

## **OUTCOME ASSESSMENT OF UPPER EXTREMITY PROSTHETIC DEVICES**

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### **INTRODUCTION**

Upper extremity prosthetic devices have been available in several types, such as body-powered and electromechanical (myoelectric- or switch-operated), for many years. There is now a significant interest among device developers and service providers in scientific studies of the long-term consequences or outcomes associated with device prescription and use. The relevant information is not well-documented at present. Consequently, there are no reliable data to refer to in evaluating and comparing various types of device or device innovations, in relation to their costs or value in terms of outcomes. This makes it difficult to convince research funders of the need to develop one kind of device over others, or funding agencies to contribute to the costs of more expensive equipment or newer technology.

While current development activity is focused on enhancing durability and functionality, service providers are also concerned about psychosocial outcomes. Acceptance of an upper-limb prosthesis is a complex process that involves occupational, psychological, and socioeconomic factors in addition to the technical performance of the device [7]. The process is further complicated for paediatric clients where issues of child development and family involvement come into play. There is no standard definition, let alone approach to measurement of a successful outcome for upper extremity fitting across clinics and development sites. Minimally, what is needed at this time is a standardized approach to the collection and evaluation of clinical data, such as utilization, satisfaction and rejection rates, and research to determine what other forms of data should be collected in a standardized fashion to assist developers and service providers in promoting positive outcomes.

Our project was developed initially to respond to the specific needs of the Amputee Program at The Hugh MacMillan Rehabilitation Centre (HMRC) in the areas described above. We realized the relevance of our research to other centres in North America, and the importance of developing a longer-term, prospective focus for our work plan, to include multi-centre collaboration in the design of assessment tools and data collection. The project's enhanced scope was ideally suited to the mission of the Ontario Rehabilitation Technology Consortium (ORTC). The Prosthetics and Orthotics Research Team and the Psychosocial Evaluation Team of the ORTC linked up with members of the HMRC clinical services to produce the research plan featured in this report.

The ORTC is developing innovative rehabilitation technology-based products and services that enhance the lives of persons with disabilities, their families and their communities. Initiated in 1991, the ORTC received a commitment of \$15 million and a 10-year mandate from the Ontario Ministry of Health beginning January 1, 1992, under the direction of Dr. Morris Milner at the HMRC. Nine research

and development teams have been established to address assistive technologies in the following areas: Communication, Hearing, Mobility, Prosthetics and Orthotics, Psychosocial Evaluation, Respiration, Seating, Telecommunication and Vision.

The Prosthetic Team, led by Dr. Stephen Naumann, HMRC, and Dr. Sandra Olney, Queen's University, is developing new lower limb prosthetic components and upper limb electronic control systems. The Psychosocial Evaluation Team (PSET), led by Dr. Jeff Jutai, HMRC, consists of social scientists who support ORTC research teams in the areas of psychosocial evaluation and consumer research.

The present membership of our research project team includes Sheila Hubbard, HMRC Amputee Program, Jeff Jutai, HMRC Research Department and ORTC, Virginia Wright, HMRC Research Department, Stephen Naumann, HMRC Rehabilitation Engineering Department and ORTC, and Reinhard Schuller, HMRC Research Department and ORTC.

### OVERVIEW OF OBJECTIVE, METHODS AND PROGRESS TO DATE

The goal of our project is to determine what factors predict the long-term functional use, and user satisfaction with upper extremity prosthetic devices. Initially we are targeting device users in the age groups of 2-to-5 years (pre-school) and 6-to-10 years (early school), relating to two distinct periods in child development. The 2-5 year age period is a time of rapid development and practice of many new skills; and, the 6-10 year period is a time of steady progress and the perfecting of skills [8].

To date, the project team has completed a critical review of the literature on outcomes assessment for prosthetic devices. Arising from this review, we have selected several measurement tools to include, or adapt for inclusion, in the prototype version of a questionnaire package that is designed for clinicians, clients and their parents to complete. Information will be collected in the following areas: demographic; nature and history of amputation or limb deficiency; history and satisfaction with device prescription and use; functional use; child behaviour and well-being; family function, cohesiveness and communication. Wherever possible, the package includes standardized, validated instruments of measurement in these areas. The components of the questionnaire package are described below.

In order to assess the content validity and feasibility of collecting these data, we are enlisting the help of groups of clinicians, device users and their parents, and non-users (i.e., people who may have abandoned or rejected a prosthetic device) in key informant reviews of the questionnaire package. Methods of review include written correspondence, focus groups, and interviews. We are using the feedback obtained from these reviews to design pilot tests for the package with small, select groups of clinicians, users and their parents. These should be completed by the end of this year. Early in 1996, we plan to begin a large-scale, multi-centre study to determine the clinical utility and predictive power of information collected by using the package over a period of several years.

### SUMMARY OF PROGRESS IN KEY AREAS

#### Focus on the Perceptions of Parents

Information will be collected from clinicians and clients, where appropriate, but parental reports will be emphasized. In agreement with others, we decided to focus on the perceptions of parents in our proposed assessment system, for the following reasons:

1. Parents are the most universally available informants;
2. Parents are the most knowledgeable about their child's behaviour across time and situations;
3. Parents are almost always involved in the evaluation and treatment of their children;
4. Parental reports, like those of all other informants, may be biased but their views of their child's behaviours are usually crucial in determining what will be done about it;

5. Problems arising in interactions with parents are likely to be especially important for children's long-term adaptation, regardless of what causes the problem;
6. In evaluating outcomes, parents' perceptions of change are important in determining whether further help will be needed or sought [1].

### **Collection of Background and Clinical Information**

Essential background, demographic, personal and clinical information is captured in an adaptation of an instrument developed by Atkins and colleagues [2]. This questionnaire was designed for use in a large-scale study of upper extremity prosthetics in the United States. It collects data relating to wearing patterns, functional use, and satisfaction, in addition to information about the nature and extent of limb deficiency, and characteristics of the fitted prosthesis. Preliminary research has shown it to be helpful in predicting wearing patterns and device preferences of children who have been fitted with myoelectric and body-powered devices. For the purposes of our research, the Atkins questionnaire was modified to enhance its generalizability to Canadian clients and services. It was extended substantially in the directions described below. Fundamentally, we needed to generate items suitable for very young children, have them be consistent with theory and research in child development, and to develop an approach to item presentation and response options that could be applied consistently across the age range of interest.

### **Assessment of Functional Outcome**

From our review of the literature, we identified a need to develop a questionnaire to assess parents' perceptions of functional use of the prosthetic device. The functional index will focus on bilateral functional activities for children with unilateral upper extremity limb loss. The activities selected for the questionnaire were chosen to represent different types of action, and age appropriate needs. The following information will be captured in the questionnaire: i) How often does the child use the prosthesis in daily activities?; ii) How is the prosthesis used in the activity (e.g., active, passive, not used)?; iii) How skilled is the child in performing the activities?; iv) How well does the child perform the same activities with the residual limb?; and v) Are there different ways a child does each activity, and in order of what frequency?

Questionnaire content was suggested from the following reviews:

- i) a search of literature from the past 10 years that looked at the evaluation of physical function of both adults and children with upper extremity limb loss;
- ii) a review of paediatric functional assessments, done in order to select developmentally appropriate activities as well as to assist in the selection of questionnaire format and questions; and,
- iii) a review of current child development literature in order to select activities that would be developmentally appropriate.

Content validity will be determined as a three stage process.

1. **Item generation:** The original activity list had 33 items in the 2-5 age section and 33 items in the 6-10 age section. The content items were categorized into dressing, grooming, feeding, play and school/community activities. This list was then sent to a group of occupational therapists and teachers at HMRC for evaluation and additional item generation. The therapists and teachers at HMRC were asked to comment on the items selected and to add any additional activities that they felt were missing and would enhance the comprehensiveness or be preferred to the items listed. The item generation process produced a total 113 activities for the 2-5 year old range and 160 for the 6+ age range.

2. Item reduction: In order to choose the best items for the final functional index, a format was devised for item reduction. Raters (occupational therapists at HMRC, external key informant therapists, and selected mothers of prosthetic clients) were asked to evaluate the items according to i) importance to a child's daily functioning (scale 1-3), ii) bilateral nature (scale 1-3) and iii) age-appropriateness (ü). Item reduction is in progress and an attempt will be made to achieve a balance among the item categories (e.g. dressing, grooming, play), context (e.g. school, home, community) and the actions associated with these items (e.g. pushing, pulling, turning).

3. Response design: The nature and format for responses is currently under development. The questions will be designed to elicit information on how the activity is performed, the nature of prosthetic utilization and how often the residual limb is used as effectively, or in preference to, the prosthetic device.

Next steps include an assessment of the instrument's test/re-test reliability for parents' perceptions over an interval of about 3 weeks. We are also planning to do a preliminary determination of validity by correlating scores with those obtained from clinician-observer assessments using The University of New Brunswick Test of Prosthetic Function [10].

### **Assessment of Psychosocial Outcome**

We propose to assess outcomes relating to child behaviour and well-being using the Child Behaviour Checklist (CBCL) - Parent Report Form [1]. The CBCL is well-researched measurement tool. It has a demonstrated usefulness in assessing psychosocial factors relating to the population of children with limb deficiencies where, for example, it has revealed a number of potentially modifiable predictors of the psychological adaption of children with limb deficiencies that may help direct intervention [4] [12]. The CBCL is an efficient, inexpensive tool for obtaining parents' reports of their child's behaviour and to relate it to norms for the child's sex and age [1]. It can be completed by the parent before a clinic visit in the waiting room or earlier at home. As its authors point out, CBCL results can alert a health service provider to areas requiring further exploration and can provide a basis for answering parents' particular concerns. Regarding children with physical disabilities, the CBCL can help to discriminate between age-appropriate problems and those specifically associated with a particular disability. For our purposes, an added advantage is that the CBCL can be used to accumulate data on the behaviours and well-being associated with various stages in the course of rehabilitative intervention. The CBCL will be included in our questionnaire package, with only minor adaption to allow for the special circumstances that may relate to limb deficiency.

In order to identify key issues associated with family function, we are including the brief version of the Family Assessment Measure (Brief-FAM) [10]. The instrument has good measurement properties and clinical relevance [3] [5], as well as ease and flexibility of administration and scoring [6]. Parents and older children in the same family will both be encouraged to complete the Brief-FAM, in order to compare their perceptions of family function, cohesiveness and communication.

Although most of the project has focussed on the parental perspective, it was felt that the information obtained would be incomplete without self-reports from the children themselves. How children feel about themselves and their satisfaction with their prostheses can be best measured through the domain of self-concept. This area has been widely explored in other populations of disabled children and adolescents, but Varni [11] is the primary researcher to date to examine self-concept in a limb deficient population, and his work has not yet been replicated.

Thus far, approximately 90 tests purporting to measure childhood self-concept have been examined and 10 scales have been short listed for further investigation. These measures are being critiqued on the basis of being: age appropriate; sensitive to change; reliable and valid; multidimensional (e.g. measuring physical self-concept separate from global self-concept); having been previously used with other populations of physically disabled children; and being philosophically consistent. It appears that two measures will need to be selected to encompass the age span. Dimensional scores from the selected self-concept instruments will be tested for correlation with the family and behavioural measures.

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