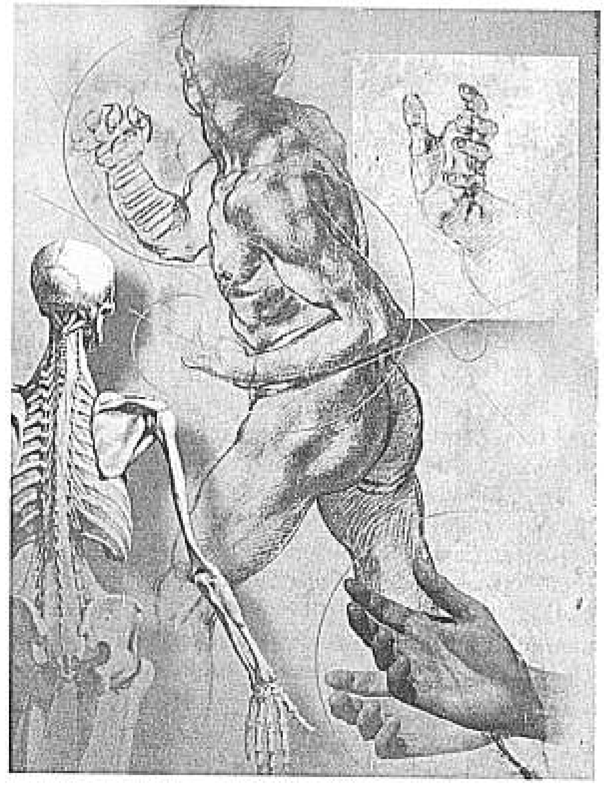
Epidemiologic Overview of Individuals with Upper-Limb Loss and Their Reported Research Priorities



Diane J. Atkins, OTR
Denise C.Y. Heard, MSE
William H. Donovan, MD

ABSTRACT

In September 1992, The Institute for Rehabilitation and Research (TIRR) in Houston was awarded a two-year grant from the National Institutes of Health/ National Center for Medical Rehabilitation Research (NIH/NCMRR). This grant was designed to 1) establish a national database of children and adults with upper-limb loss and 2) evaluate past use of prostheses, current trends in technology and prosthetic preferences of these individuals to help define future prosthetic research.

More than 6,600 one-page surveys were sent to individuals throughout the country with upper-limb loss or absence. Of those surveys, 2,477 were returned, and demographic information was recorded. A more comprehensive seven-page survey was then sent to the respondents who agreed to participate. A total of 1,575 of these surveys were returned: 1,020 by body-powered users, 438 by electric users and 117 by bilateral users of prostheses.

The results of the surveys indicate users of body-powered and electric prostheses identify surprisingly similar elements as necessary in the design of a better upper-limb prosthesis. These qualities include additional wrist movement, better control mechanisms that require less visual attention and the ability to make coordinated motions of two joints. Desired near-term improvements for body-powered prostheses include better cables and harness comfort, whereas those for electric prostheses include better gloving material, better batteries and charging units, and improved reliability for the hand and its electrodes. This article discusses the specific functions that various levels of upper-extremity amputees gain from their prostheses as well as the device features that aid or detract from their functions.

Introduction

As Childress (1) stated in 1985, "Adequate replacement of the human hand and arm is one of the most difficult problems facing medical technology." That statement remains true today due in part to limited funding resources. These limitations are compounded by the fact that clinicians and researchers 1) do not know the actual incidence of upper-limb loss in the United States and 2) do not have an effective mechanism of contacting individuals who use upper-limb prostheses to request their input as to priorities in prosthetic design. Both of these issues are addressed in this Introduction.

While reviewing patient populations and the use of prostheses and orthoses in 1973, LeBlanc (2) stated, "Because of the way health services are delivered in the United States, no accurate fig-

DIANE J. ATKINS, OTR, is coordinator of both the Amputee Program and the Brachial Plexus and Hand Clinics at The Institute for Rehabilitation and Research (TIRR) in Houston. She also is an assistant professor in the Department of Physical Medicine and Rehabilitation at Baylor College of Medicine in Houston.

DENISE C.Y. HEARD, MSE, is a senior research associate involved in the Amputee Program at TIRR.

WILLIAM H. DONOVAN, MD, is executive vice president for medical affairs, co-director of the Spinal Cord Injury Program and director of the Amputee Program at TIRR. He also is professor and chairman of the Department of Physical Medicine and Rehabilitation at the University of Texas Health Science Center–Houston.

ures are available concerning the orthopaedic population, treatment methods, and other information that would be useful to administrators, clinicians and research groups." Leonard and Meier (3) reinforced that statement in a 1993 text entitled *Rehabilitation Medicine: Principles and Practice,* indicating a review of the data collected by the National Center for Health Statistics provides estimates only of the incidence of amputations.

One of the most comprehensive studies in the literature was conducted by Kay and Newman (4) in 1975. This study reviewed 6,000 new amputees by involving 143 prosthetic facilities, all members of the American Orthotic and Prosthetic Association (AOPA), in 39 states and the District of Columbia. Although this study was comprehensive in its analyses of causes of amputations, male/female ratio, levels of amputation and distribution by age, no direct contact was made with individuals who have amputations.

Previously, Glattly (5) had conducted a sizable study of 12,000 new amputees in the United States in 1964. This "amputee census" was a joint project of AOPA and the Committee on Prosthetic-Orthotic Education of the National Academy of Sciences. Glattly stated the project title, "Amputee Census," was a misnomer since no national or regional head count of amputees was involved, and no estimate of prevalence could be derived from the data. Only basic demographic data were recorded in this study (state of residence; age and sex of amputee; date of amputation; date prosthesis received; site and cause of amputation). To date, this is the largest epidemiologic study of upper-limb amputees conducted in the United States, and no updated information has been recorded since.

From 1983 to 1985 LaPlante and Stoddard (6) completed "Data on Disability from the National Health Interview Survey" and recorded approximately 97,000 individuals with absences of arm(s) or hand(s). The report stated, "One important limitation of [these] data is the reliance on self-reporting and proxy responses for those not present, unable to respond or under the age of 17."

Other government-sponsored reports and censuses have been generated through the years relating to persons who have disabilities and the use of devices to enhance function (6-10). The methods of gathering and reporting this information are diverse; the published reports show very little consistency.

Researchers and clinicians such as Krebs *et al.* (11) expressed a similar frustration when trying to study the prosthetic management of children with limb deficiencies. Krebs *et al.* state, unlike in European countries, "No standard data collection efforts are required of health facilities treating children with amputations in the United States, and therefore no comprehensive characterization of this population is available."

Similarly, while trying to gather an accurate estimate of all children with congenital upper-limb deficiencies in North America, McDonnell *et al.* (12) stated that incidence and prevalence of those conditions can be determined only approximately and with considerable difficulty because of classification systems that tend to lump all anomalies. However, they pointed out that accurate accounting and detailed records are kept in some European countries (13). Since 1955, the artificial limb fitting services in England, Wales and Northern Ireland have gathered data on all amputees referred for the first time. These data included only basic information until 1970 when computers enabled the collection of more encompassing information such as limb fitting, limb training, discontinuation of limb use and amputee whereabouts (14).

Clearly, it appears a mechanism to record the incidence of and relevant data relating to upper-limb (and lower-limb) amputees is necessary in the United States, and it is this premise that led to the establishment of the National Upper-Limb Amputee Database at TIRR in Houston.

In 1985, LeBlanc (15) stated, "Standard body-powered upper-limb prostheses have not changed significantly since developments in the 1950s [that] were spurred by World War II. [Prosthetists] still employ ancient technology using a shoulder harness and steel cables for operation." This observation, still true today, may be due in part to the fact that research and development have never been consumer-driven.

Individuals with upper-limb loss represent a consumer group that takes an active role in the rehabilitation and prosthetic experience and keeps abreast of current trends in prosthetic and rehabilitation advances. To date, the forum for individuals with upper-limb loss to express their opinions about their prosthetic experiences often has been limited to discussions with private physicians, prosthetists and therapists. Many articles have been written regarding future development, particularly of myoelectric prostheses (16-21). However, few studies have specifically asked the individuals who use such devices what improvements they would like to see in body-powered or electric prostheses.

Consumer involvement in the amputee rehabilitation process has occurred in many European countries during the past 15 years. Several studies have addressed function and acceptance of prostheses as well as recommendations for change (22,23). Two extensive studies in 1983 and 1989 were conducted by Van Lunteren *et al.* (24, 25) in the Netherlands. Their goal was to gain greater insight into the types of activities for which prostheses can be useful and to compare newly designed prototypes with existing devices so they could advise the designers. More than 50 children and adults were followed throughout an entire day, and hundreds of gripping action patterns were observed.

In Canada, Millstein *et al.* (26) retrospectively reviewed 314 adult upper-limb amputees at the Ontario Workers' Compensation Board. A questionnaire was used to determine the function and acceptance of users of body- and electrically powered prostheses. Questions addressed the amount of time prostheses were worn, their use and reliability, and the problems the amputees encountered.

The few efforts undertaken in the United States have had very specific focuses and have encompassed small patient populations. In 1984, the "Improvement of Body-Powered Upper-Limb Prostheses Project" (15) was launched with funding from the National Institute on Disability and Rehabilitation Research. In 1988, Melendez and LeBlanc (27) pursued a unique study that examined an "invisible" population of amputees who never wore or no longer wear prostheses. Their survey of 25 nonwearers reinforced the need for specific prosthetic design research.

In 1991, Nielsen (28) conducted a national survey of 109 amputees that asked 29 questions regarding demographic variables, prosthetic function and the specific role of the prosthetist in patients' rehabilitation experience.

More recently, a 123-item questionnaire was designed by Nicholas *et al.* (29) at Rush University School of Medicine in 1993. Ninety-four patients from two amputee clinics were asked questions regarding patients' perceptions, problems, and feelings relative to their prostheses and their lives as amputees. None of these reports, however, explored the background and prosthetic experiences of individuals with upper-limb loss on as large a scale as the present study.

For this project, 1,575 children and adults across the United States responded to surveys investigating such areas as etiology, income and employment, therapy and training, prosthetic cost and maintenance, wearing and use patterns, functional abilities, and preferences for areas of improvement. In completing the surveys, and by providing additional written comments and suggestions, respondents were able to express their opinions knowing their responses would be shared with many professionals and lay people involved in the field of upper-extremity limb loss.

While this database includes less than 5 percent of all upper-limb amputees in the United States, this population is the largest sample assembled to date of children and adults who use upper-limb body-powered and electric prostheses.

Method

Six stages were involved in the method used in this study: conducting pilot studies, distributing a single-page survey, developing three functionally distinct surveys, organizing the answers in the database, developing data analysis techniques and consulting with experts in the field.

Pilot Studies

During the first year of the study, the primary focus was on developing and testing the survey instruments. Initially, a pilot instrument was administered to approximately 300 individuals and/or parents of children with amputation. Usable responses were received from 38 adults and 44 children.

After TIRR staff reviewed the responses to this pilot survey, a second draft was prepared. This second pilot survey was then distributed to two new groups. The first group, the Advisory Review Board, consisted of physicians, prosthetists, therapists, social workers, and engineers with expertise in amputation, rehabilitation and prosthetics. The second group included 15 adults and parents of 14 children with varying levels of upper-limb absence.

After reviewing answers to the questions and the written comments from the returned pilot surveys, suggestions from these combined groups were incorporated to make a more clear and concise survey instrument.

Single-Page Survey Distribution

The first step in contacting individuals with upper-limb loss was sending each prospective participant an introductory letter and a simple one-page survey. The survey questions requested baseline information such as the participant's 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.

To identify individuals across the country with upper-limb loss, we enlisted the assistance of prosthetists, physicians, rehabilitation facilities, children's hospitals and clinics, general hospitals, adult support groups, parent support groups, university hospitals and medical schools, manufacturers, and the Veterans' Administration (VA). In response to our nationwide request for assistance in locating as many people as possible with upper-limb loss, 104 of these entities assisted us with mailing the one-page survey and "Informed Consent" form to their patient populations.

We asked administrators of each collaborating organization to mail a cover letter, survey, consent form and a TIRR return, stamped, self-addressed envelope to each of their clients with upper-limb loss. Included were people with body-powered and/or electric prostheses as well as those who use no prostheses at all.

The people willing to participate returned the survey and a signed consent form to TIRR in the self-addressed envelope. This identifying information was coded and entered in the database.

By the conclusion of the first year of the study, more than 6,600 one-page surveys had been sent to individuals with upper-limb loss throughout the country; of those, 2,477 were returned with 98 percent of the participants agreeing to complete a longer, more detailed survey.

Development of Three Functionally Distinct Surveys

At this point, members of the Advisory Review Board brought another important aspect of the survey design to the researchers' attention. Since the componentry and functional operation of body-powered prostheses are distinctly different from those of electric prostheses, two separate surveys were designed. Additionally, since the functional needs and abilities of bilateral upper-extremity prosthetic users are significantly different from those of unilateral prosthetic users, a third survey also was designed.

Based on the format of the revised pilot instrument, three separate survey instruments (body-powered, electric and bilateral) were finalized for distribution. These longer surveys gathered such information as components used, therapy and rehabilitation experiences, funding, maintenance and repairs, functional abilities, and recommended "preferred prosthetic enhancements."

Based on the type of prosthesis identified in the one-page survey, the researchers sent the appropriate long survey to each participant. A two-week response period was given for completion and return of this survey.

Questions Asked of Database

Considering the vast amount of data collected through the surveys, data analysis and presentation of each individual question on each of the three long surveys is not practical. Therefore, the researchers grouped the responses to answer two overarching questions:

1) What are the users' perceptions of their prosthetic devices as they relate to cost and maintenance considerations?

2) What priorities are identified by users as the most important areas for improvement in current prosthetic devices and future designs?

Data Analysis Techniques

Data were summarized for all surveys according to ethnicity, gender, age (child = 0-17, adult = 18 and older), level of amputation, etiology, unilateral or bilateral involvement, and type of prosthesis(es).

Data relating to Question 1, which dealt with cost and maintenance, were stratified by percent for each age group and type of prosthesis. Data relating to Question 2, dealing with functional priorities, were summarized from a list of preselected items pertaining to topics from prosthetic appearance to additional functional features that would be helpful.

Each response to the second question was then compared to its relative rating using the Friedman nonparametric ANOVA for repeated measures. This was done for both electric and body-powered prostheses.

Expert Consultants

In view of the potential importance of the data to professionals in associated fields, several experts in the area of prosthetics and amputee rehabilitation were invited to evaluate the collected data. Four consultants, each with a special area of interest, agreed to participate.

Each consultant reviewed the survey questionnaires and was asked to identify several areas they felt should be analyzed. In response, the researchers provided a detailed analysis from the database and returned it to the consultants.

The researchers then asked: 1) How does this information relate to what has occurred in the past? 2) What trends are we seeing today? and 3) What are the implications for the future?

Results

The results of each survey have been broken down into their respective categories.

One-Page Survey

A total of 2,477 individuals responded to the initial one-page survey. Male respondents accounted for 63 percent of the population, and females accounted for 37 percent. The mean age for the total population was 27.9 years (±22.5).

Children aged 17 or younger represented 47 percent of the total population, and adults represented 53 percent. The mean age for the 1,216 adults was 45.43 years (±16.77), and the mean age for the 1,077 children was 8.04 years (±4.48).

The most common level of amputation was transradial; 617 children and 488 adults reported this level. Congenital limb deficiency was reported as the primary cause of limb absence in the children (91 percent), and traumatic injury was reported as the predominant cause of limb loss by adults (76 percent).

When asked to identify the type of prostheses worn, 63 percent identified a body-powered hook, and 37 percent used an electric hand. (Note: These percentages do not take into account those who use both or those who use none.)

Long Survey

A total of 1,575 seven-page surveys was returned, representing a 64-percent return rate from the one-page survey population. Of those, 1,020 completed body-powered, 438 completed electric and 117 completed bilateral long surveys. Each response on the survey was coded and entered into a database.

Body-Powered Long Survey

Sixty-nine percent of the 1,020 individuals who responded to the body-powered survey were male; 31 percent were female.

The mean age for the total population was 32.1 years (±24.1), which indicates a higher adult component in this population when compared with the electric survey population. Children aged 17 and younger represented 39 percent of the total, and adults represented 61 percent. The mean age for the 607 adults was 48.28 years (±16.77), and the mean age for the 395 children was 7.21 years (±4.28).

Transradial was the most common level of absence; 246 children and 235 adults reported this level. Congenital limb deficiency was most often reported as the cause of limb absence in the child population (93 percent), and traumatic injury again was reported as the most prominent cause of limb loss by adults (81 percent).

Electric Long Survey

Male respondents accounted for 55 percent of the 438 individuals who responded to the electric survey, and females accounted for 45 percent.

The mean age for the total population was 24.9 years (±20.4). Children aged 17 or younger represented 51 percent of the total, and adults represented 48 percent. (No date of birth was given by three individuals, equaling 1 percent.) The mean age for the 211 adults was 42.64 years (±15.09), and the mean

TRANSRADIAL BODY-POWERED USER PREFERENCES FOR IMPROVEMENTS

Item	Item name	Mean* ranking	Rank order of priority	$p<0.05$**
d	Wrist rotated the terminal device	4.72	1	8 factors
i	Could do coordinated motions of two joints at the same time	4.75	2	8 factors
f	Wrist moved the terminal device from side to side	5.07	3	6 factors
e	Wrist moved the terminal device up and down	5.17	4	5 factors
j	Required less visual attention to perform certain functions	5.43	5	2 factors
g	Could hold small objects better	5.49	6	2 factors
h	Could hold large objects better	5.51	7	2 factors
c	Could use it in vigorous activities	5.52	8	2 factors
b	Weighed less	6.55	9	
a	Looked more like a human hand	6.80	10	

* The lower ranking is the higher preference.
** Ranked significantly higher than x number of other items.

Table 1. **Prioritization of the desirable features for transradial users as rated in Question 40 of the body-powered survey indicates the greatest desire is for improved wrist rotation abilities.**

age for the 224 children was 8.11 years (±4.14).

Transradial again was the most common level of absence for children (n=135) as well as adults (n=93). Congenital limb deficiency was reported as the principal cause of limb absence in the child population (95 percent), and traumatic injury again was reported as the most prominent cause of limb loss by adults (77 percent).

Bilateral Long Survey

Male respondents accounted for 57 percent of the 117 individuals who responded to the bilateral survey, and females accounted for 43 percent.

The mean age for the total population was 32.1 years (±21.3). Again, adults represented a greater percentage of the population. Children aged 17 and younger represented 36 percent of the total, and adults represented 61 percent. (No date of birth was given by three individuals, equaling 3 percent.) The mean age for the 72 adults was 44.43 years (±16.52), and the mean age for the 42 children was 10.26 years (±4.45).

Transradial was the most common level of amputation reported for both right and left losses (n=31). Bilateral shoulder disarticulation and bilateral transhumeral limb loss were the second most common levels, with the incidence of each at 17. Congenital limb deficiency was most often reported as the cause of limb absence in the child population (82 percent), and traumatic injury again was most frequently reported as the cause of limb loss by adults (65 percent).

Survey Questions

The following questions (1 and 2) were selected and asked of the database as outlined in the method section.

1) *What are users' perceptions of their prosthetic devices as they relate to cost and maintenance of a prosthetic device?*

Participants were asked to rate the costs of their prostheses with respect to their functions. A scale (5-0) ranging from "about right" (5) to "too expensive/unreasonable" (0) was presented. (The scale also included a response for "don't know.")

In the child population, the responses to these questions were for the most part, made by the parents. Areas regarding function and preferences are often parents' reflections of what they observe or desire for their children.

A higher percentage of adults and children with body-powered prostheses felt the costs of their prostheses were "about right" (17.38 percent and 8.22 percent, respectively) compared to the 5.59 percent of adults and 2.73 percent of children with electric prostheses who answered the same. At the other end of the scale, electric users reported "too expensive, unreasonable" more often than body-powered users (electric/adult: 22.35 percent vs. body-powered/adult: 14.72 percent, and electric/child: 18.03 percent vs. body-powered/child: 6.51 percent). In both child populations, the highest percentage of responses were "don't know" (body-powered/child: 62.67 percent, electric/ child: 33.88 percent).

Both electric and body-powered survey populations were presented with a list of possible maintenance items. Individuals were asked to identify the top three items with the most frequent maintenance problems encountered over the past year. Of note, an optional "other" category was available for items to be written in if they were not included in the list provided. These written comments have not yet been evaluated and are not incorporated in the results.

Overwhelmingly, both adult and children body-powered users reported cables as needing the most frequent repair (children: 48.1 percent, adults: 66.7 percent). Replacement of gloves for body-powered hands rated considerably higher among children (23.1 percent) than among adults (7.8 percent). Similarly, glove replacement was the most frequent repair noted by electric users (children: 35.1 percent, adults: 34.1 percent). For the electric prostheses, adults and children reported battery replacement as the second most frequent repair (children: 20.3 percent, adults: 25.8 percent).

2) *What priorities are identified by users as the most important areas for improvement in prosthetic devices?*

Question 40 in the long survey asked users to rate 10 prosthetic features by completing the statement "I would like my preferred body-powered prosthesis better if...." The ranking of the 10 items was based on the rating scale of 1-5 with the lower-ranking number equal to the most preferred (1 = "strongly agree," 5 = "strongly disagree"). The Friedman rank order of the 10 items indicated the top priorities for transradial prosthetic users were as follows: "wrist rotated the terminal device" ranked first (mean = 4.72, >5 other factors); "could do coordinated motions of two joints at the same time" ranked second (mean = 4.75, >1 other factor); "wrist moved the terminal device from side to side" ranked third (mean = 5.07, >4 other factors); and "wrist moved the terminal device up and down" ranked fourth (mean = 5.17, >3 other factors) (see *Table 1*).

The top priorities for transhumeral prosthetic users were as follows: "could do coordinated motions of two joints at the same time" ranked first (mean = 4.57, >1 other factor); "wrist rotated the terminal device" ranked second (mean = 5.04, >1 other factor); "required less visual attention to perform certain functions" ranked third (mean = 5.11, >0 other factor); and "wrist moved the terminal device from side to side" ranked fourth (mean = 5.27, >1 other factor) (see *Table 2*).

TRANSHUMERAL BODY-POWERED USER PREFERENCES FOR IMPROVEMENTS

Item	Item name	Mean* ranking	Rank order of priority	$p<0.05$**
i	Could do coordinated motions of two joints at the same time	4.57	1	9 factors
d	Wrist rotated the terminal device	5.04	2	2 factors
j	Required less visual attention to perform certain functions	5.11	3	2 factors
f	Wrist moved the terminal device from side to side	5.27	4	2 factors
h	Could hold large objects better	5.29	5	2 factors
e	Wrist moved the terminal device up and down	5.34	6	2 factors
c	Could use it in vigorous activities	5.48	7	2 factors
g	Could hold small objects better	5.50	8	2 factors
b	Weighed less	6.42	9	1 factor
a	Looked more like a human hand	6.96	10	

* The lower ranking is the higher preference.
** Ranked significantly higher than x number of other items.

Table 2. **Prioritization of the desirable features for transhumeral users as rated in Question 40 of the body-powered survey indicates the greatest desire is for the ability to make coordinated motions of two joints at the same time.**

Question 43 of the body-powered survey asked individuals to identify the top five activities (from a list of 34) they would like to be able to perform with their body-powered prostheses. The top five choices for transradial users were: 1) Open a door with a knob; 2) Use a spoon or fork; 3) Fasten a button; 4) Tie shoelaces; and 5) Cut meat. The top five choices for transhumeral users were: 1) Cut meat; 2) Tie shoelaces; 3) Open a door with a knob; 4) Use a hammer and nail; and 5) Use a spoon or fork.

Question 41 in the long survey asked users to rate 17 prosthetic features by completing the statement "I would like my preferred electric prosthesis better if...." The ranking of the 17 items was based on the rating scale of 1-5 with the lower-ranking number equal to the most preferred (1 = "strongly agree," 5 = "strongly disagree").

The Friedman rank order of the 17 items indicated the top priorities of transradial and transhumeral users were as follows: "bending fingers" ranked first (mean = 7.64, >12 other factors); "a thumb [that] moved out to the side" ranked second (mean = 7.89, >11 other factors); "a prosthesis requiring less visual attention" ranked third (mean = 8.07, >8 factors); and "a thumb [that] could touch each finger individually" ranked fourth (mean = 8.27 >6 factors) (see *Table 3*).

Question 44 of the electric survey asked individuals to identify the top five activities (from a list of 34) they would like to be able to perform with their electric prostheses. The top five choices for transradial users were: 1) Type/use a word processor; 2) Open a door with a knob; 3) Tie shoelaces; 4) Use a spoon or fork; and 5) Drink from a glass. The top five choices for transhumeral users were: 1) Type/use a word processor; 2) Cut meat; 3) Tie shoelaces; 4) Open a door with a knob; and 5) Use a spoon or fork.

Discussion

As previously stated, little is known about the characteristics of individuals in the United States who have lost their limbs (4). The establishment of the National Upper-Limb Amputee Database is an attempt to identify a representative national sample of upper-limb amputees to address such areas as etiology and levels of limb loss; current trends in fitting body-powered and electric prostheses; function; perceptions of cost of maintenance and repair of prostheses; and perhaps most important, priorities defined by users as essential in the design of a better upper-limb prosthesis.

A demographic and epidemiologic overview has been presented for each of the four survey populations: 1) one-page survey respondents (2,477), 2) body-powered long survey respondents (1,020), 3) electric long-survey respondents (438), and 4) bilateral long-survey respondents (117).

In each of these populations, a transradial amputation was by far the most common level of amputation (one-page: 50 percent; body-powered: 48 percent; electric: 53 percent). These findings are consistent with the results of surveys conducted by the Committee on Prosthetic-Orthotic Education (CPOE) in 1961-1963 (5) and 1965-1967 (30)—a total of approximately 4,000 individuals with unilateral upper-

TRANSRADIAL ELECTRIC-POWERED USER PREFERENCES FOR IMPROVEMENTS

Item	Item name	Mean* ranking	Rank order of priority	$p<0.05$**
f	Fingers could bend	7.64	1	12 factors
h	Thumb moved out to side	7.89	2	11 factors
q	Required less visual attention to perform functions	8.07	3	8 factors
g	Thumb could touch each finger individually	8.27	4	6 factors
n	Could hold small objects better	8.27	5	6 factors
k	Wrist rotated terminal device	8.49	6	5 factors
o	Could hold large objects better	8.70	7	4 factors
b	Could use it in vigorous activities	8.72	8	3 factors
l	Wrist moved terminal device up and down	8.78	9	3 factors
i	Middle joint of thumb could bend	8.93	10	3 factors
j	Thumb could press side of index finger	8.99	11	2 factors
c	Glove held up better	9.07	12	2 factors
m	Wrist moved terminal device from side to side	9.32	13	2 factors
p	Could do coordinated motions of two joints at the same time	9.47	14	2 factors
e	Could control level of grip force	9.71	15	2 factors
a	Looked more like a human hand	10.69	16	
d	Had a stronger grip	12.00	17	

* The lower ranking is the higher preference.
** Ranked significantly higher than x number of other items.

Table 3. **Prioritization of the desirable features for electric users as rated in Question 41 of the electric survey indicates the greatest desire is for bending fingers.**

limb amputations were reviewed. The frequency of transradial amputation was reported to be 57 percent compared to 5 percent at the shoulder, 23 percent above the elbow and 12 percent at the wrist or hand (2).

When addressing the etiology of limb loss or absence in 2,477 children and adults in this survey population, congenital limb deficiency was clearly the most frequently reported cause of limb absence in children (91 percent). A similar incidence of congenital conditions was reported by McDonnell *et al.* (12) in 1988. In the latter study, data from 45 children's clinics in Canada and the United States consisting of 4,105 cases showed congenital limb deficiencies accounted for 85 percent of this total population.

Traumatic injury was reported most frequently by adults (76 percent) in this National Upper-Limb Amputee Database. Leonard and Meier (3) in the text *Rehabilitation Medicine: Principles and Practice* also identify trauma as the leading cause of amputation in male upper-limb amputees (75 percent) aged 15-45.

There was a higher prevalence of males (78 percent) than females (22 percent) in the adult limb-loss population and an even prevalence of males (50 percent) and females (50 percent) in the child population. Krebs *et al.* (11) state more boys (59 percent) than girls (41 percent) comprise the population of children with upper- as well as lower-limb absence, regardless of age. Similarly, Kay and Newman (4) in 1975 reported a 1.5:1 male to female ratio in congenital limb deficiencies. Prior to that study, in 1964, Glattly (5) discovered a 1.2:1 ratio of males to females in the congenital amputee population.

Our population shows a surprisingly equal prevalence of males and females with congenital limb deficiency. This finding, along with the high incidence of congenital transradial limb absence in this study's population, may merit further investigation. Documentation of a male:female ratio in adult amputees could not be found in the literature.

A 1988 survey by LeBlanc (31) reported the types of terminal devices sold by manufacturers and indicated a 72-percent use of hooks and a 28-percent use of hands. That survey is supported by reports of actual use in this study with 63 percent of the subjects reporting the use of body-powered prostheses and 37 percent of the subjects reporting the use of electric prostheses. As LeBlanc notes in his consultant summary report of this project, "If we assume that hooks/body-powered and hands/electrically powered ratios are similar, then the use of electric hands has increased 9 percent in the past six years." He suggests this figure is due to the much higher use of myoelectric prostheses by children.

In the one-page survey, adults were the most common users of body-powered prostheses (65 percent). Fitting trends in adults appear to be more consistent with the theory that body-powered hook prostheses are the terminal device of choice for adults because of their functional needs relating to manual labor, construction and farming. In a study of 314 adult upper-limb amputees, Millstein *et al.* (26) at the Ontario Workers' Compensation Board in Canada report those amputees who used cable-operated prostheses had jobs that required heavy lifting, handling of greasy or sharp materials, and exposure to extremes in weather (damaging to electrically powered prostheses). A body-powered prosthesis was more often selected because of its ruggedness and durability.

In the one-page survey, children were the most frequent users of electric prostheses (59 percent). This observation is supported by studies conducted in Sweden, England and Canada in the late 1970s and early 1980s that demonstrated electric fittings were not only feasible but immensely popular with young children and their families (32). Appearance and wanting the "best" in "state-of-the-art" prostheses have become primary concerns among parents of limb-deficient children. This raises an important question to all prescribing physicians and amputee teams: *Are we fitting the parents or the child?*

The question of maintenance and repair of upper-limb prostheses was asked of children and adults who use body-powered and electric prostheses. Not surprisingly, cables were reported as needing the most frequent repair (children: 48.1 percent, adults 66.7 percent). As LeBlanc reports in his analysis of children and adults who use body-powered prostheses, problems of cable repair and harness discomfort have existed for a long time and are difficult to solve. He further states, "Common sense suggests that we must mount more effort to seek solutions to improve these common occurrences, particularly if health-care cost containment is forcing reimbursement down and creating more need for body-powered systems" (33).

When users of electric prostheses were asked to describe their most frequent repair, glove replacement and battery replacement were most often reported. Gloves have always been a problem in body-powered as well as electric hands. As Childress notes, very little technical progress has occurred in this area. "Small trends have been seen toward the use of silicone gloves; however, this has not proven to be very successful. Gloves of the future must be better than current ones. They must be attractive, tough, stain-resistant and affordable" (34).

Childress further comments that batteries are a perennial problem in prosthetics. High prosthesis use hastens battery failure, and few technological improvements have occurred in the past 20 years. Nickel-cadmium cells continue to be the preferred choice in prosthetics. The development of new higher-power batteries for portable computers, telephones, etc., has not been helpful in the field of prosthetics because the load factors are much different in prostheses. Childress states that in prosthetics high power is needed for short periods of time. High-energy batteries available today, such as those needed for portable computers, etc., are not sufficient for prostheses (34).

One of the most important areas of focus in this two-year project was the priorities that users of body-powered and electric prostheses identify in the design of a better upper-limb prosthesis.

Transradial, body-powered respondents stated they would be more satisfied with their prostheses if: 1) the wrist rotated the terminal device, 2) two joints could perform coordinated motions at the same time, 3) the wrist moved the terminal device from side to side and 4) the wrist moved the terminal device up and down. The transhumeral population suggested they would be more content with their prostheses if: 1) two joints could perform coordinated motions at the same time, 2) the wrist rotated the terminal device, 3) less visual attention was required to perform certain functions and 4) the wrist moved the terminal device from side to side.

Clearly, wrist movement is of great importance to users, which should be taken into account for future research design in body-powered prostheses. To suit the transhumeral population, creating control schemes for performing functions in a more coordinated manner with less visual attention is another challenge for the future. Advancing harnessing and cabling systems, or even developing new control mechanisms, also should be rewarding areas to pursue.

These data also suggest that having the ability to hold both small and large objects is important. As LeBlanc states in his report of body-powered users, "holding" is an important function worthy of investigation and experimentation. He adds, "The temptation for designers of hands is to try to duplicate the human hand. This is an insurmountable task. One must downsize the expectations of the prosthetic hand and design into it only the most important functional features."

Heckathorne, in his analysis of bilateral upper-limb amputees who primarily use body-powered hooks, concurs that users are clearly concerned with improved function of their prostheses. "Many bilateral users are concerned with a single general objective—the ability to efficiently handle a greater variety of objects and apply higher forces, improved ability to orient the prehensor (especially with respect to improved wrist action) and better control of prehension with the inclusion of feedback of prehension force" (35).

Options desired by users of transradial and transhumeral electric prostheses included 1) bending fingers, 2) a thumb that moved out to the side, 3) a prosthesis requiring less visual attention, and 4) a thumb that could touch each finger individually.

It is now established that an improved hand design is a high priority for amputees who use electric prostheses. Scott comments, "Whether it is feasible to achieve independent finger movement, or whether a conformable grip, in which the fingers adapt automatically to the shape of an object, would be an adequate response to this need, are questions requiring further study. Balancing the cost vs. benefit will be important: Costs such as added weight and reduced reliability have defeated many elegant designs in the past" (36).

Childress responds that "powered finger prototypes have been developed in research laboratories, and practical applications may be possible before the end of the decade." He adds, "These powered prostheses, with individual finger movements, possibly may be coupled with direct skeletal attachment" (34).

Future Direction

This survey establishes many areas that should be included in future prosthetic research endeavors to enhance consumer usage as well as provide additional useful information. Future surveys might include the following:

1) An analysis of individuals and their use patterns of body-powered and electric prostheses with respect to age grouping: 0-5 (young children), 6-12 (children), 13-19 (teenagers), 20-60 (adults) and over 60 (seniors). Clearly,

Body-powered		Electric	
Near-term	**Future Work**	**Near-term**	**Future Work**
Cables	Wrist movement	Gloving material	Greater finger movement
Harness comfort	Control mechanisms for:	Batteries/charging units-	Less visual attention
Gloving material	a. less visual attention	Reliability of hand and electrodes	Wrist movement
	b. ability to do coordinated motions of two joints		

Table 4. **The findings of the study indicate different near-term and future considerations are needed to develop body-powered and electronic upper-limb prostheses.**

the functional needs of these individual groups are unique and distinctly different. Important questions to be asked in this research are: "What is the best age to fit a child with a prosthesis?" and "How does age at fitting affect a child's functional outcome?"

2) An "activity analysis" of each functional task could be undertaken to clearly define and describe the type of grasp and nature of finger prehension used in each task described. For example, holding a ball requires a spherical grasp whereas holding a glass requires a cylindrical grasp. A tip pinch is necessary when picking up a needle, and a lateral grasp is required to hold a key or dollar bill.

Combining these grasps in more complex activities such as opening a door with a key, cutting meat, tying shoelaces and buckling a belt is significantly more complex and would require significant scrutiny of the movement required of each activity. Each activity would then be reviewed as it relates to accomplishment with a body-powered terminal device or electric hand.

3) Written commentary on prosthetic experiences could be included to provide more detailed insight into problems. Many of the respondents to the survey provided much more information than required by the survey questions. Some even provided drawings and detailed ideas on how they might improve (or have already improved) their own prostheses. Still others shared why they no longer wear prostheses and the factors contributing to their decision to discontinue use.

The categorization and analysis of such written information is time-consuming and was not incorporated into the scope of this project. These written comments will be a valuable contribution in future qualitative research studies.

4) For dissemination of information, direct access to the database via computer networking would be advantageous for further studies. By providing access to the database via computer modem, professionals and lay people could access certain parts of the database for their own search purposes.

These data represent opinions from the largest pool ever assembled of individuals from across the United States with upper-extremity limb loss or absence. Specific findings of this research must be distributed to medical professionals as well as to people experiencing limb loss and family members of children with limb loss.

At the very least, a bulletin-board software approach would allow anyone to submit questions about the database. Researchers at TIRR could respond to inquiries by providing relevant data and analytical results in formats and language appropriate to the person making the request. Systems such as these would assure the database could serve populations interested in upper-limb prosthetics.

Summary of Identified Priorities

Table 4 summarizes the priorities identified by the individuals completing this survey. The categories for body-powered and electric prosthesis wearers are divided into two groups: near-term and future work. The future work items will involve advances in control systems or other user interfaces not currently available.

The near-term progress may be possible by investigating advances in other fields. The authors advise some caution in interpreting these results. Transradial users comprise the majority of the user population, and they would not choose elbow or shoulder movements as important for future development. This may bias the results toward hand and wrist function. Future work should carefully compare transradial and transhumeral groups to determine separate priorities.

Conclusions

The authors believe this two-year study of close to 2,500 upper-limb amputees represents an important first step in establishing a unique and comprehensive database. Not only is it important to document what has occurred in the prosthetic rehabilitation experience of these consumers, but it also is important to hear from them the specific enhancements providers and researchers can create to improve the subjects' quality of life. Future funding of these projects is of utmost importance to pursue these technological advances and increase the functional capabilities of those we are committed to assist. □

References

1. Childress DS. Historical aspects of powered-limb prostheses. Clin Pros and Orth 1985; 9:1:2-13.

2. LeBlanc MA. Patient population and other estimates of prosthetics and orthotics in the USA. Orth and Pros September 1973; 27:3:38-44.

3. Leonard JA, Meier RH. Prosthetics. In: DeLisa JA (ed). Rehabilitation medicine: principles and practice. Philadelphia: J.B. Lippincott Co., 1993:330-45.

4. Kay HW, Newman JD. Relative incidences of new amputations: statistical comparisons of 6,000 new amputees. Orth and Pros June 1975; 29:2:3-16.

5. Glattly HW. A statistical study of 12,000 new amputees. Southern Med J November 1964; 57:1:1373-78.

6. LaPlante MA. Data on disability from the national health interview survey, 1983-85: an info use report. Washington, D.C.:

U.S. National Institute on Disability and Rehabilitation Research, 1988.

7. Prevalence of selected chronic conditions. Hyattsville, Md.: National Center for Health Statistics, State of Maryland Vital and Health Statistics, 1979-81; 10:155:29,32.

8. Detailed diagnoses and procedures for patients discharged from short-stay hospitals. Hyattsville, Md.: National Center for Health Statistics, State of Maryland Vital and Health Statistics,1984; 13:86:182, 279-80.

9. Table 1—Selected population and housing characteristics for the United States. The 1990 U.S. Census. 1990.

10. Digest of data of persons with disabilities. Mathematical policy research. Washington, D.C.: U.S. National Institute on Disability and Rehabilitation Research, January 1992:28-30.

11. Krebs DE, Edelstein JE, Thornby MA. Prosthetic management of children with limb deficiencies. Phys Ther December 1991; 71:12:920-34.

12. McDonnell PM, Scott RN, McKay LA. Incidence of congenital upper-limb deficiencies. J of the Assn of Children's Pros-Orth Clinics Spring 1988; 23:1:8-14.

13. Kejlaa GH. The social and economic outcome after upper-limb amputation. Pros and Orth Int 1992; 16:25-31.

14. Gregory-Dean A. Amputations: statistics and trends. Annals of the Royal College of Surg of England 1991; 73:137-42.

15. LeBlanc MA. Innovation and improvement of body-powered arm prostheses: a first step. Clin Pros and Orth 1985; 9:1:13-6.

16. Scott RN, Parker PA. Myoelectric prostheses: state of the art. J of Med Eng and Tech July/Aug 1988; 12:4:143-51.

17. Dalsey R *et al.* Myoelectric prosthetic replacement in the upper-extremity amputee. Orthop Rev June 1989; XVIII:6:697-702.

18. Bergman K, Ornholmer L, Zackresson K, Thyberg M. Functional benefit of an adaptive myoelectric prosthetic hand compared to a conventional myoelectric hand. Pros and Orth Int 1992; 16:32-7.

19. Edelstein JE, Berger N. Performance comparison among children fitted with myoelectric and body-powered hand. Arch Phys Med Rehab 1993; 74:376-80.

20. Ballance R, Wilson BN, Harder JA. Factors affecting myoelectric prosthetic use and wearing patterns in the juvenile unilateral transradial amputee. Canad J of Occup Ther 1989; 56:3:132-7.

21. Kruger LM, Fishman S. Myoelectric and body-powered prostheses. J of Ped Orthop 1993; 13:68-75.

22. Kejlaa GH. Consumer concerns and functional values of prostheses to upper-limb amputees. Pros and Orth Int 1993; 17:157-63.

23. Burger H, Marincek C. Upper-limb prosthetic use in Slovenia. Pros and Orth Int 1994; 18:25-33.

24. Van Lunteren A, Van Lunteren-Gerritsen GNM, Stassen NC, Zuithoff MJ. A field evaluation of arm prostheses for unilateral amputees. Pros and Orth Int 1983; 7:141-51.

25. Van Lunteren A, Van Lunteren-Gerritsen GNM. On the use of prostheses by children with a unilateral congenital forearm defect. J of Rehab Sci 1989; 2:1:10-2.

26. Millstein SG, Hegar H, Hunter GA. Prosthetic use in adult upper-limb amputees: a comparison of body-powered and electrically powered prostheses. Pros and Orth Int 1986; 10:27-34.

27. Melendez D, LeBlanc M. Survey of arm amputees not wearing prostheses: implications for research and service. J of the Assoc of Children's Pros-Orth Clinics 1989; 23:3:62-9.

28. Nielsen CC. A survey of amputees: functional level and life satisfaction, information needs, and the prosthetist's role. JPO 1991; 3:3:125-9.

29. Nicholas JJ *et al.* Problems experienced and perceived by prosthetic patients. JPO January 1993; 5:1:16-9.

30. Davies EJ, Fritz BR, Clippinger FW. Amputees and their prostheses. Artificial Limbs 1970; 14:2:19-48.

31. LeBlanc MA. Use of prosthetic prehensors. Pros and Orth Int 1988;12:152-4.

32. Hubbard S, Bush G, Kurtz I, Naumann S. Myoelectric prostheses for the limb-deficient child. Phys Med and Rehab Clinics of North America November 1991; 2:4:847-66.

33. Le Blanc MA. Expert analysis of the TIRR National Upper-Limb Amputee Database. Archived at The Institute for Rehabilitation and Research in Houston, November 1994.

34. Childress DS. Expert analysis of the TIRR National Upper-Limb Amputee Database. Archived at The Institute for Rehabilitation and Research in Houston, November 1994.

35. Heckathorne CW. Expert analysis of the TIRR National Upper-Limb Amputee Database. Archived at The Institute for Rehabilitation and Research in Houston, November 1994.

36. Scott RN. Expert analysis of the TIRR National Upper-Limb Amputee Database. Archived at The Institute for Rehabilitation and Research in Houston, November 1994.

Acknowledgments

This research was made possible through funding by the National Institutes of Health, National Center for Medical Rehabilitation Research, #5 R01 30203-01.

The authors thank four individuals who acted as expert consultants: Dudley S. Childress, PHD, Northwestern University; Craig W. Heckathorne, MSEE, Northwestern University; Maurice A. LeBlanc, MSME, CP, Lucile Salter Packard Children's Hospital at Stanford; and Robert N. Scott, PEng, University of New Brunswick.

Our sincere thanks also is extended to Brenda Rae Lunsford, MS, MAPT, for her contributions in assisting with data analysis and in reviewing this document; Kristin Farry, PHD, who provided a great deal of time and effort toward data preparation and evaluation from an engineering standpoint; and Norman Smith for his contributions.

We also are extremely grateful to all of the hospitals, clinics, prosthetists, support groups, VA centers and Shriners Hospitals that distributed our surveys to their populations, and to the individuals with upper-limb loss who took the time to complete the surveys and share with us their personal experiences.