

THE IMPLEMENTATION OF PROSTETIC UPPER EXTREMITY FUNCTIONAL INDEX (PUFI) IN FOLLOW-UP OF CHILDREN WITH UPPER LIMB REDUCTION DEFICIENCY (ULRD)

I van der Ham, C van Dijk-Koot, LM Buffart, H.J. Stam, ME Roebroek, C van der Sluis*,
JMFB Pesch-Batenburg,
Erasmus MC, University Medical Centre Rotterdam, the Netherlands
UMCG, University Medical Centre Groningen, the Netherlands*

Introduction

Over the past years, the importance of adequate assessment of arm and prosthetic functioning in children with ULRD has become clear. Research has shown that the use of standardized instruments adds relevant information on functioning of children with an ULRD. (1,2) The PUFIs are one of the validated instruments that was developed to assess the functional status in children with prosthesis (3). Since 2004 we implemented the PUFIs at the department of Rehabilitation medicine of the Erasmus University Medical Centre and more recently, at the University Medical Centre Groningen as a standard procedure to monitor functional outcome and prosthetic management of children with ULRD. This prospective study is an evaluation of the data collected so far.

Method

Patients

All children visiting the outpatient department of rehabilitation medicine of our centers fill out the PUFIs-questionnaire when they have an appointment once a year. The PUFIs results are printed and are discussed during the visit at the attending physician.

We assessed 40 children (23 girls, 17 boys), 27 children in Rotterdam, 13 in Groningen with the PUFIs at the mean age of 9.8 years (SD 4.0 years, range 8.3 years), all between 4 and 18 years. Two children had an acquired deficiency; the others had a congenital deficiency of the upper limb. Almost all children had a deficiency distal from the elbow and proximal from the wrist, one had a deficiency above elbow, another one had a bilateral deficiency. Fifteen children had a deficiency on the right side, 24 deficiencies were on the left side.

Instrument

The PUFIs (Prosthetic Upper extremity Functional Index) evaluates the extent to which a child actually uses the prosthetic limb for daily activities, the comparative ease of task performance with and without the prosthesis, and its perceived usefulness, which are respectively scored on a 6-point nominal scale, 5-point ordinal scale and 3-point ordinal scale. Higher scores represent more ease of performance and higher usefulness of the prostheses. Sum scores range from 0 to 100. In addition, we calculated an adapted score in which only those activities are scored, for which the prosthesis is actually used. In previous studies, the PUFIs showed good validity and test-retest reliability. (1,2)

There are two versions: the young child version, (age 3-6 years), containing 26 items, and the older child (age ≥ 7 years) with 38 items, which have 14 activities in common. In our department, in children up to 12 years old, the parents and the child fill out the older child version. Fifteen parents completed the young child-version, 25 children were assessed with the older child version, and in 5 cases the test was also completed by one of the parents. Fourteen children had more than one assessment in time.

Statistical analysis

For cross-sectional analysis, the last completed assessment of a child was used. In older child assessments the child's evaluation was used, also when a parent's version was available.

We compared the performance of activities for children who wear a prosthesis (users) with those of children who do not wear a prosthesis (non-users) using the t-test for independent samples. A t-test for dependent samples was used to compare the performance of children who have a prosthesis, tested for activities with and without their device. P-values ≤ 0.05 were considered significant.

Results

Use of prosthesis

Seventeen of 40 children do not use a prosthesis (non-users), of the 23 children using a prosthesis (users). Twenty-five wore a myoelectric prosthesis, 5 a passive (cosmetic) prosthesis. Of the prosthetic users 5 wore their prosthesis 0-2 hours/day during weekdays.

Method of performance.

In users and non-users bimanual activities are performed independently, users/nonusers need help in 2/3% and are not able to do the activity in 4/1%. Users can use their prosthesis active or passive in 51% of all activities. There is a significant difference ($p < 0.000$) between users and non-users in performing activities with the residual limb. One-handed performance of activities did not differ between users and non-users.

Table 1: method of use prosthesis or residual limb.

Method of performance % of activities	users n=23, mean (SD)	non-users n=17, mean (SD)
prosthesis actively	22 (21)	0 (0)
prosthesis passively	29 (22)	0 (0)
residual limb	34 (28)	88 (10)*
one-handed	10 (12)	8 (9)
some help	2 (3)	3 (3)
cannot do	4 (9)	1 (2)

* Significant difference between users and non-users

Type of activities

In the young child-group, the prosthesis was frequently used for almost all activities. Top 5 includes cycling, eat raisins, open juice pack, climb a slide. Older children reported cycling as an activity in which they used their prosthesis most often, whereas parents hardly reported this activity. Other favorites include: draw a line, open a pencil case, and open a bag of crisps.

Ease of performance

For prosthetic users overall scores on ease of performance were moderate, mean 71.3 (SD 12.6). For only those activities for which the prosthesis was actually used scores on ease of performance were significantly better 86.8 (SD 8.8) ($p = 0.000$). A significant difference was found for users doing activities with prosthesis compared to performance without prosthesis ($p = 0.029$). Comparing the performance of users with non-users, users seemed to have lower scores on overall performance ($p = 0.002$). However, specific performance of activities for which the prosthesis is used, is comparable between both groups (mean score 86.8 versus 89.9)

Table 3: Ease of performance of functional activities.

	Mean	Differences non-users/users without prosthesis	Differences non-users/users with prosthesis	Differences users with prosthesis/without prosthesis
<i>Ease of performance</i>				
Non-users	89.9	$p=0.041^*$	$P=0.002^*$	
Users - without prosthesis	82.8			$p=0.029^*$
Users - with prosthesis	71.3			
<i>Ease, specific activities</i>				
Users - with prosthesis	86.8		$\dagger p=0.227$	$\dagger p=0.195$

* Significant differences between groups

† Differences calculated for users with prosthesis for specific activities

Usefulness

Users perceived their prosthesis useful, mean score was 53.8 (SD 23.3); in specific activities in which they used their prosthesis active or passively usefulness is significantly higher, 78.2 (SD 16.1) ($p<0.000$).

Follow up

Eleven children had two follow-up measurements, 3 children had three, with a mean interval of 1,3 years between the assessments.

Overall, there was a tendency of improved performance over time in the children with prosthesis. The perceived usefulness of the prosthesis for specific activities improved 5 to 10 points in 3 children, 4 children improved 15 to 20 points, and 2 improved more than 30 points. Two children did not change; one child scored about 5 points, 2 about 10 points lower.

Discussion

In previous studies we demonstrated that users (with and without prosthesis) and non-users perform good in functional activities. The present study confirmed that children tend to use their prosthesis for specific activities. In our rehabilitation centers, children and parents get extensive information about the possible benefits of a prosthesis. This gives insight whether prosthesis could be useful, and if so, what type of prosthesis would best fit their individual need. This approach is based on the current practice in our departments, that that possibly not all children need to wear prostheses and that a prosthesis can be beneficial for specific activities, or for a broad range of activities. (4)

The PUFU can be used to evaluate performance and usefulness in users of a prosthesis both on an individual level, and in a larger cohort.

This project contributed to the development of a network with other rehabilitation centers in the Netherlands aiming to combine our data and hereby increase our knowledge on the functioning of children with ULRD. (5) Although the PUFU is developed for use in children with prosthesis, we find part of the PUFU also useful for evaluation of children without prosthesis, especially since no other functional performance measures are available. We look forward to current development of the UFI for the non-prosthetic group.

Conclusion

The study showed that assessing functional activities in children with ULRD using the PUFi provides useful information to monitor patients and to assist clinical judgement and adequate goal setting. Also, the results suggested that the PUFi is capable of measuring change over time in an individual child.

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