeutic Level III. See Instructions for Authors for a complete description of levels of evidence.

Disclosure: The authors indicated that no external funding was received for any aspect of this work. On the Disclosure of Potential Conflicts of Interest forms, which are provided with the online version of the article, one or more of the authors checked “yes” to indicate that the author had a relevant financial relationship in the biomedical arena outside the submitted work and “yes” to indicate that the author had other relationships or activities that could be perceived to influence, or have the potential to influence, what was written in this work (http://links.lww.com/JBJSOA/A91).

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limb reconstruction to become an alternative to amputation. Although such lengthening reconstructive surgery is becoming more common, research regarding psychological outcomes and patient satisfaction is limited. Some studies have documented acceptable patient satisfaction and psychosocial adjustment, whereas others have demonstrated complications and adjustment difficulties. A recent evaluation comparing outcomes in adults managed with amputation or staged reconstruction failed to demonstrate clinically meaningful differences on questionnaires measuring function and psychosocial status, although the patients were not physically examined at the time of follow-up. Other studies have demonstrated a perceived advantage in association with amputation but have focused primarily on functional outcomes and patient satisfaction and have not addressed psychosocial outcomes or prosthetic management.

The purpose of the present study was to examine the functional and psychosocial outcomes at mid-childhood in children who had undergone either amputation or staged reconstruction and lengthening beginning in infancy for the treatment of severe fibular hemimelia.

Materials and Methods

After institutional review board approval, participants who had been managed with amputation were recruited from the Texas Scottish Rite Hospital for Children and participants who had been managed with lengthening reconstructive surgery were recruited from the Rubin Institute of Advanced Orthopedics. Patient databases were surveyed at each institution to identify patients who had been managed between 1996 and 2004. Seventy-five patients who had been managed with amputation and 64 who had been managed with staged reconstruction between 1996 and 2004 were identified. The inclusion criteria for the present study were a diagnosis of severe fibular hemimelia (Achterman-Kalamchi Type II; Paley Type III), an age of ≥5 years at the time of study, and reconstructive surgical treatment performed ≥2 years prior to the date of enrollment. Potential subjects were required to be at least 5 years of age and at least 2 years after the most recent reconstructive procedure so that they could fully participate in the functional assessments. Exclusion criteria included bilateral congenital fibular hemimelia, severe femoral abnormality, or any orthopaedic procedure within 12 months prior to enrollment. Of the 24 subjects who met these criteria in the amputation group, 3 declined to participate and 1 was ineligible because of recent revision of the residual limb. Of the 24 subjects in the lengthening reconstructive surgery group, 2 declined to participate. Thus, the present study included 20 patients who had been managed with amputation and 22 patients who had been managed with lengthening reconstructive surgery. The medical records of the participants were retrospectively reviewed for the nature and number of surgical procedures, the ages at which the procedures were performed, any documented surgical complications, and any other pertinent medical history. The average age of the patients at the time of evaluation was 9 years (range, 5 to 15 years). In the amputation group, the number of prostheses delivered and prosthetic repairs made between the amputation and the date of functional assessment were also recorded.

Surgical Methods

Patients in the amputation group were managed with Syme or Boyd amputation. All patients in the lengthening reconstructive surgery group underwent reconstructive ankle surgery (SUPERankle procedure) as described by Paley and Robbins. The SUPERankle procedure involves soft-tissue releases of the ankle, supramalleolar opening-wedge and/or subtalar osteotomy, a second osteotomy to lengthen the tibia at the level of the diaphyseal angular deformity, and application of a circular external fixator. Second and third lengthenings were planned and/or performed in the lengthening reconstructive surgery group.

Psychosocial Questionnaires

Parents and patients completed standardized psychosocial measures on health-related quality of life, including the Pediatric Quality of Life Inventory (PedsQL) Family Impact Module, the PedsQL Version 4.0 Generic Core Scale, and the PedsQL Pediatric Pain Questionnaire-Visual Analog Scale (PPQ-VAS). Child self-concept was examined with use of the Piers-Harris Children’s Self-Concept Scale, Second Edition (Piers-Harris 2). The Behavior Assessment System for Children, Second Edition (BASC-2) was used to screen for behavioral and emotional disorders via both parent and patient reports. Parents of patients in the amputation group completed the Childhood Amputee Prosthetics Project-Prosthetics Satisfaction Inventory (CAPP-PSI). Supplemental items were added to allow parents to rate their child’s as well as their own satisfaction with the amputation and to comment about their choice of amputation over limb salvage. A child-report version of the CAPP-PSI was adapted from the parent version by the authors of the present study. This version included 8 items and utilized 10-cm visual analog scales as the response format (maximum total score, 80).

Parents of patients in the lengthening reconstructive surgery group completed the Limb-Lengthening Satisfaction
Questionnaire (LLSQ) adapted from the CAPP-PSI with permission. Parents rated their child’s as well as their own satisfaction with the leg’s appearance, function, and amount of lengthening achieved as well as with the child’s ability to perform daily activities. Parents also rated their own satisfaction with treatment, including their awareness of treatment options, satisfaction with their treatment decision, and willingness to undertake additional lengthenings in the future. A child version of the LLSQ was created; this version included 5 items and utilized 10-cm visual analog scales (maximum total score, 50).

All parents completed a School and Activities Data Sheet (SADS). On scales ranging from 0 (“not at all”) to 4 (“very much”), parents rated the extent to which orthopaedic treatment impacted the child’s school performance and activity with peers in the past month, in the past year, and overall. Items were summed to create an “impact” total score, ranging from 0 to 32, with higher scores indicating higher positive impact.

**Gait Analysis**
Fifteen patients in the amputation group and all 22 patients in the limb-lengthening group completed instrumented gait analysis. Five patients in the amputation group did not complete gait testing: 4 declined to participate, and 1 could not complete the testing because of excessive weight, preventing reliable anatomical surface marker placement. Patients in the amputation group used their prostheses and regular shoes. Patients in the lengthening reconstructive surgery group walked barefoot or wore their normal shoes; 5 had shoe lifts ranging from 3.5 to 10 cm and were tested with the lift. Subjects underwent computerized motion analysis, including anthropometric measurements, passive range of motion, and kinematic and kinetic analysis. In the amputation group, motion analysis was conducted with use of a Motion Capture System (VICON) operating at 120 Hz. Motion capture for the lengthening reconstructive surgery group was conducted using a Motion Analysis system (Motion Analysis). During kinematic data collection, kinetic data were collected simultaneously with use of multiple embedded force plates. Kinematic modeling was done at each institution according to its standard processing protocols; a 15-marker lower-extremity modified Helen Hayes marker set was used for kinematic testing. The data for the amputation group were processed with use of Clinical Manager software (VICON), whereas the data for the lengthening reconstructive surgery group were processed within the Cortex software (Motion Analysis). Subjects completed a timed 25-yard (23 m) lengthening reconstructive surgery group) or 50-yard (46 m) (amputation group) dash. Times for the 25-yard dash were doubled to allow for comparison between groups.

**Statistical Methods**
Chi-square tests were utilized to examine differences between the groups in terms of parent education, income, ethnicity, and sex. T tests were used to examine differences in age. Multivariate analysis of variance (MANOVA) was used to evaluate differences between the groups in terms of outcomes variables. Demographic variables related to group membership were included within MANOVA tests when group effects were detected.

| TABLE I Treatment Group Characteristics | Amputation Group (N = 20) | Limb Reconstruction Group (N = 22) | P Value | Power Value |
|-----------------------------------------|--------------------------|------------------------------------|---------|-------------|
| Age at time of review* (yr)             | 10.0 ± 3.0 (5-14)        | 8.7 ± 2.6 (5-15)                  | 0.057   | 0.482       |
| Male:female ratio (no. of patients)     | 14:6                     | 9:13                               | 0.059   | 0.555       |
| Ethnicity (Caucasian:non-Caucasian) (no. of patients) | 9:11                     | 16:6                               | 0.07    | 0.494       |
| Highest parent education (no. of patients) | 0.003                  |                                    |         |             |
| Less than college                       | 7                        | 0                                  |         |             |
| Some college or college                 | 12                       | 15                                 |         |             |
| Graduate school                         | 1                        | 7                                  |         |             |
| Family income (no. of patients)         | 0.002                    |                                    |         |             |
| <$50,000                                | 10                       | 1                                  |         |             |
| $50,000-$100,000                        | 6                        | 8                                  |         |             |
| >$100,000                               | 4                        | 13                                 |         |             |
| Time since amputation or first lengthening* (yr) | 8.3 ± 3.5                | 6.3 ± 3.0                          | 0.065   | 0.458       |
| No. of procedures per patient*†         | 1.2 ± 0.4                | 3.5 ± 1.9                         | <0.001  |             |
| Surgical complications†                 | 0                        | 9 (41%)†                           | —       | —           |
| Limb-length discrepancy at time of review* (cm) | NA                      | 6.1 (0.6-15.0)                    | —       | —           |

*The values are given as the mean, with or without the standard deviation, with the range in parentheses. NA = not applicable. †Obtained from retrospective medical record review. ‡Joint contracture (5), nerve injury (1), premature consolidation (2), pin-site infection (1).
Results

Participants underwent amputation or first lengthening at an average age of 1.7 and 1.9 years, respectively; in most cases, such treatment was performed at least 7 years prior to the age at which the functional, movement science, and psychosocial investigations were performed. There were significant differences between the groups in terms of parent education (p = 0.003) and income (p = 0.002), with a near-significant difference in terms of ethnicity (p = 0.07) (Table I). The amputation group tended to have lower income and education levels relative to the lengthening reconstructive surgery group. Differences between the groups approached significance in terms of sex (p = 0.059) and age (p = 0.057). To account for observed differences in outcomes, we included education, ethnicity, and income variables as fixed factors in analyses of variance.

Medical and Clinical Comparisons

In the amputation group, 19 patients had a Syme amputation and 1 had a Boyd amputation. On physician physical examination at the time of review, 5 patients were noted to have valgus knee deformity. All prostheses included a dynamic-response foot. In the lengthening reconstructive surgery group, 16 patients (73%) had completed 1 lengthening at the time of the study (mean, 1.4 lengthenings; range, 1 to 3 lengthenings) and all 22 patients were expected to require at least 1 further lengthening procedure.

Treatment Satisfaction, School, Activities

For the amputation group, the mean total score (and standard deviation) on the parent form of the CAPP-PSI was 44.2 ± 9.6 (range, 26 to 56) and the mean score on the child form was 68.2 ± 6.7 (range, 49 to 80). For the lengthening reconstructive surgery group, the mean parent score on the LLSQ was 25.1 ± 5.9 (range, 13 to 32) and the mean child score was 41.7 ± 7.2 (range, 19 to 48). For parents, the total score averaged 79% of the maximum score of 56 for the amputation group and 63% of the maximum score of 40 for the lengthening reconstructive surgery group. For children, the total score averaged 85% of the maximum score of 80 for the amputation group and 84% of the maximum score of 50 for the lengthening reconstructive surgery group. The total scores on these measures were not compared directly across treatments because many items on each measure were treatment-specific.

Table II presents mean values (and standard deviations) for the comparable items between the CAPP-PSI, LLSQ, and related child adaptations. There were no significant differences between treatment groups for the parent-proxy child ratings (p = 0.151), parent self-reported items (p = 0.638), and child self-reported items (p = 0.130). Ethnicity, parent education, and income did not have significant effects on these measures. Parents and children in both groups tended to report satisfaction with the treatment method selected. On the SADS, no difference in the average total score was found between the amputation group (18.1 ± 7.8) and the lengthening reconstructive surgery group (19.7 ± 5.6) (p = 0.48).

Health-Related Quality of Life, Pain, Self-Concept, Behavior

Health-related quality-of-life scores are shown in Table III. For the parent-proxy ratings of child health-related quality of life, the males in the amputation group tended to have lower scores.
|                                | Amputation Group* | Limb Reconstruction Group* | MANOVA P Value | Univariate P Value† | Power Value |
|--------------------------------|-------------------|-----------------------------|----------------|---------------------|-------------|
| Parent-proxy health-related quality of life | —                 | —                           | 0.006 (treatment main effect) | —           | —           |
| Total                          | 73.9 ± 18.2       | 86.3 ± 13.4                 | NS             | —                   | —           |
| Physical                       | 76.4 ± 23.6       | 82.9 ± 19.0                 | NS             | —                   | —           |
| Emotional                      | 76.3 ± 24.1       | 86.7 ± 14.7                 | NS             | —                   | —           |
| Social                         | 73.8 ± 22.2       | 87.6 ± 15.8                 | NS             | —                   | —           |
| School                         | 66.2 ± 23.0       | 90.0 ± 14.6                 | <0.001         | —                   | —           |
| Child-form health-related quality of life | —                 | —                           | 0.014 (treatment-by-income interaction) | —           | —           |
| Total                          | 81.6 ± 10.9       | 83.0 ± 12.5                 | NS             | —                   | —           |
| Physical                       | 81.7 ± 18.9       | 83.4 ± 16.7                 | NS             | —                   | —           |
| Emotional                      | 83.2 ± 16.5       | 85.5 ± 14.0                 | NS             | —                   | —           |
| Social                         | 87.8 ± 14.8       | 83.6 ± 17.6                 | NS             | —                   | —           |
| School                         | 74.5 ± 15.8       | 78.9 ± 19.8                 | NS             | —                   | —           |
| PedsQL Family Impact Module    | —                 | —                           | 0.311          | —                   | 0.491       |
| Total                          | 78.6 ± 24.8       | 85.4 ± 13.4                 | NS             | —                   | —           |
| Physical                       | 84.1 ± 25.9       | 83.3 ± 15.3                 | NS             | —                   | —           |
| Emotional                      | 73.9 ± 26.0       | 83.6 ± 19.5                 | NS             | —                   | —           |
| Social                         | 82.6 ± 28.9       | 91.7 ± 20.0                 | NS             | —                   | —           |
| Cognitive                      | 79.3 ± 27.6       | 92.1 ± 14.6                 | NS             | —                   | —           |
| Communication                  | 77.5 ± 28.0       | 87.3 ± 16.6                 | NS             | —                   | —           |
| Worry                          | 69.3 ± 25.5       | 74.5 ± 22.1                 | NS             | —                   | —           |
| Daily activities               | 81.8 ± 27.7       | 89.7 ± 20.7                 | NS             | —                   | —           |
| Family relations               | 81.0 ± 26.2       | 85.2 ± 24.0                 | NS             | —                   | —           |
| PPQ-VAS                        | —                 | —                           | 0.359          | —                   | 0.316       |
| Child—current pain             | 1.0 ± 1.7         | 0.9 ± 1.7                   | NS             | —                   | —           |
| Child—worst in past week       | 2.0 ± 2.9         | 2.1 ± 3.1                   | NS             | —                   | —           |
| Parent-proxy—current pain      | 0.4 ± 0.7         | 0.3 ± 0.5                   | NS             | —                   | —           |
| Parent-proxy—worst in past week| 1.4 ± 2.4         | 0.4 ± 0.8                   | NS             | —                   | —           |
| Piers-Harris self-concept scales| —                 | —                           | 0.909          | —                   | 0.134       |
| Total                          | 52.8 ± 9.9        | 55.9 ± 11.9                 | NS             | —                   | —           |
| Physical                       | 49.8 ± 9.6        | 51.4 ± 9.3                  | NS             | —                   | —           |
| Behavioral                     | 49.4 ± 9.7        | 52.7 ± 9.3                  | NS             | —                   | —           |
| Intellectual                   | 52.1 ± 8.6        | 55.8 ± 8.7                  | NS             | —                   | —           |
| Freedom from anxiety           | 53.5 ± 7.8        | 55.1 ± 8.6                  | NS             | —                   | —           |
| Popularity                     | 51.3 ± 9.3        | 53.5 ± 11.4                 | NS             | —                   | —           |
| Happiness                      | 50.9 ± 7.9        | 53.3 ± 9.2                  | NS             | —                   | —           |
| BASC-2: parent report          | —                 | —                           | 0.104          | —                   | 0.560       |
| Internalizing                  | 52.3 ± 10.7       | 45.5 ± 10.1                 | NS             | —                   | —           |
| Externalizing                  | 52.7 ± 11.9       | 46.6 ± 8.5                  | NS             | —                   | —           |
| Attention problems             | 53.6 ± 11.5       | 46.1 ± 9.4                  | NS             | —                   | —           |
| Behavioral symptoms index      | 53.0 ± 12.8       | 44.4 ± 8.3                  | NS             | —                   | —           |
| BASC-2: self-report            | —                 | —                           | 0.498          | —                   | 0.233       |
| Internalizing                  | 45.5 ± 5.8        | 44.9 ± 11.9                 | NS             | —                   | —           |
| Inattention-hyperactivity      | 50.6 ± 12.2       | 46.9 ± 12.8                 | NS             | —                   | —           |
| Attention problems             | 51.4 ± 10.7       | 46.4 ± 13.5                 | NS             | —                   | —           |
| Emotional symptoms index       | 45.5 ± 6.4        | 44.1 ± 13.6                 | NS             | —                   | —           |

*The values are given as the mean and the standard deviation. †NS = not significant.
relative to both standardized norms and the scores for the lengthening reconstructive surgery group on the school domain. For child-reported health-related quality of life, post-hoc analysis showed no significant differences between treatment groups. For example, the tendency for patients in higher-income families to have higher scores was not significant (p = 0.087). On the PedsQL Family Impact Module, while many parents expressed some worry about their child condition, there were no significant differences when comparing treatments (p = 0.311).

Data from the PPQ-VAS revealed that most patients perceived pain as a non-factor in their functioning at the time of the study (Table III). As with the PPQ-VAS, scores from the BASC-2 and Piers-Harris instruments were within normal limits, with no clinically meaningful differences between groups.

**Gait Analysis**

Several significant differences were noted between the amputation and lengthening reconstructive surgery groups, and both groups were significantly different from normal age-matched controls (Table IV). While there were slight differences in cadence (amputation group, p = 0.033) and walking speed (lengthening reconstructive surgery group, p = 0.022) compared with the controls, both groups were within 90% of their age-matched healthy peers.

Kinematic and kinetic analysis indicated that both groups had slight crouch at the knee during midstance. The patients in the lengthening reconstructive surgery group had greater ankle range of motion (p < 0.001) and less calcaneus (p < 0.001) compared with the amputation group. These differences were observed despite the decreased ankle range of motion seen in the amputation group compared with the lengthening reconstructive surgery group, where there was no difference between the groups in terms of peak ankle push-off power at toe-off (p = 0.279). Both groups showed significantly decreased peak ankle moment (p < 0.001) and peak ankle power (p < 0.001) compared with the control group.

**Discussion**

The data in the present study are preliminary as the information presented here does not represent outcomes at skeletal maturity, and we believe that it will be important and informative to repeat these assessments in this cohort after the subjects achieve skeletal maturity. Our findings mirror those of other studies that have suggested that psychosocial adjustment to either amputation or limb-lengthening treatment is possible and probable. Participants from both groups reported satisfaction with treatment and functioning, and health-related quality-of-life scores were generally consistent with those of other individuals who reported no serious health conditions. Self-concept scores were within normal limits and behavior problems were largely denied.

Analyses failed to find significant differences between the groups in terms of contrasting psychosocial adjustment or physical functioning. While parent-proxy health-related quality-of-life scores were higher in certain instances, it is important to note the considerable difference in demographic characteristics of the 2 treatment groups. The lengthening reconstructive surgery group was appreciably more affluent and educated and included more Caucasians, while the amputation group contained more ethnic minorities and families with lower income and education levels. It is possible that the sample of patients in the lengthening reconstructive surgery group was a product of those families that presented with recommendations for amputation. The means to acquire and implement additional treatment options may be reflective of the higher socioeconomic status among those families. We also observed a higher number of females within the lengthening reconstructive surgery group. This finding may have been due to an increased willingness of parents of females to lengthen a limb because of the negative perception associated with wearing a prosthesis. At any rate, neither treatment group appeared to be at a significantly greater risk for psychosocial problems relative to the other at this stage of maturation.
As might be expected, both treatment groups demonstrated significant functional differences relative to normal controls on gait analysis. Despite these kinematic differences, cadence parameters showed that both groups were generally able to keep up with their peers. The majority of participants reported no pain, and virtually every family in the study reported to investigators that they would choose the same mode of treatment again. This finding is consistent with those of Ramaker et al., who reported an 88% rate of patient satisfaction with the results of Ilizarov treatment. Both groups will require further surgical procedures during the remainder of skeletal maturation, with all of the participants in the lengthening reconstructive group expected to have at least 1, and in many cases 2, future lengthening procedures. As such, it is conceivable that such intervention could contribute to more impaired performance within the group in the future.

The present study does not fully support the findings reported by McCarthy et al., who concluded that children with fibular hemimelia who were managed with amputation were more satisfied than those who were managed with lengthening. McCarthy et al. compared groups at different ages, whereas we evaluated patients of approximately the same age at the time of follow-up. In a comparison of amputation versus reconstruction, Naudie et al. concluded that, because of residual recurrent foot deformity, amputation was the preferred option. It is likely that the ankle reconstructive procedure described by Paley and Robbins may avoid the recurrent residual foot deformities that have resulted in reports of poor outcomes after lengthening reconstructive surgery. Patel et al. also noted that the costs associated with prosthetic management may substantially exceed those associated with limb-lengthening over a patient’s lifetime. The outcomes of limb reconstruction seen in the study by Patel et al. have been corroborated in more recent studies involving the use of the SUPERankle procedure for staged reconstruction in patients with fibular hemimelia.

In conclusion, we have demonstrated that psychosocial adjustment and health-related quality of life after primary amputation or limb salvage and reconstruction in patients with severe fibular hemimelia are comparable and frequently within normal limits for a healthy population at this stage of development and treatment. The quality of performance on gait tests was similar between the groups, although in most cases it was significantly different from that for age-matched controls. Parents and surgeons must weigh life-long prosthetic requirements against significantly greater number of surgical interventions for limb salvage and reconstruction when selecting a treatment strategy for severe fibular hemimelia.

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