

THE UPPER EXTREMITY PROSTHETIC PRESCRIPTION: USER SATISFACTION AND INDICATORS FOR CHANGE

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INTRODUCTION

It has been documented that there are between 85,000 to 90,000 individuals with upper limb-loss in the United States, half of whom wear no prosthesis at all. [1,2] The question of why some people with upper-limb loss do not wear, and actively use their prosthesis, must be asked.

In order to address some of these issues, The Institute for Rehabilitation and Research (IIRR) in Houston, Texas, applied for a grant from the National Center for Medical Rehabilitation Research (NCMRR), a newly formed center under the National Institute of Health (NIH). In September, 1992, IIRR was awarded a two-year grant designed to accomplish the following; (1) to establish a national data base of persons with upper-limb loss and (2) to develop a comprehensive survey to evaluate their past use, current needs and preferences, and specific considerations that will help define future upper-limb prosthetic research. The original intent of this grant was to focus on an improved design of an electric prosthesis only. In response to a tremendous number of telephone calls and remarks recorded in a one-page survey from body-powered prosthetic users, additional goals have been included that will address (1) the identified shortcomings of body-powered and electric prostheses and (2) the essential functions that users of body-powered and electric prostheses identify as being necessary in the design of a better upper-limb prosthesis.

BACKGROUND

The emphasis of the first funded year primarily addressed the first goal of establishing a national data base of children and adults with upper-limb loss. To do this, it was necessary to enlist the assistance of prosthetists, physicians, rehabilitation facilities, children's hospitals and clinics, general hospitals, adult and child support groups, university hospitals and medical schools, as well as manufacturers across the country to identify as many people as possible with upper-limb loss. These included body-powered and/or electric prosthetic users, as well as those who use no prosthesis at all.

An initial goal of this project was to design a simple one-page survey that included baseline information, such as the participants name, address, ethnic origin, date of birth, etiology, level of limb-loss, type of prosthesis, prosthetic use and type of job if employed. Additionally, a single page "Informed Consent" form was prepared.

In response to the nationwide request for assistance in locating people with upper-limb loss, 99 centers (clinics, hospitals, prosthetists, support groups, etc.) across the United States assisted with mailing the one-page survey and "Informed Consent". The response to this initial one-page survey has been most encouraging. IIRR received an average of 5-7 phone calls a day from individuals, particularly mothers of limb deficient children, who were extremely interested and anxious to participate. By June 1993, 4,843 one page surveys had been sent to children and adults with upper-limb loss throughout the country and 1,594 surveys had been returned. Completed surveys continue to be received daily and it is anticipated a total of approximately 2,500 will be received by the deadline of July 31, 1993. The number of responses at that time will constitute the initial data base of

people with upper-limb loss created for this study. Thus far 97% of the respondents have agreed to complete another, more comprehensive questionnaire that will be sent during the second year.

The major points of the one-page survey are summarized in the following charts and graphs. It should be noted that these are the preliminary findings only, and provide us with a starting point to more comprehensively address these and many other data points during our second funded year.

ESTIMATED INCIDENCE OF CONGENITAL UPPER-LIMB LOSS

In the past ten years, there has been essentially no reliable information gathered which allows for an exact determination of how many children are born with upper-limb loss and how many adults or children have lost their arm (or arms) secondary to trauma or disease. Several countries have attempted to estimate the incidence of congenital limb deficiencies; however, these estimates vary considerably. The most consistent similarity is noted between the Canadian Congenital Anomalies Surveillance System (CCASS) from 1980-1984, and the data reported by the Association of Children's Prosthetic and Orthotic Clinics (ACPOC) in 1980. Surveys done by the United States Center for Disease Control from 1979-1983, and researchers in Italy in 1985, both resulted in ratios consistent with the data found from the CCASS survey. From the birth census data, the estimated incidence of congenital upper-limb deficiencies is approximately 1:4200 live births [3].

PRELIMINARY RESULTS

Age and Sex

Of the 1,594 respondents, 596 (37%) were children under the age of 18. The responses of 507 children with upper-limb loss under 13 were filled out by adults. Of the children, 53% were male and 47% were female. This represents a male/female pediatric incidence of limb deficiency consistent with that reported by the majority of children's clinics throughout the United States.

For the purpose of this analysis, the "child" population included all participants under the age of 18. However, the final Year Two report will categorize results for three distinct population groups: (1) Child, ages 0-12; (2) Adolescent, ages 13-17 and; (3) Adult, ages 18 and over. This acknowledges the different developmental and functional needs of each of these groups.

Of the 1,594 respondents, 988 (62%) were adults. Of the adults, 78% were male and 22% were female. Although there are no national statistics to support this male/female ratio, it should be noted that these percentages are consistent with the populations of larger rehabilitation centers. The Institute for Rehabilitation and Research has a ratio of 83% male to 17% female, and Linda Miner, OTR, at the University of Michigan Program estimated an 80% male to 20% female population.

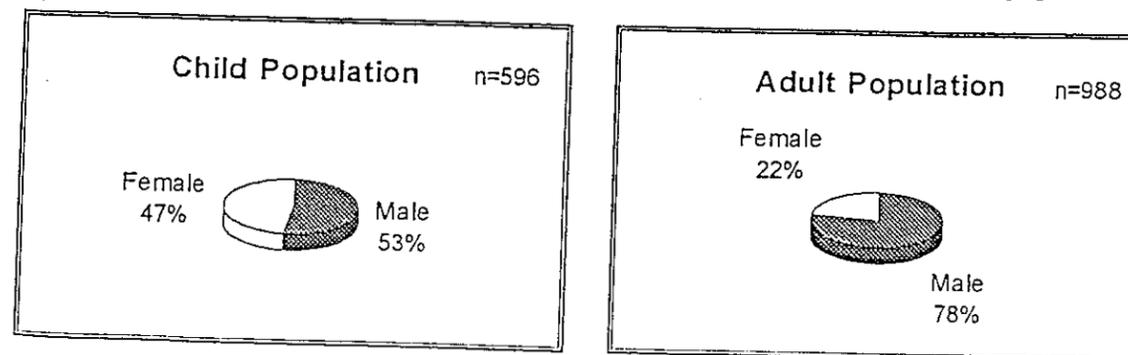


Figure 1: Male/Female Ratio in Survey Population

Ethnicity

Respondents in both child and adult populations were mostly white (88%) Four percent were Black, 4% Hispanic, and 2% other. Every effort was made to obtain appropriate representation based on gender and ethnicity. It is hoped that the minority representation will be increased in Year Two.

Etiology of the Upper-Limb Loss

In response to the question "How did you lose your arm(s)?", 88% of the children reported a congenital loss or their arm(s), whereas among adults, only 14% report this as the etiology of their limb loss(es). Among adults, the principal cause of limb loss is trauma (77%), whereas only 9% of children lost their arms in this manner. Disease was the cause of limb loss in 2% of children versus 8% of adults.

Children	Congenital	Trauma	Disease
	532 88.5%	55 9.2%	14 2.3%

Adults	Congenital	Trauma	Disease
	138 14.1%	761 77.4%	84 8.5%

Figure 2: Etiology of Limb Loss in Child and Adult Survey Population

Level of Amputation

Among children with upper-limb loss, of whom 88% had congenital losses, 56% had left arm losses, 37% had right arm losses, and 7% had lost both arms (0.5% did not report). Among adults, of whom 86% had lost their arm(s) due to trauma or disease, 44% report left arm loss, 46% had right arm loss and 10% report loss of both arms.

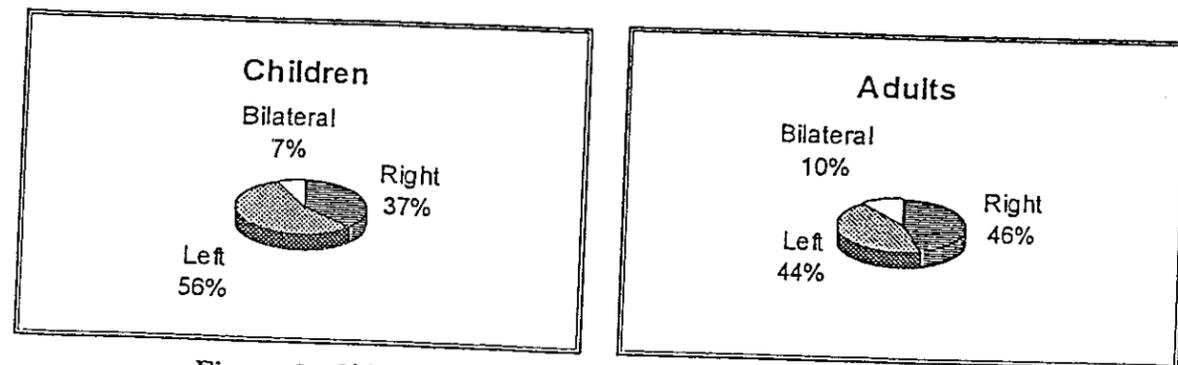
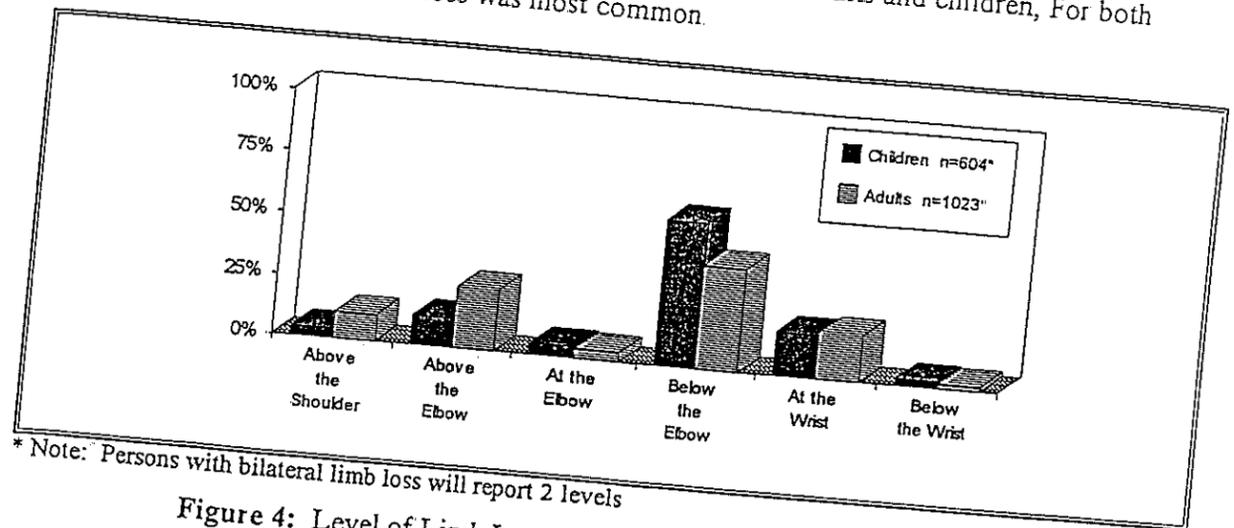


Figure 3: Side of Limb Loss in Child and Adult Survey Population

The following graph illustrates the levels of limb loss for adults and children, For both populations, below the elbow loss was most common.

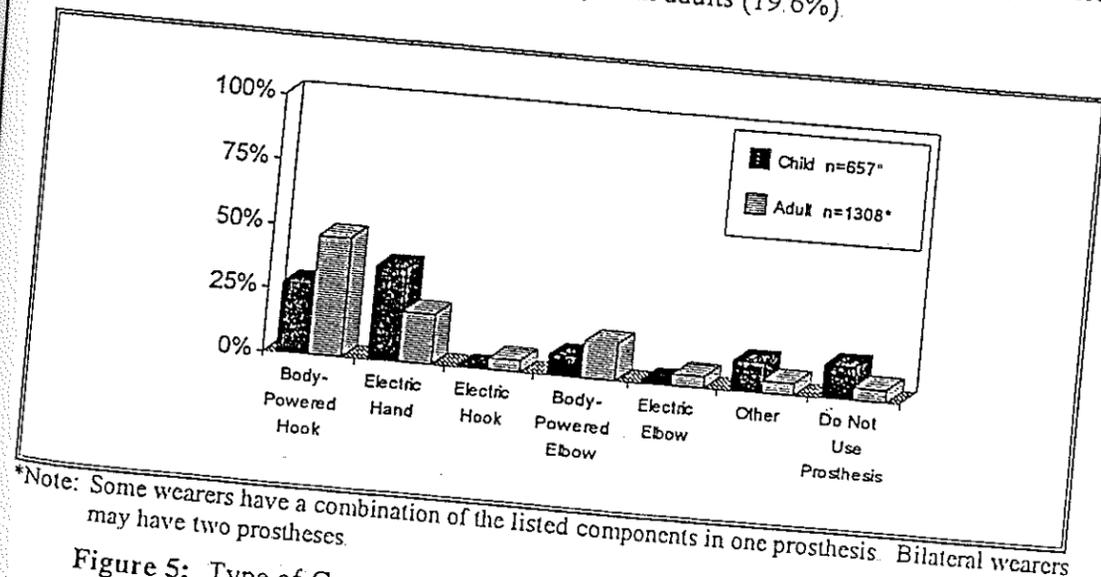


* Note: Persons with bilateral limb loss will report 2 levels

Figure 4: Level of Limb Loss in Child and Adult Survey Population

Prosthetic Componentry

The graph below represents the most commonly used prosthetic devices. Fifteen percent of children and 7% of adults reported using no prosthesis. Adults are significantly more likely to report using a hook than children (47% of adults use hooks compared to only 27% of children). The next most commonly used device, the electric hand, was used by significantly more children (36.7%) than adults (19.6%).



*Note: Some wearers have a combination of the listed components in one prosthesis. Bilateral wearers may have two prostheses.

Figure 5: Type of Component Used in Child and Adult Survey Population

Prostheses Use

The following responses, by age group, answers the question "How much do you use your preferred prosthesis?" Analysis of variance indicates that adults tend to use their prostheses (i.e. "All the Time") more than children ($F=56.2, p<0.0001$.)

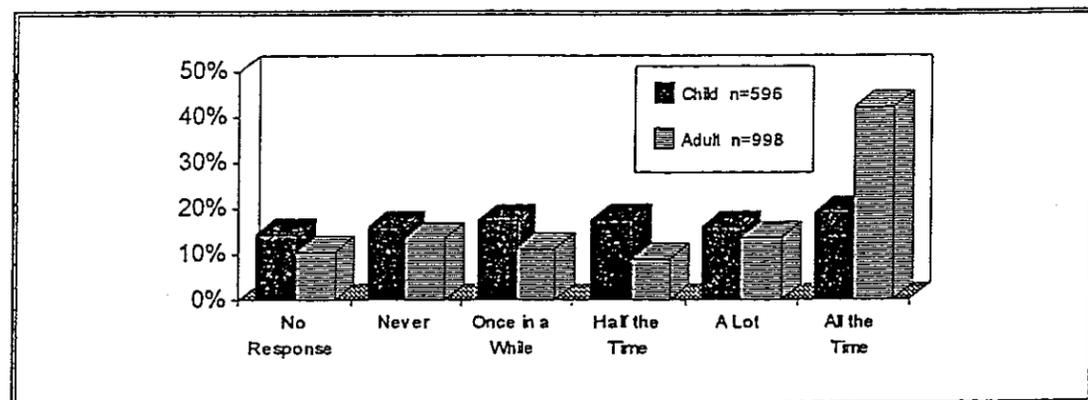


Figure 6: Extent of Use in Child and Adult Survey Population

The following table reports the extent of use, by children and adults, for each of the common prosthetic types. As can be seen from these data, 43% of the children who have an electric hand report using their prosthesis "A Lot" or "All the time," while 69% of the adults who have a body powered hook report using their prosthesis "A Lot" or "All the time."

CHILD	Never	Once in a While	Half the Time	A Lot	All the Time	GRAND TOTAL	%
Body Powered Hook	26	38	32	33	45	174	43%
Electric Hand	25	52	60	54	44	235	57%
TOTAL	51	90	92	87	89	409	100%
%	12%	22%	23%	21%	22%	100%	-

ADULT	Never	Once in a While	Half the Time	A Lot	All the Time	GRAND TOTAL	%
Body Powered Hook	46	66	57	94	334	597	71%
Electric Hand	28	35	30	44	109	246	29%
TOTAL	74	101	87	138	443	843	100%
%	9%	12%	10%	16%	53%	100%	-

Figure 7: Extent of Use by Age Group and Component

FUTURE PLANS

In order to accomplish the proposed research aims of this study, a longer, more detailed survey needed to be developed. At this point, another important aspect of the survey design was brought forward. Since the componentry and functional operation of a body powered prosthesis are distinctly different from an electric prosthesis, two separate surveys were necessary. Additionally, knowing

that the functional needs and abilities of a bilateral upper-extremity prosthetic user are quite different from a unilateral prosthetic user, a third survey type was also designed. Therefore, three separate survey instruments, **Body-Powered**, **Electric**, and **Bilateral**, were finalized for distribution to persons with specific prosthetic needs identified using the one-page survey.

Upon completion of data entry from these three surveys, a comprehensive statistical analysis will be performed. From this analysis, a report will be generated summarizing the key findings. Important questions to be answered include:

- (1) What are the current patterns in prosthetic prescription based on age and level of limb loss?
- (2) What are the functional expectations of prosthetic users, and are there notable differences in user expectations related to age, level of limb loss, and type of prosthesis utilized?
- (3) Is there a correlation between the number of hours of prosthetic training and the individual's functional outcome?
- (4) What are the types and frequency of prosthetic repairs?
- (5) What are user perceptions of their prosthetic devices as they relate to cost, function, maintenance, sensory feedback, appearance and the weight of a prosthetic device?
- (6) What priorities are identified by users as most important for improvement in prosthetic devices?

A comprehensive summary of this report will be written, shared and presented at major professional meetings. A "Newsletter" with an abbreviated summary of the results, and a progress report on the project, will be sent to all participants who returned surveys.

The final goal of the second funded year will be to accomplish the last specific aim, namely, to identify the key priorities that will direct future prosthetic design, research and development, based upon the functional needs and preferences described by the survey population. These new design approaches will seek to enhance the functional capabilities of individuals with upper-limb loss who use prostheses.

A group of experts in prosthetics and related fields will act as consultants. A team of engineers, manufacturers, prosthetists, researchers, and therapists will evaluate the study results in light of user perceptions of current prosthetic device capabilities and user needs and preferences. Based on these findings, a series of priorities will be established for an improved prosthesis. These priorities will be translated into engineering specifications that can guide future prosthetic research and development.

In conclusion, with technological advances and ongoing development of new light weight materials, of miniaturized motors and actuators, of better control mechanisms, etc., the future of upper-limb prosthetic research and design is on the brink of significant change. It is important that this change takes into account the needs and preferences of persons with upper-limb loss who rely on technology to assist them in carrying out day-to-day tasks. This study represents an important first step in assuring that prosthetic users have substantive involvement in technological innovation.

- [1] LaPlante, M.P., "Disability Risks of Chronic Illness and Impairments. Disability Statistics Report 2," National Institute on Disability and Rehabilitation Research, 1991, 8. Source: National Institute on Disability and Rehabilitation Research, "Digest of Data of Person's with Disabilities," Washington, DC, Mathematica Policy Research, p 29, Table N, January 1992.
- [2] National Health Center for Health Statistics, "Prevalence of Selected Impairments," Hyattsville, MD. State of Maryland Vital and Health Statistics, Series 10. No. 134. p 16, Table Q, 1977.
- [3] McDonnell, P., Scott, R. & McKay, L. "Incidence of Congenital Upper-Limb Deficiencies." Journal of the Association of Children's Prosthetic Orthotic Clinics. Vol 23, No. 1, p 11. Table 1. Spring 1988.