FUNCTIONAL OUTCOME OF ADOLESCENTS AND YOUNG ADULTS WITH CONGENITAL UPPER LIMB REDUCTION DEFICIENCY

SAM Lambregts¹², F Doornbosch¹², ME Roebroeck¹, M Rol², JH Arendzen³, JMFB Pesch-Batenburg¹, HJ Stam¹

¹Erasmus MC, University Medical Centre Rotterdam
²Sophia Rehabilitation Centre, The Hague
³LUMC, University Medical Centre Leiden, the Netherlands
e-mail: suzanne.lambregts@wanadoo.nl

BACKGROUND
In the Netherlands approximately seventy children with a congenital upper limb reduction deficiency will be born each year. One third of these children will be eligible for a prosthesis. Little is known about the functional outcome of adolescents and young adults with congenital upper limb deficiency. This study is the second part of a project to investigate the functional outcome of adolescents and young adults with an unilateral congenital upper limb deficiency in the south-west region of the Netherlands. The first part consisted of a description of functional status and level of participation of this group by using postal questionnaires. In this part the adolescents and young adults have undergone a functional assessment.

PURPOSE
This study is performed to gain insight into the functional outcome of adolescents and young adults with an unilateral congenital upper limb reduction deficiency, with or without using a prosthesis. Functional outcome addresses performance of activities and capacity of the upper limbs, the prosthetic skills and the benefit of the prosthesis.

METHODS
Subjects
A cohort of 39 adolescents and young adults aged between 12-35 years with a unilateral congenital upper limb deficiency participated in the first part of the study. All of them were patients at the departments of rehabilitation medicine in the south-west region of the Netherlands. Twenty-seven people agreed to participate in the second part of the study. Twenty-one people with a below-elbow deficiency were selected. One person, who does not use a prosthesis, was lost due of moving to another country between the first and the second part of the study. The mean age was 22.7 ± 6.7 years and there were 11 women and 9 men in the sample. Nine of them used a prosthesis, six used a myoelectric device and three used a passive device. Wearing pattern of the prosthesis, the Skill Index Ranking Scale (SIRS) and other characteristics of the subjects are shown in table 1. The SIRS provide an ordinal scale of a person’s ability with prosthesis (0-14). For example ranking 4 means: spontaneously place the terminal device in position and use it for support; ranking 14: control the grip while moving the arm, throw things from above the shoulder.
Subject | Gender | Age | Prosthesis | Wearing (hrs/day) | SIRS
---|---|---|---|---|---
1 | M | 29.0 | No | 0 | 
2 | V | 20.3 | Yes: myo | 11-15 | 14 
3 | V | 19.6 | No | 0 | 
4 | V | 22.3 | No | 0 | 
5 | M | 15.6 | Yes: passive | 11-15 | 4 
6 | V | 16.0 | No | 0 | 
7 | V | 26.8 | Yes: myo | 6-10 | 14 
8 | M | 20.0 | No | 0 | 
9 | M | 14.7 | No | 0 | 
10 | V | 33.5 | No | 0 | 
11 | V | 18.4 | Yes: passive | 11-15 | 4 
12 | V | 23.2 | Yes*: myo | 0 | * 
13 | M | 27.5 | Yes: myo | 11-15 | 13 
14 | M | 34.8 | Yes: passive | 6-10 | 4 
15 | V | 29.3 | No | 0 | 
16 | M | 15.3 | No | 0 | 
17 | V | 22.5 | Yes: myo | 6-10 | 12 
18 | M | 15.8 | Yes: myo | 6-10 | 12 
19 | M | 33.4 | No | 0 | 
20 | V | 16.6 | No | 0 | 

Table 1. Characteristics of subjects
*Does not wear prosthesis because of oedema

Procedures
Each participant had one visit to one of the departments of the rehabilitation medicine in the south-west region of the Netherlands or were visited at home. Each participant performed the Unilateral Below Elbow Test (UBET) and people using a prosthesis performed the Southampton Hand Assessment Procedure (SHAP). All functional tests were administered by the same investigator (SAML). For people using a prosthesis, the UBET was first performed with the prosthesis followed by test performance without using a prosthesis.

In addition, each participant filled out the Child Amputee Prosthetics Project-Functional Status Inventory (CAPP-FSI) and the Prosthetic Upper extremity Functional Index (PUFI).

Performance of users with prostheses were compared to non-users (without prostheses) by means of a t-test for independent samples; comparison of users with and without prosthesis by means of a t-test for dependent samples.

Instruments
Capacity and prosthetic skills were measured by functional tests scored by a professional: the Unilateral Below Elbow Test (UBET) and the Southampton Hand Assessment Procedure (SHAP). The UBET consists of 9 bimanual activities (the adolescent version, 11-21 years) which have to be performed with and without the prosthesis. The completion of a task and the method of use with the prosthesis or residual limb is scored for each task. The completion of task is scored on a 5-point scale from “no difficulty (= 4)” to “unable to complete the task (= 0)”. Sum scores range from 0 to 36. Method of prosthetic use or residual limb is scored on a nominal scale describing 4 methods of grasp and stabilisation.

The SHAP consists of manipulating a series of lightweight and heavyweight objects of different shapes with the prosthesis based on specific grip patterns and in addition 14 daily activities performed with the prosthesis. The kind of grip and the time of performance of each task or activity is measured.
Performance of activities was assessed by self-administered questionnaires: the Child Amputee Prosthetics Project-Functional Status Inventory (CAPP-FSI) and the Prosthetic Upper extremity Functional Index (PUFI).

The CAPP-FSI consists of 34 upper-extremity daily activities and is focused on the level of independence of performing each activity (range 0-4; 0 = dependent, 4 = independent) and the frequency these activities are completed with the prosthesis versus without.

The PUF1 consists of 38 daily activities (the older-child version) and evaluates the extent to which a person actually uses the prosthetic limb for these activities, the comparative ease of task performance with and without the prosthesis and its perceived usefulness. This is scored respectively on a 6-point nominal scale, 5-point ordinal scale and 3-point ordinal scale. Higher scores represent less difficulty in performance and higher usefulness of the prostheses. Sum scores range from 0 to 100.

RESULTS
All twenty adolescents and young adults completed the questionnaires and tests. Due to oedema, one prosthetic user was unable to perform the UBET and SHAP with prosthesis.

The way people can use their prosthesis or residual limb in performing activities is scored in the UBET and SHAP. The way people do use their prosthesis or residual limb in performing daily activities is scored in the CAPP-FSI and PUF1.

Prosthetic skills
Users manipulate objects with a tripod or spherical grip. Most of the daily activities of the SHAP were difficult to perform with the prosthesis. The most difficult tasks were pick up coins, to undo buttons, turning a page and pouring from a jug.

Method of performance
Results of the PUF1 showed that 93 % of the activities were performed independently; in users this percentage is 90 %, in non-users 95 %. According to the CAPP-FSI and PUF1 independent performance was found in 71% of functional activities. Activities that were most often performed with a person’s assistance according the PUF1 were: to put on a necklace, cut meat with knife and fork, chop fruit, use a can opener, hammer a nail and skipping rope, and according to the CAPP-FSI: peel an apple, sew a button, blow-dry hair and cut meat with knife and fork.

Method of performance is scored by the UBET and PUF1 as shown in Table 2. Subjects can use their prostheses actively or passively in 84 % of the activities as shown by the UBET. However, in daily live persons do use their prostheses in 30 % of the activities as reported by the PUF1.

<table>
<thead>
<tr>
<th>Can do (UBET)</th>
<th>Does do (PUFI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Method of use prostesis/ arm</td>
<td>Users with (n = 9)</td>
</tr>
<tr>
<td>Actively</td>
<td>35 ± 26</td>
</tr>
<tr>
<td>Passively</td>
<td>49 ± 33</td>
</tr>
<tr>
<td>Elbow/trunk</td>
<td>0 ± 0</td>
</tr>
<tr>
<td>One-handed</td>
<td>14 ± 33</td>
</tr>
<tr>
<td>Cannot do</td>
<td>2 ± 6</td>
</tr>
<tr>
<td>Cannot do</td>
<td>4 ± 4</td>
</tr>
</tbody>
</table>

Table 2. Method of use of prosthesis or residual limb in UBET and PUF1. Mean percentage of activities ± standard deviation.
Difficulty and effectiveness of performance
Sum-scores of tests and questionnaires regarding effectiveness or ease of performance are presented in table 3.

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Mean</th>
<th>SD</th>
<th>Min</th>
<th>Max</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>UBET</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Competition of task score</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Range 0 – 36)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-users</td>
<td>34.0</td>
<td>2.1</td>
<td>29</td>
<td>36</td>
<td>0.27</td>
</tr>
<tr>
<td>Users - with prosthesis</td>
<td>32.9</td>
<td>2.3</td>
<td>28</td>
<td>35</td>
<td>0.12</td>
</tr>
<tr>
<td>Users - without prosthesis</td>
<td>34.0</td>
<td>1.7</td>
<td>31</td>
<td>36</td>
<td></td>
</tr>
<tr>
<td>PUF1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ease of performance</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Range 0 – 100)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-users</td>
<td>93.2</td>
<td>6.0</td>
<td>82.8</td>
<td>98.6</td>
<td>0.000</td>
</tr>
<tr>
<td>Users - with prosthesis</td>
<td>60.3</td>
<td>23.3</td>
<td>11.2</td>
<td>91.4</td>
<td>0.007</td>
</tr>
<tr>
<td>Users – without prosthesis</td>
<td>87.5</td>
<td>4.9</td>
<td>78.4</td>
<td>94.0</td>
<td></td>
</tr>
<tr>
<td>Usefulness of prosthesis</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(Range 0 – 100)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Users – with prosthesis</td>
<td>46.7</td>
<td>21.6</td>
<td>9.7</td>
<td>81.0</td>
<td></td>
</tr>
</tbody>
</table>

Table 3. Mean sum scores and standard deviation (SD) and minimum (Min) and maximum (Max) sum scores of UBET and PUF1 of all subjects, non-users (n = 11) and users (n = 9) of prosthesis.

Non-users compared to users with prosthesis performed activities equally well as measured by the UBET. However in daily life, measured by the PUF1, non-users had less difficulty in performance of activities compared to users performing with prosthesis (p = 0.000).

However, when we only take the activities into account in which the prosthesis is actually used (30% of the activities, see table 1) subjects perform these activities easily with prosthesis (sum-score: 94.6 % ± 5.0).

Usefulness of prosthesis
Wearers used the prosthesis on average 10 hours a day and its usefulness was reported to be 46.7 % (SD 21.6) assessed by the PUF1. Usefulness scored by users of a myoelectric prostheses was 55.5 % (SD 18.4). Most activities of daily living, such as dressing tasks, are usually performed without prosthesis. However, persons find the prostheses very useful in specific activities (sum-score: 85.5 % ± 9.7) such as riding a bicycle, pushing a lawnmower and twist the lid of a bottle.

CONCLUSIONS
Adolescents and young adults with a congenital below elbow reduction deficiency perform well in functional activities with or without using a prosthesis. Subjects are very independent in performing daily activities. Nine of the twenty subjects wore a prosthesis on average 10 hours a day. They find their prostheses very useful in specific activities and can perform these activities very easily with prosthesis.

These results suggest that prosthetic devices have additional value in persons with a congenital below elbow reduction deficiency in specific activities rather than in overall performance of activities of daily living.

REFERENCES

Distributed under a Creative Commons Attribution-Noncommercial-No Derivative Works 3.0 United States License by UNB and the Institute of Biomedical Engineering, through a partnership with Duke University and the Open Prosthetics Project.