Letters to The Editor

Limb-Lengthening versus Amputation for Fibular Hemimelia

To The Editor:

We read with interest the article “Fibular Hemimelia: Comparison of Outcome Measurements After Amputation and Lengthening” (2000;82:1732-5), by McCarthy et al. The conclusion, “children who undergo early amputation for the treatment of fibular hemimelia are more active, have less pain, are more satisfied with the result of the treatment, have fewer complications, undergo fewer procedures, and incur less cost than those who undergo lengthening. . . . even though good results can be obtained with lengthening procedures,” warrants closer scrutiny.

First, the number of patients who underwent limb-lengthening in this study is very small (eleven limbs in ten patients). Only six patients were treated with the Ilizarov method, and five were treated with the older Wagner method, which is associated with more complications and poorer results. The mean age at the time of amputation was 1.2 years (range, seven months to 2.3 years) compared with a mean age of 9.7 years (range, 5.5 to 18.3 years) at the time of the initial lengthening procedure. The children in the lengthening group were followed until an average age of 8.1 years, while the children in the amputation group were followed until an average age of 16.8 years in comparison with the children in the amputation group, who were followed until an average age of 8.1 years. The patients in the lengthening group were therefore treated later, making treatment more difficult, especially that involving large leg-length discrepancies that require as many as three lengthening procedures or two such procedures and one epiphysiodesis. It is more difficult to obtain and maintain correction of foot deformities that are not treated at an early age. The two groups in the study by McCarthy et al. are therefore disparate; use of a case-matched control format would have produced a more scientifically valid study. When the children in the amputation group, who were followed until an average age of only 8.1 years, grow to be larger and heavier adolescents and, later, adults, their oxygen demands will progressively rise, and they will tire easily. This phenomenon as well as the total dependency on their prostheses and the long-term difficulties of stump care may adversely affect their satisfaction with the procedure in their later years.

A table detailing patient age and gender, severity of the deformity, number and nature of surgeries performed, and associated complications would have allowed the reader to more easily scrutinize the data. In our experience, the number of rays in the foot and the percentage of fibular shortening compared with the length of the ipsilateral tibia have little correlation to the degree of severity of the hemimelia or the final result of the surgery. The authors place great emphasis on patient satisfaction without going into any detail as to how this was measured. Standard outcomes instruments such as the Short Form-36 or the Children Health Information Service Rand Scale are more reliable measures than the scale used in this study.

A very important issue not discussed by the authors is that is of the surgeon’s clinical experience with limb-lengthening and reconstruction procedures. Of the twenty-one complications in the limb-lengthening group, five were pin-site infections, which are easily treatable with antibiotics and/or pin exchange. Bone-graft dislodgment, another complication listed, is unique to the Wagner technique. Tibial angulation has been observed to occur in association with fractures, amputation stumps, and the tethering effect of the fibular anlage, as has been described by Cozijn. We minimize its occurrence by excising the anlage and overcorrecting the bone regenerated by distraction toward varus alignment. Similarly, anlage excision with soft-tissue release and Achilles-tendon lengthening, along with a supramalleolar varus and extension osteotomy and/or a subtalar osteotomy, allows for lasting correction of the ankle valgus and equinus. This correction is made during the first lengthening procedure, which can be performed when the patient is as young as twelve to eighteen months of age. Daily intensive physical therapy that focuses on knee extension helps to prevent flexion contractions, as does the injection of botox (botulinum toxin) into the gastrocnemius and soleus muscle complex and the hamstring muscles. The tibial frame can be extended to the femur with use of a knee hinge and an anterior extension bar, which allows the knee to be locked in extension after physical therapy and at night. If a contracture develops, a limited soft-tissue release is required. We faced similar problems with limb-lengthening procedures at our center in the earlier days; our results have improved as our methods have evolved over time. We anticipate problems and obstacles and manage complications with early intervention.

McCarthy et al. raised the issue of cost, stating that amputation for the management of fibular hemimelia requires fewer surgical procedures and therefore seems to be less expensive than limb-lengthening and reconstruction. In the Discussion section, they candidly admit that “the cost analysis did not include the cost of prosthetics, which can be quite high throughout a patient’s lifetime.” The accurate figure for prosthetic management after amputation (US $30,000 for the surgery alone) is in the range of US $403,000 over the lifetime of the patient. This estimate does not take into account postoperative problems relating to stump breakdown, phantom pain, spurs, and stump overgrowth. The cost per procedure over the course of the limb-lengthening treatment ranges.
Finally, the very young age of the children in the amputation group (the oldest child being 2.3 years of age) effectively precludes their involvement in the decision-making process related to choice of treatment. The irreversible and destructive nature of amputation surgery raises many ethical issues and makes many parents uneasy about deciding in favor of treatment with amputation. If given an opportunity to participate in the decision-making process at an appropriate age and given the option of undergoing limb reconstruction with reproducible results, would the child have made the same decision in favor of amputation? Many older children resent irreversible surgical decisions made on their behalf.

We are of the opinion that, if a limb can be safely and reliably lengthened, reconstructed, and preserved, amputation should be the surgical treatment of last resort. Whenever feasible, efforts should be made to involve the child in the decision-making process, especially when an ablative procedure such as amputation is being considered.

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J.J. McCarthy, G.L. Glancy,
F.M. Chang, and R.E. Eilert reply:
We thank Drs. Patel, Paley, and Herzenberg for their insightful comments, and we would like to address each of them in order.

First, we agree that the number of patients in our study is quite small, although there are only two other studies that directly compare lengthening with amputation (both with a similar number of patients). Our study is unique because we focus on clinical outcomes.

We recognize that, although the duration of follow-up was similar for both groups, the age at follow-up was different. This is primarily because the amputations were performed in patients at a much earlier age. Our patients who have undergone amputation have not experienced clinical deterioration as they have become older, and this observation is supported in the literature. Additionally, patients are not “totally” dependent upon their prostheses, as they can ambulate without them.

Second, Drs. Patel, Paley, and Herzenberg request a table detailing patient age and gender, severity of deformity, number and nature of surgeries performed, and associated complications. Although not presented in the form of a table, this information is included in the text of the article. The authors of the letter find that, in their experience, the number of rays in the foot and the percentage of the fibular experience, the number of rays in the foot and the percentage of the fibular.

Third, Dr. Patel and colleagues suggest that we use the Children Health Information Service Rand Scale; this does not directly assess patient satisfaction. In our article, we used a patient self-reporting system (involving “yes” or “no” answers) to determine if the patients were satisfied with the results of treatment. Assessments of activity level and level of pain were determined with use of a Likert-type scale as shown in Table 1.

Fourth, all procedures were performed by the senior authors, who have a great deal of clinical experience both with limb-lengthening procedures and in the area of pediatric orthopaedics. As stated in our article, the patients in the lengthening group actually did quite well. In fact, if the complications in our patients were reviewed and classified according to the system of Paley, in which complications were categorized as “problems,” “obstacles,” or “complications,” we would have had no true major complications. We appreciate the diligence of Dr. Patel and colleagues in anticipating problems and obstacles in the treatment of hemimelia, and we certainly make an effort to do the same.

Fifth, as stated in the article, “we primarily used the cost analysis as a measure of the duration and complexity of the treatment and do not believe that cost should play a deciding role in determining the treatment plan.” The article that was cited by Dr. Patel and colleagues in regard to the projected cost per treatment dealt with procedures undertaken for conditions with many different etiologies; although we agree that the costs associated with treatment after an amputation can be extremely high, many problems secondary to amputation, such as stump overgrowth, spurs, and stump breakdown, were uncommon in our patients who had either a Syme or a Boyd amputation.

Lastly, we would like to address the comment about the benefit of including children in the decision-making process related to choice of treatment. Deciding whether a child should have surgery is difficult for parents, and, understandably, they would like to have the child involved in the decision. As the authors discussed, treatment for correction of the foot begins when the patient is quite young, at approximately the same age as that of patients having conversion for a standard prosthesis by a Syme or Boyd amputation. Involving a two or three-year-old child in such a decision-making process is unreasonable. The counterargument might be to wait until the child is an adult before allowing him or her to make the choice, in which case, care could certainly be compromised, as was already noted. The reference cited by Dr. Patel and colleagues regarding children resenting surgical decisions made on their behalf (As Nature Made Him: The Boy Who Was Raised As a Girl) is not hypothesis-based or peer-reviewed, nor can it be appropriately applied to...