USING COMPUTERS TO MAKE OUTCOME MEASUREMENT EASIER: INTRODUCTION TO THE SOFTWARE VERSION OF THE PROSTHETIC UPPER EXTREMITY FUNCTIONAL STATUS INDEX (THE PUFI)

F. Virginia Wright, B.Sc (PT), M.Sc; Sheila Hubbard, Dip P & OT, BSc(PT); Jeffrey Jutai, PhD; Stephen Naumann, PhD; Reinhard Schuller, MSc
Bloorview MacMillan Centre, Toronto, Ontario

The work presented in this paper is part of a larger project designed to evaluate the long-term benefits, both functional and psychosocial, of upper limb prosthetics for children. Given the lack of a comprehensive functional status measure designed specifically for children who wear upper extremity prostheses, there is a corresponding absence of knowledge of the functional benefits that a child derives from using one of these devices.

At the time we started this project the only available evaluation tool for this population was the University of New Brunswick's Test of Upper Extremity Function. This observational test was designed for use by therapists to assess a child's prosthetic skill and progress during functional use training. However, other relevant questions arise relating to the extent to which the child actually uses the prosthetic limb for daily activities, the extent of independence achieved with its use, pattern of use from early childhood years through adolescence, and patterns of use associated with different types of prostheses. To address these issues, a new parent/child, self-report questionnaire, the Prosthetic Upper Extremity Functional Index or PUFI was developed by our clinical research group.

Intended to be used as an outcome measure (evaluate client's abilities over extended follow-up period), development of the PUFI started about 5 years ago and has occurred in a series of stages. This multi-stage developmental process has been typical for other functional measures such as the PEDI, [1] and the GMFM. [2] Initial steps included a literature review, generation of a list of two-handed activities common to childhood, a content validity check to ensure "2-handedness" of the tasks, an item reduction process to select the most relevant tasks, development of response options and clinician consensus on content and format.

The instrument begins with Part One: a short questionnaire asking parents to rate overall usefulness of the prosthesis for their child (very, somewhat or not at all) for cosmetic benefit and then 8 broad functional categories. These include personal care, dressing, relaxation at home, school, work, social events, sports and play. This section gives us a global view of parent's/child's impressions of the prosthesis and serves as an introductory section to familiarize the respondents with the concept of function.

Part Two of the PUFI was designed to: evaluate the ways that a child performs 2-handed activities; evaluate the success and value of the prosthetic device use as compared to functional ability without a prosthesis; identify performance difficulties associated with device use; and evaluate change in a child's abilities over time. The PUFI contains 5 response columns for each functional activity. Each column provides different information about the use of the prosthesis (ability to do the task, usual method of performance, ease of prosthetic use, usefulness of the prosthesis, and ease of performance without the prosthesis). The total scores for each column are calculated separately to give a picture of the child's overall status in each column for all tasks.

We designed 2 versions of Part Two to enhance its developmental appropriateness. The younger child version (ages 3-5) has 26 items while the school-aged version (ages 6 - 18) has 38 items. Both versions were designed to be parent report questionnaires. However, the older child version was modified so those children above the age of 8 could respond to the questions themselves, in effect creating a 3rd questionnaire format. The response options structure and scoring of the two versions are the same, allowing continued use of the PUFI with a child through his/her developing years

The second stage consisted of a reliability study. The PUFI's test-retest, inter-rater reliability and aspects of construct validity were evaluated with a sample of children at Bloorview MacMillan. The 25 subjects included 10 young children (3 1/2-5) and 15 older children (6-16) fitted with myoelectric prostheses.

Test-retest results for columns B (usual method of performance), D (usefulness of the prosthesis for the specific task) and E (ease of performance without the prosthesis) were above 0.7. The children appeared to be more consistent in their responses than their parents. Column C, (ease of prosthetic use), proved to be the least reliable. This may have been due to a problem in interpretation of the distinction between the response options.

Inter-rater reliability of parents and children was also examined. Intra-class correlation coefficients were high for Columns B (method of performance) and E (ease of performance without the prosthesis) but low for columns C (ease of performance with the prosthesis) and D (usefulness responses). Again, we felt it was necessary to examine the problem of differentiation of response options for Column C. In the case of column D (usefulness), parent/child agreement was low because the children generally reported their prostheses as being more useful than their parents did. This may be the result of an environmental effect as the children were school-aged and therefore, away from parental observation for a large portion of the day.

Subtle refinements were then done to enhance clarification of wording in the instrument and measures taken to ensure that directions were clear to clients/families. Obviously the pilot study numbers were too small for definitive conclusions but we felt confident that the PUFI would prove to be a reliable measure of a child's ability to perform upper extremity activities with and without a prosthesis.

Stage three, a multi-centre trial designed to investigate the construct validity of the PUFI, (comparison of PUFI scores with UNB and actual observation of PUFI tasks) commenced on May 1, 1998 and will conclude on August 31, 1999. In addition to the PUFI, the families are also being asked to complete two other scales which measure family dynamics: the Family Assessment measure, FAM, [3] to measure areas of family strengths and weaknesses and the Impact on Family Scale [4] to study burden/stress factors.

Four paediatric amputee teams (not including Bloorview MacMillan) in Canada and the United States are participating. Data for 26 children has been entered to date and it is expected that 40 children will be enrolled in total. Involvement of these four centres will provide opportunity to test PUFI with a variety of different types of prostheses. The results will be combined with Bloorview MacMillan validity data.

At the end, we will take a final look at the items to make sure that each one is telling us something of value. Items consistently considered non-applicable or gender-biased will be eliminated. Ultimately we will also want to evaluate PUFI's ability to measure change over time.

In its present form, the PUFI (like other parent and client self-report measures) requires that the child and parent complete multiple, word-only paper forms which may act as deterrents to full completion by respondents. Scoring of paper forms is also time-consuming and cumbersome for clinicians because of the use of reverse patterns in scoring for some questions, separate scoring domains within the questionnaire, multiple choice options and many items, i.e. 38 items on the older - child PUFI but up to 200 items on some other questionnaires. Scoring difficulties encountered by clinicians may inhibit timely sharing of results with families and limit use of the measures. There are also potential problems with: the accuracy of scoring measures that have several domains and multiple response options, the conversion of raw scores to scaled scores and normative scores, and the ability to generate meaningful numeric, descriptive or graphic summaries of the results for the client/family.

It was therefore decided to proceed with a project to design and evaluate point-of-service software to provide a user-friendly, efficient and accurate method for administering and scoring the PUFI. This software will enable the children/parents to use a computer to complete the PUFI questionnaires independently. Using appealing graphics and icons, the software will have a clearly guided completion format with periodic feedback to client, sequential presentation of items, and a mechanism to ensure that questions are not skipped (reduction of missing data). Built-in scoring will allow immediate summarization of scores once the questionnaire is completed so that

results can be shared promptly with the child/parents. Items achieving a criterion score will be displayed to identify strengths, problems, and facilitate goal setting. Results will be saved and called up after subsequent completions to allow ready comparisons of follow-up results. A demonstration version of the PUFI software will be included in this presentation.

We are currently seeking collaboration for field and reliability testing of the software version of the PUFI. Development of the protocol for this field test is being done in accordance with standard practices for pre-testing questionnaires [5]. Field trials will involve having some children/parents at each facility complete the PUFI using the software, and then rate their impressions on the experience using a clinical utility questionnaire. Clinicians will also be asked to rate their experience with the PUFI software focusing on training, administration, feasibility, and scoring issues.

The investigative team and computer programmer will make revisions to the software based on the results of the field-testing. Once completed, test-retest reliability evaluation, in which the child does two separate completions of the computerized PUFI, 2-3 weeks apart, will be undertaken at Bloorview MacMillan and the external facilities. We are hoping to enroll up to 6 children per facility in order to obtain a sample size of 30 children. The reliability phase of the project is expected to commence in November of 1999. The reliability results will be compared with the test-retest results from our previous reliability study with the original PUFI paper forms to ensure that the computerized PUFI approach is at least as reliable as the paper forms. Assuming the reliability results are acceptable, final revisions will be made to the software and manual, and they will be made available to the participating Centres for clinical and research use.

The combined use of the UNB Test (to assess the child's ability to use the prosthesis in a controlled situation) and the PUFI (to evaluate actual performance within a natural environment) is recommended as the way to gain a comprehensive picture of the child's functional capabilities and actual use of a prosthesis. The use of one measure i.e. the PUFI, should increase the interpretability of the other, i.e. the U.N.B. Test.

The cost-benefit of prosthetic fitting for children has been a subject of debate for many years now. The issue is a complex one involving both functional and psychosocial factors and cannot be resolved through the use of a single evaluation tool. Functional benefits of prosthetic fitting do need to be evaluated within the context of a total outcome measure core set. Additional information such as developmental level, family support, peer acceptance, athletic and extra-curricular needs as well as levels of psychosocial adaptation to disability and emotional functioning need to be considered as well. The psychosocial impact of wearing a prosthesis will be explored further in research work planned for this coming year.

REFERENCES

1. Haley, S M , et al. "Pediatric Evaluation of Disability Inventory", New England Medical Centre Hospitals, Boston, 1992.
2. Russell, D., et al. "The Gross Motor Function Measure: a means to evaluate the effects of physical therapy", Dev Med Child Neurol, 31, 341-352, 1989.
3. Skinner, H.A., Steinhauer, PD, Santa-Barbara, J. "Family Assessment Measure III (FAM-III). Multi- Toronto Health Systems, Inc., 1998
4. Stein, R.E., Riessman, C.K. "The development of an impact - on - family scale: preliminary findings", Medical Care, 18 (4), 465-72, 1980.
5. Blair, J , Presser, S. "Survey procedures for conducting cognitive interviews to pretest questionnaires: a review of theory and practice", In Proceedings of the Section on Survey Methods research, Alexandria, Virginia: American Statistical Association, 1993