

PRIORITIES FOR IMPROVING MYOELECTRIC PROSTHESES AS DEFINED BY THE CHILD USERS AND THEIR PARENTS

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INTRODUCTION

Individuals with upper limb loss are taking a greater interest and a more active role in their rehabilitation and prosthetic experiences. Many now recognize that they can influence the type and scope of rehabilitation programs being provided and are searching for the most effective means of using this influence in promoting services and prostheses that address their needs.

Using a survey format, The Institute for Rehabilitation and Research, (TIRR) provided a unique avenue for individuals with upper limb loss to voice their opinions on many aspects of their prosthetic experience. In September, 1992, with support from the National Institutes of Health / National Center for Medical Rehabilitation Research (NIH/NCMRR) and in collaboration with many centers involved with amputee rehabilitation across the country, TIRR received responses from over 2,400 individuals with upper limb loss. The National Upper Limb Amputee Data Base was established by December, 1993. The availability of this data provided by these individuals represents an important contribution toward efforts to develop rehabilitation solutions to problems faced by people with upper limb loss. For the first time, data on a substantial number of persons with upper limb loss is available to guide efforts toward the development of technological and service programs designed to address the needs of these individuals.

This paper will present the responses from a specific subset of the data base population; namely those respondents under the age of 18 who currently use a myoelectric prosthesis or who have used one in the past. General demographic and etiologic data describing this population will be presented, as well as information on the type, cost and wearing patterns of the myoelectric prosthesis used. Perhaps of most importance to the professional in the field will be the examination of those aspects currently lacking in the available technology that the users view as most important to incorporate when improving the quality and utility of a prosthetic device. User opinions about physical properties of their current myoelectric prosthesis such as weight, appearance, maintenance and battery life will also be addressed.

BACKGROUND

In September of 1992, TIRR received funding from National Center for Medical Rehabilitation Research (NCMRR) for a two-year research project. This funding was intended to: 1) establish

a national data base on upper-limb loss, 2) develop a comprehensive survey to obtain information on prosthetic use and on the perceived needs and preferences of persons with upper limb loss with regard to prosthetic services, and 3) identify priorities for future upper limb prosthetic research and development. The survey was designed to gather data from people with upper limb loss who use body-powered prostheses, those who use electric prostheses, and those who do not use any prostheses.

The focus of the initial phase of this project was to identify as many people as possible with upper limb loss. Assistance in this effort was secured from prosthetists, physicians, rehabilitation facilities, children's hospitals and clinics, general hospitals, adult support groups, parent support groups, university hospitals and medical schools, and manufacturers.

As a first-step in developing the national data base, a one-page survey was developed requesting information from people with upper limb loss. This information included name, address, ethnic origin, date of birth, etiology, level of amputation, type of prosthesis, prosthetic use and type of job if employed. Additionally, a single page "Informed Consent" form was prepared.

Identification of people with upper limb loss was facilitated by staff members of 104 centers (clinics, hospitals, prosthetists, support groups, etc.) across the United States who helped with mailing the one-page survey, consent forms and a stamped, self-addressed return envelope to each child and adult with upper limb loss served by the center. People with limb loss willing to participate returned the survey and a signed consent form to TIRR in the self-addressed envelope. This identifying information was entered in the data base. To date approximately 6,200 one-page surveys have been sent and returns have been received from well over 2,400 participants. This reflects a return rate of slightly over 38%. This one-page survey response data was used to create the National Upper-Limb Amputee Data Base.

Based on information provided by individuals completing the one-page survey, another survey requesting more detail was sent. Three versions of the more detailed survey were prepared and sent to individuals according to whether the one-page survey data indicated that the person (1) had lost one limb and used a body-powered prosthesis, (2) had lost one limb and used a myoelectric prosthesis, or (3) had lost both upper limbs. Persons who indicated that they did not use a prosthesis were sent a body-powered or myoelectric survey (based upon the type of prosthesis previously used) and asked to answer only those questions with which they felt comfortable. Persons who had made the choice to not wear a prosthesis or who reported never having been fitted with a prosthesis, were sent a body-powered survey and requested to answer only the applicable questions on demographics and etiology.

To date, 1,505 individuals have completed and returned the long, 7-page surveys. This represents a 61% response rate from the group who completed the initial one-page survey. Results from 2,468 single page surveys are presented in this paper, and particular emphasis is placed upon

summary data from 212 long myoelectric questionnaires from child users.

RESULTS

One-Page Survey: At this time, 2,468 individuals responded to the initial, one-page questionnaire. Ninety seven point three percent of these respondents said they would be willing to complete a longer survey. Of the population, 1,210 were adults and 1,075 were children under the age of 18. (183 individuals did not identify a year of birth.) The ratio of male to female in the adult population is 78% male to 22% female, and for the child population, the ratio is 50% male to 50% female. This is consistent with the patient population seen at TIRR on an outpatient basis. Among the adults, limb loss due to traumatic injury was most frequently indicated, with 75.6% reporting this etiology. The child population, as might be expected, overwhelmingly reported a congenital limb deficiency with 91.4% of the children citing this cause.

Table 1 represents the levels of unilateral limb loss in the adult and child population. The majority of children indicated limb loss below the elbow. Adults also show a high incidence of below elbow limb loss, but experience a marked increase of above elbow loss when compared to the children. Shoulder disarticulations are also more common among adults.

Table 1: Levels of Unilateral Limb Loss in the Child and Adult Populations

CHILDREN (n=1,075)					ADULTS (n=1,210)				
PH	BE/WD	AE/ED	SD	Bilat	PH	BE/WD	AE/ED	SD	Bilat
7.1%	71.6%	11.9%	2.7%	6.7%	1.4%	56.9%	24%	9.4%	8.3%

When asked to identify the type of component used, 55.7% of adults chose the body-powered hook compared to only 34.0% of children. Myoelectric hand use was indicated by 34.2% of children as compared to 28.1% of adults. Ten point eight percent of adults reported using no prosthesis and 5.4% indicated "other" types were used (ex. passive, sports terminal devices, etc.) In the child population, 17.8% use no prosthesis and 14.0% use "other" types.

A scale to rate prosthetic use was presented on the survey, and individuals were asked to estimate their use time ranging from "never" to "all the time." Adults showed a higher percentage of "all the time" use (49.7%) when compared to children (23.0%) Conversely, children were more likely to be "occasional" users, (60.4% of children vs. 38.2% of adults.)

As mentioned previously, three longer versions of the survey were created to address individual areas associated with each group (body powered, myoelectric and bilateral.) The body powered survey was completed by 989 individuals, the myoelectric survey by 399 people, and the bilat-

eral survey by 117. For the myoelectric population, adults represented 46.7% (186) of the population with children as the remaining 53.3% (212). The remainder of this paper will focus on 212 children who use myoelectric prostheses and who completed the longer, 7-page myoelectric survey.

Long Myoelectric Survey: Child Respondents. Male children accounted for 40.5% of the child population and female children for 59.5%. Figure 1 shows the breakdown of the child population based upon the following age groups: 0-3 years, infant/toddler; 4-6 years, preschool; 7-12 years, grade school; and 13-17 years, adolescent.

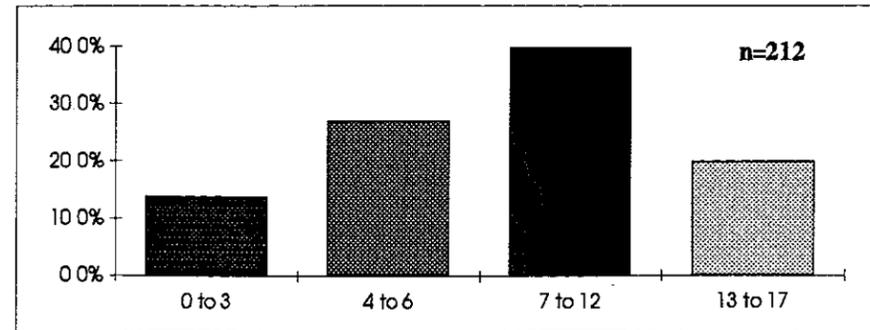


Figure 1: Age Breakdown of Child Population

Forty one point three percent of the children had limb loss on the right side while the remaining 58.7% experienced loss on the left side. Similar to the one page survey results, below elbow/wrist disarticulation was the most often reported with 76.6% of the children indicating this level. Above elbow/elbow disarticulation followed with 12.9%, next was partial hand at 6.2% and lastly was shoulder disarticulation at 4.3%. Once again, a congenital limb loss ranked above all other etiologies at 95.8%. Limb loss due to trauma accounted for 3.3% and disease for 0.9%.

Asked to identify the type of prosthesis used, 89.6% of the children identified an electric hand. Seven point seven percent used an electric elbow in combination with the electric hand. The remainder indicated either an electric hook or a body-powered elbow with an electric hand. When asked if they had therapy to learn to use their prosthesis, 89% said yes. Of those that did have therapy, 96% stated that therapy was valuable in learning to use the prosthesis. Figure 2 shows a rather equal distribution in the amount of therapy received. Greater than thirty hours of training was the level most often selected.

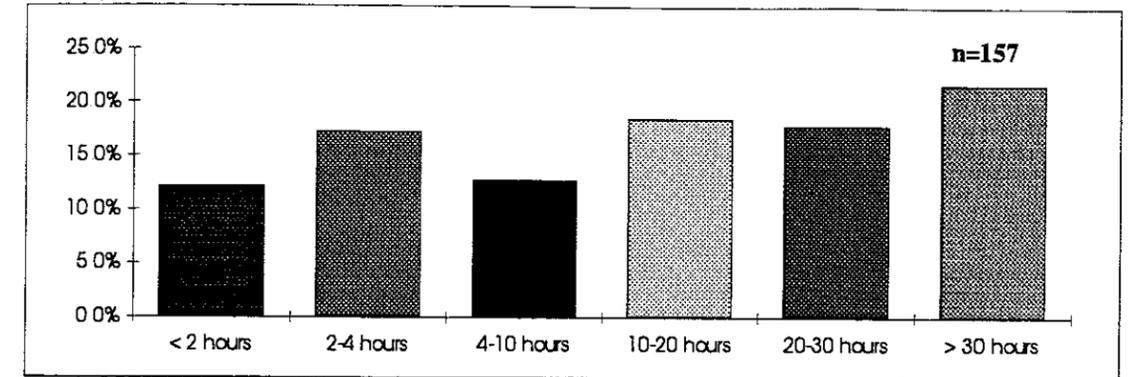


Figure 2: Hours of Therapy Received by the Child Population

Cost of a myoelectric prosthesis is a large concern of many parents whose children use myoelectric prostheses. Figure 3 demonstrates the response to the question "Considering what your prosthesis does for you, how would you rate its cost?" It is evident that some parents are concerned about the high cost of myoelectric prostheses. A certain portion of the survey population could not comment on this issue because they received partial or total financial support for the prosthesis through institutions such as Shriners Hospitals, Scottish Rite Hospitals, Variety Clubs, etc., and therefore were unaware of the total costs.

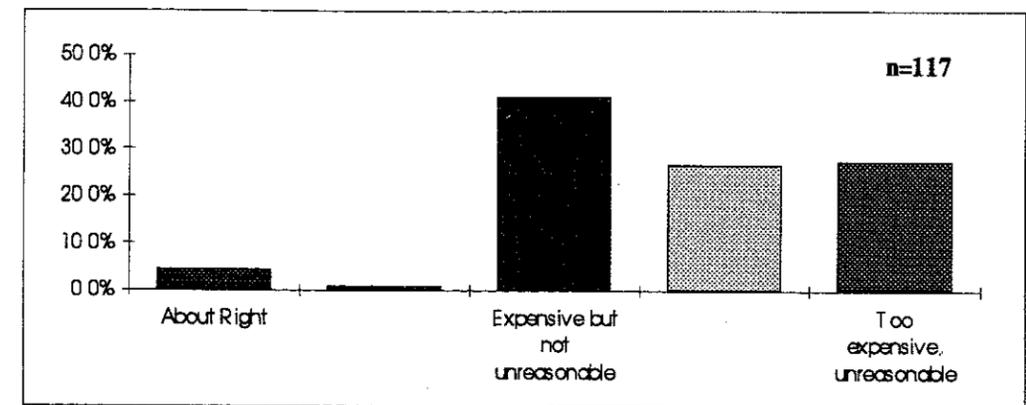


Figure 3: Cost Rating of Myoelectric Prostheses.

Figures 4 and 5 show the difference between the total "wearing" time of the prosthesis and the "use" time of the grasping features offered by the prosthesis. The majority of children fall in the center category of "occasional" use and wear. Figure 5 suggests that "occasional" use is most common and when compared to Figure 4, suggests that "all the time" wearing patterns do not necessarily lead to "all the time" use patterns. This has important implications when one places what may prove to be unrealistic expectations placed upon a child to wear their prosthesis "all the time."

A child will wear a prosthesis when they find it useful for them, and simply remove it when they can accomplish an activity more quickly and efficiently without it. Excessive heat, certain types of games and play that occur in and around water and dirt do not lend themselves to a child needing to wear and use the prosthesis "all the time."

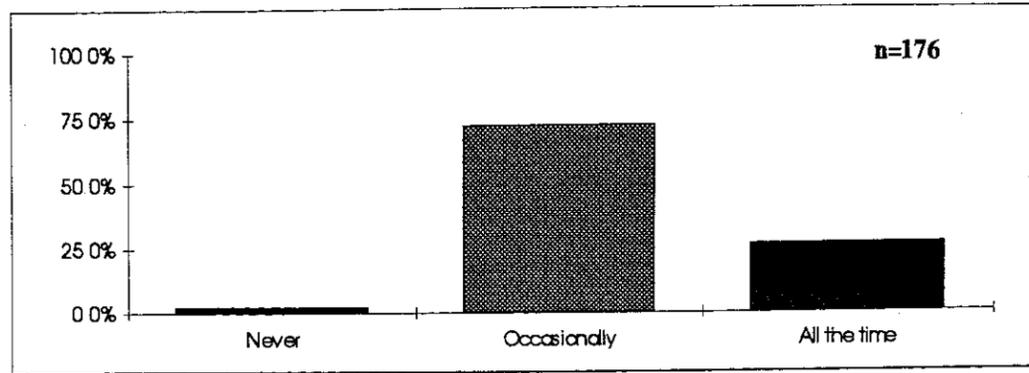


Figure 4: Wearing Patterns of Children with Myoelectric Prostheses.

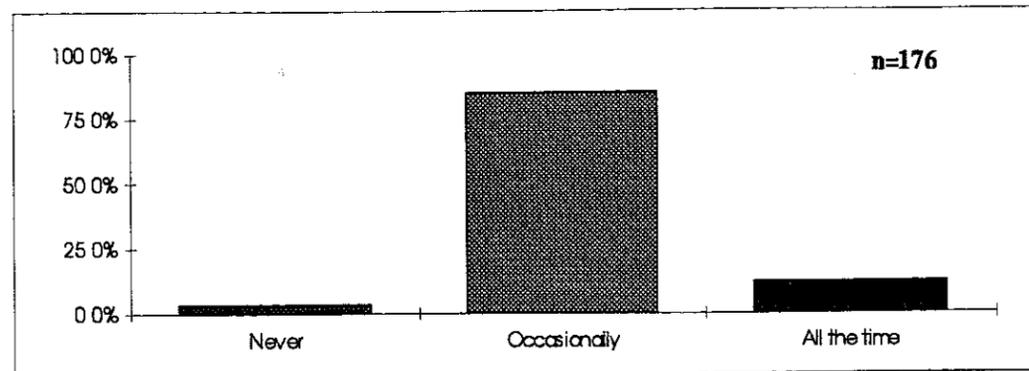


Figure 5: Use Patterns of Children with Myoelectric Prostheses.

The final three sections of the survey asked individuals to rate certain aspects of their prostheses on a scale from one to five; one being "excellent", five being "not acceptable." The first statement, "Considering your present prosthesis, please rate the following factors:", had 19 items ranging from appearance, to weight, to finger movement, to electric reliability, etc. At the end of the list, participants were asked to circle the three items from the list that would be most important to improve. The second statement, "I would like my prosthesis better if...", offered 17 statements to finish the sentence. Again these final statements dealt with a variety of prosthetic issues. Participants were once again asked to circle the three statements which were most important to them. Table 2 presents the top answers taken from the circled items on the surveys. Many of the items

circled on the children's surveys were also identified as important by the adult population.

The most important things I would like to see improved about my prosthesis....	I would like my prosthesis better if....
Glove Material	...I could use it in vigorous activities
Length of Battery Operation	...the fingers could bend
Finger Movement	...the glove held up better
Total Weight	...the wrist moved the palm up and down
Electric Reliability	...it required less of my visual attention to perform certain functions
Speed of Opening and Closing	...I could do coordinated motions of two joints at the same time

Table 2: Priorities for Improvements

The third and final section of the survey presented a list of 34 different activities and asked the individual if he/she could perform these activities using the prosthesis. Nineteen activities were one handed and the remainder were two handed activities. "Yes", "No" and "Don't Know" were the available choices. They were again asked to choose the five activities that they cannot currently do, but would like to be able to do with their prosthesis. Table 3 lists the top activities identified by the child population.

Activities I would like to be able to do:
Tie Shoe Laces
Drink from a Glass
Cut Meat
Open a Door with a Knob
Type/Use a Word Processor
Fasten a Button

Table 3: Desired Activities

CONCLUSIONS

This data base project represents an important beginning step in assuring that users have substantive involvement in any future technological innovations in the field of prosthetics. Their needs and preferences are of utmost importance since they rely on this technology to assist them in daily activities. Through this survey, children and adults with various types of prostheses, have provided ideas and comments which will serve as ground work for considering future prosthetic advances.