The psychological and social functioning of 14 children and 12 adolescents after Ilizarov leg lengthening

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ABSTRACT — We studied the psychological and social impact of the Ilizarov leg lengthening procedure in 26 patients (aged 6–17 years), who had completed the treatment at least 2 months previously. Measurements of depression and anxiety were performed preoperatively and at follow-up. Questions about functioning at school, daily life activities and treatment-related experiences were answered by the patient and his/her parents.

The school or work results showed no significant decline during the lengthening procedure. Serious sleeping problems occurred during the procedure. There was no subjective improvement in physical skill after the procedure and almost one-fourth of the children still had complaints about their leg.

We conclude that the Ilizarov procedure caused no serious psychological disturbances.

A large leg-length discrepancy may cause functional and cosmetic problems in children. In consequence, psychological and social problems may arise. When the length inequality is 4 cm or more, operative lengthening should be considered (Siffert 1987). One of the currently used surgical techniques of leg lengthening is the Ilizarov method (Ilizarov 1990, van Roermund 1994).

The leg lengthening procedure is psychologically stressful because of its long duration and many complications, such as pin-track infection, joint stiffness, (sub)luxation, premature consolidation, disturbance in nerve function and vascular problems (Paley 1990, Aaron and Eilert 1996). Therefore, leg lengthening can have a strong psychological impact on the patients and their families. Serious emotional problems during hospitalization have been reported (Hrutkay and Eilert 1990). However, in a follow-up study of 45 children after correction of complex deformities of the leg(s), all children showed normal behavior and no signs of depression (Ghoneem et al. 1996).

The aim of our study was to investigate psychological and social functioning during and after Ilizarov lengthening.

Patients and methods

Between January 1990 and July 1996, we treated 41 patients, born between 1973 and 1993, with the Ilizarov lengthening method. To be included in this study, the surgical intervention had to be done more than 1 year previously and the patients had to have completed the procedure at least 2 months previously. This resulted in a study group of 31 patients, born between 1973 and 1988. 2 patients were lost to follow-up, 2 refused to participate and 1 patient did not complete the procedure and was also excluded. Finally, 26 patients (14 boys) were included in the study. The mean duration of the follow-up after the initial surgery was 40 (16–67) months. At the start of the treatment, 14 children were between 6 and 11 years old, 12 patients were between 12 and 17 years old. 20 patients went to school, 4 combined school and work, one had a job and one neither went to school nor had a job.

The cause of the leg length inequality was congenital in 17 patients, an infection in 5 patients, fracture

in 3 patients and was unknown in 1 patient.

Before the Ilizarov leg lengthening procedure, 3 patients had undergone a different lengthening procedure, 2 patients already had 2 earlier Ilizarov lengthening procedures. At follow-up, 1 patient had had a lengthening procedure after the Ilizarov leg lengthening. The mean leg length inequality (LLI) was 6 (2.2–18) cm.

All patients were operated on by the same surgeon. All lengthening procedures were done by metaphyseal corticotomy and callus distraction. The procedure was performed on 17 femurs and 9 tibias.

The mean acquired lengthening was 4.8 (2–8) cm. After the procedure, the mean remaining LLI was 2.1 (-0.7–15) cm. The complications reported during the procedure were 4 fractures, (frequent) superficial and 3 deep infections of the pin-site and 1 temporary subluxation of the knee. After the procedure, 7 patients had complications. 1 patient had a femur fracture. 1 patient had a femur fracture twice and a femur 50° varus. 1 patient had a femur 14° valgus, 1 a tibia 17° valgus and 1 a femur 20° valgus. 1 patient had reduced flexion/extension of the knee (5°–65°), that improved after treatment (0–120°). 1 patient had reduced flexion of the knee (0–90°), that improved after treatment (0–110°).

In the preprocedure psychological assessment, depression was assessed by a validated Dutch self-report inventory for children (de Wit 1987) and by a validated Dutch version of the Zung Depression Scale for adolescents (Zung 1965). Anxiety was assessed by the Dutch version of the Spielberger test for State and Trait anxiety (Spielberger et al. 1973). All these measurements were repeated in the follow-up study.

Furthermore, a specific questionnaire was developed concerning the current functioning at school, daily life activities such as eating, sleeping, physical and social activities, and treatment-related experiences. The patients answered the same questions in retrospect for the period before and during the procedure and shortly after the removal of the plaster. They also answered some questions to evaluate the care given during the Ilizarov procedure. For each question there were 5 alternative answers (very positive-positive-neutral-negative-very negative). For example, physical performance in walking or school gymnastics could be qualified as very good, good, normal, poor, and very poor. For convenience of comparison, results are generally presented for the combined positive answers and the combined negative answers, respectively. The parents answered the same questions simultaneously, but separately. We interviewed the patients and their parents at home. All answers were given at follow-up, 16–67 months after initial surgery.

Data were analyzed for 26 patients and 25 parents. By means of the Mc Nemar test, differences were tested for statistical significance.

Results

The results are presented primarily for the answers of the patients. The data from parents are mentioned only if different from the patient's data.

Anxiety/depression. At the preprocedure assessment, all patients had normal scores (between –1 standard deviation (sd) and +1 sd from the mean) on the depression tests. At follow-up, 1 patient had a score of more than 2 sd above average (more depressed). For the state of anxiety, 2 patients who scored above normal (more anxiety) at the preprocedure assessment, scored normal at the follow-up. For the trait of anxiety, 3 patients scored above-normal before the procedure, but normal at follow-up. In 2 patients, the reverse was found.

School/work. All patients except 1 were positive about their present school or work situation. 1 child had poor results even before the lengthening. 9 children had poor results during the lengthening and only 1 of these children still had such results soon after removal of the plaster (Table 1). At follow-up, 3 patients had poor school/work results. The attitudes of teachers at school towards the leg lengthening were perceived to be positive by 23 patients, negative by 2 and neutral by 1 patient. Practical help provided at school was judged to be good by 21 patients, normal by 2 and bad by 3 patients. Moral support was perceived to be good in 18 patients, normal in 4 and bad in 4. The reactions of classmates were positive in 21 patients, neutral in 3 and negative in 2.

Sleeping. 12 patients had sleeping problems during the procedure. Of these patients, only 2

still had sleeping problems shortly after the removal of the plaster. 14 patients did not have sleeping problems at all (Table 2).

16 patients reported discomfort at night during the procedure, whereas 10 patients almost never had complaints during the night. After the procedure, 9 patients still had discomfort at night. They complained most about the pain and the difficulty in moving freely with the frame. Fear during the night in the period of the limb lengthening occurred in 7 patients. In the period shortly thereafter, 25 patients were hardly ever afraid again. At follow-up, 20 patients were almost never frightened during the night, 5 felt frightened sometimes and 1 was often frightened during the night.

Eating. 19 patients had a good appetite at follow-up, 6 had a normal appetite and 1 a poor appetite. No changes in appetite or eating behavior were reported in the lengthening period.

Physical activities. Most children (18) thought they could walk (very) well or normally before, as well as after lengthening. Of the 6 that walked poorly before the procedure, 1 child did not perceive improvement after the removal of the plaster (Table 3). Of the 5 patients who walked poorly before the procedure and (very) well or normally after the removal of the plaster, 3 had had no complications, and 1 a valgus (tibial 17°) and 1 an anterior bowing of the femur (20°). The child who walked poorly before and after had a femur 14° valgus. More parents than children reported that walking had become worse after removal of the plaster, but the difference was not significant (Table 3).

As to school gymnastics, 22 children thought they performed (very) well or normally before the Ilizarov lengthening procedure and 4 (very) poorly. After the procedure, 21 felt they performed (very) well or normally and 4 performed (very) poorly. 1 patient stopped participating in gymnastics after the procedure. 19 patients reported that before the procedure they could do gymnastics as well as their classmates could. At follow-up, 12 patients could do gymnastics as well as their classmates and 8 thought they were worse. For the latter patients, the follow-up period was at least 2 years after the initial surgery. 6 patients had no gymnastics at school; such lessons were not scheduled in the regular program anymore. To the question whether they could do physically anything they wanted to do, 17 patients answered "yes" and 9 said "no". 17 patients said there was nothing they could do better now than they could before the lengthening.

Table 1. School/work results, during lengthening and shortly after removal of the plaster, as answered by patients in retrospect at follow-up (in numbers of patients)

During the Ilizarov procedure	Shortly after removal of the plaster	
	Good/sufficient	Poor
Good/sufficient	17	0
Poor	8	1

Table 2. Sleep quality, during lengthening and shortly after removal of the plaster, as assessed by patients in retrospect at follow-up (in numbers of patients)

During the Ilizarov procedure	Shortly after removal of the plaster	
	Good/sufficient	Bad
Good/sufficient	14	0
Bad	10	2

Differences are significant, $p < 0.01$

Table 3. Quality of walking, before lengthening and shortly after removal of the plaster, as assessed by patients / parents in retrospect at follow-up (in numbers of patients)

Before the Ilizarov procedure	After removal of the plaster	
	(Very) good/normal	(Very) poor
(Very) good/normal	18 / 15	2 / 6
(Very) poor	5 / 3	1 / 1

Social activities. 22 patients were content with their current social life. Before the lengthening procedure, 13 patients had much contact with friends, 8 spent a normal amount of time with their friends, 5 had very few such contacts with friends. After the procedure 15 had much contacts with their friends, 6 had normal and 5 very few contacts with friends.

Treatment-related experiences. 7 patients found it difficult to take care of their leg with the frame,

8 patients gave a neutral answer and 11 patients said it was not difficult. 10 patients said it was difficult to take care of the pin-track infections, 3 thought it was not very difficult, and 5 said it was easy. 8 patients had no infections or did not take care of their own infections. After the plaster was removed, 1 patient considered the leg as an "ill" leg, 16 patients regarded the leg as "different" and 9 patients regarded their leg as "normal". At follow-up, 22 patients viewed their leg as normal again, 4 considered their leg to be "different". 6 patients still had complaints at the time of the follow-up (very) often, 5 had complaints sometimes, 15 patients had complaints (almost) never. 15 patients felt they were "changed" by the Ilizarov procedure: had become more independent, were more "grown-up". 21 patients were content with their lives, 4 patients gave a neutral answer and 1 was not content.

We asked the patients whether they would still choose the Ilizarov lengthening procedure if they had to make the decision again. 23 patients gave a positive answer, 3 would not choose this procedure again. Of these 3 patients, 2 had a remaining LLI of less than 1 cm, 1 had a remaining LLI of more than 3 cm. Only 1 of the 3 patients had had a complication (reduced flexion of the knee, 0°–90°).

Almost all the parents and patients were content about the information given before the procedure. 9 parents considered the psychological assessment not necessary for themselves. In general, the patient and his or her parents felt they had been well prepared and, when they looked back, they had had a realistic understanding of the procedure. They were content about the period in the hospital, the period with the frame at home and the care after the whole procedure was over. They were well prepared to go home after hospitalization. They gave our Ilizarov team some recommendations, such as for better pain control and for supplying special wheelchairs for children.

Discussion

Our study demonstrated that the Ilizarov leg-lengthening procedure had an effect on the psychological and social functioning of the patients. The greatest effect was caused by the impediments of the frame, the pain, and the pin-track infections. However, there were no significant changes in depression or anxiety before and after the procedure. The good psychological outcome might be partly explained by the comprehensive support of our special Ilizarov team. This support consists of a preprocedure psychological assessment of the psychological resilience and risk factors in the patient and the family. Their understanding of the procedure, their coping strategies, expectations and motivation are assessed as well. Afterwards, advice about the ability of the patient to endure the procedure is given. In about 20%, the procedure is delayed. Sometimes, this delay is used to provide behavioral or family treatment and improve coping skills. The importance of education and support from the Ilizarov team was stressed by Hrutkay and Eilert (1990), who reported substantial psychological problems during hospitalization in 14 of 22 patients. A group of 45 children between 3 and 18 years, given a thorough psychological preparation, showed normal psychological functioning at follow-up after 2–6 years (Ghoneem et al. 1996).

There was no significant improvement in walking or other physical skills shortly after the lengthening procedure. Quality of walking was not related to the presence/absence of complications. Almost one fourth of the patients still had complaints about their leg. In this respect, there seemed to be no short-term benefits of the lengthening procedure. The rationale of the procedure is to prevent handicaps in the long run: it is an investment in the future of these children. It is important to include this element in the process of preparatory education of the patients and their parents.

When looking back, nearly all patients and parents were positive about the procedure and the support they received from school and from our Ilizarov team: if they had to, they would choose the Ilizarov leg lengthening again. In our group, this positive attitude was even stronger than in the group of Ghoneem et al. (1996): 87% versus 67% stated that they would undergo the treatment again, if it was indicated. There was no relationship between this final judgment and the remaining LLI or presence/absence of complications.

Although our study was retrospective, the good correspondence between the answers given by the patients and by their parents warrants the conclusion that our results give a realistic picture of experiences during and after the Ilizarov procedure.

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