ORIGINAL RESEARCH ARTICLE

A Small-Scale Survey of Bilateral Upper-Limb Loss Individuals

Harold H. Sears, PhD, Kim Doolan, BS, Denise D. Keenan, OTR

ABSTRACT

Introduction: Bilateral upper-limb loss (Bil UL Loss) is perhaps the greatest challenge for upper-limb prosthetic care, now even more than ever as we witness the increase of sepsis as a cause of limb loss.

Methods: This small-n survey has recruited 28 individuals with Bil UL Loss, 27 of whom are prosthesis wearers. Twelve of the 28 lost four limbs to sepsis; 17 of the 27 prosthesis wearers use body-powered hooks, six use electric hooks, and four use electric hands as their dominant terminal device (within this report, dominant side is the wearer's postloss dominant side, i.e., the side the subject used more frequently). The survey used person-to-person interviews to compile the broad data about how tasks are performed, how many tasks are performed, whether two prostheses are used, and other details.

Results: Users of each type of prosthesis demonstrate a high level of function. Electric hook users scored slightly higher in number of tasks and other measures. However, no outcomes were significant statistically, except the use of the dominant side prosthesis, which was three times higher than the nondominant side usage. Users identified a dozen categories for desired improvements, with greater dependability and greater grip security as the most commonly requested.

Discussion: The information will be useful for not only for clinical guidance, but hopefully also to help guide the development of future prosthetic devices, considering that the disabled community has called for prioritizing the actual needs and desires of the consumers to guide future developments.

Conclusions: The planning and execution of this small-scale study could be a model for other groups to collect useful outcomes data without requiring a research grant, without large institutional oversight, and by only a small group of interested professionals with access to a reasonable number of individuals with a severe disability.

Clinical Relevance: All caregivers of individuals with bilateral limb loss could benefit from both the data presented and the challenges revealed by this survey group. Future prosthetic designs as well as training and other therapies will also hopefully benefit from the needs expressed directly by these consumers. (*J Prosthet Orthot*. 2022;34:95–107)

KEY INDEXING TERMS: bilateral limb loss, quadrimembral limb loss, upper-limb prosthetics, small-n study, body-powered prosthesis, electric prosthesis, electric hook, electric hand

Bilateral upper-limb loss (Bil UL Loss) presents multiple daunting challenges to both the individual patient and the caregiver. There are few published articles about this population, but expert clinicians stress the necessity of prioritizing the clients' needs, to direct and "fine-tune" prosthetic solutions.[1] Both clinicians (prosthetists, doctors, therapists) and developers (engineers, inventors, manufacturers, etc.) are lacking first-hand data about Bil UL Loss individuals and their needs. From personal interviews with these individuals, this small study hopes to contribute relevant knowledge toward both clinical and development needs to guide improvements for the Bil UL Loss population.

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The landmark 1996 study by The Institute for Rehabilitation and Research (TIRR) in Houston, Texas,[2] gave indications of the needs of the entire upper-limb loss (ULL) population from a study size of 1575 respondents. However, the state of technology in upper-limb prosthetics has evolved in 23 years and should be revisited. This smaller-scale study focuses only on Bil UL Loss individuals, but like the TIRR study, the focus remains on the needs of the individuals. To emphasize further, a 2018 Amputee Coalition publication[3] cited the pressing need to establish outcomes reflecting the needs and priorities of the limb loss population.

SURVEY RATIONALE AND OBJECTIVES

SMALL-SCALE APPROACH

From previous experience with similar surveys,[4–6] the in-depth information from personal interviews has been successful in documenting prosthesis use and also identifying perceived needs. Recruiting a large segment of the entire population of individuals with Bil UL Loss would have been a complex, time-consuming, and costly endeavor. However, the in-depth information obtained from 28 subjects in this small study provided a wide breadth of information.

The data collected were as follows:

- Descriptive data, that is, the types of prosthetic components, or assistance used by the subjects:

  - Body-powered (BP) or electric terminal devices (TDs), wrists, and elbows
  - Other assistive devices used
  - Assistance received from other persons

- Use Data

  - Number of tasks successfully performed by the subjects as well as the tasks that present challenges to their performance
  - Functional indicators of prosthesis use for each task, for example, two-handed (two-prostheses) performance, use of prehension or passive function of the prosthesis, and use of the dominant and nondominant side prostheses
  - For each task, the functions lacking in the prostheses or assistive devices
  - For each prosthetic device, the most frequent repairs required

- Comparisons

  - Data compiled about prosthetic use, such as number of tasks performed, dominant side and nondominant side use, two-handed and one-handed use, prehension, and passive function could lead to useful comparisons between types of prosthetic devices as well as between types of subjects.
  - Other measures of subjects' opinions were gathered such as wearers' ratings of their prosthesis usefulness and their suggested improvements to their devices. These measures were also compared for comparisons and insights.

METHODS

SCALE OF THE STUDY

This study was designed to be small-n and conducted with a small team, in a relatively short period. The simple assumptions and background upon which the study was based include the following:

- Data were collected directly from subjects within the population with Bil UL Loss, who were recruited by direct contact.
- Statistical significance was unlikely in such a small-scale study, so summaries were provided on the use of prostheses by the subgroups in this survey, revealing perceived needs and wearer priorities. If warranted, these results may lead to future investigations, perhaps with larger subject numbers.
- No grant funding was required, thus no delays for proposal writing and applications.
- No oversight by a large institution, thus less staff to coordinate.
- The authors (who are nearly the total staff of the project) each have 30+ years of experience in the prosthetic field, working as engineer/manager, prosthetic coordinator, and therapist, and the first author has conducted earlier surveys, with published results.

RECRUITMENT

The Bil UL Loss subjects were recruited by direct contact or by referral from caregivers within the fields of prosthetics and rehabilitation. Prosthesis use of 1 year or more was required, although one nonwearer was interviewed. No respondents were excluded for age nor language spoken, although all respondents were English-speaking adults.

Many (approximately half of the 28 subjects) were recruited at the Fifth Skills for Life (SFL5) Workshop, attended by over 70 persons with Bil UL Loss, held in Houston, Texas, in October 2018. This recruitment approach may have overrepresented successful rehabilitation results, but the SFL Workshop attracts both the highly experienced prosthetic wearers as well as relative newcomers who come to be educated and to network with the experienced Bil UL Loss attendees.

INSTITUTIONAL REVIEW BOARD OVERSIGHT

The protocols and informed consent documents were reviewed by a certified private institutional review board (IRB) (Ethical and Independent Review Services, Corte Madera, CA, USA), and the study was certified to be exempt from IRB oversight, citing no risk to subjects. All subjects signed the same informed consent form reviewed by the IRB, and none were compensated for their participation.

QUESTIONNAIRE DESIGN

DESCRIPTIVE DATA AND INTERVIEW PROCESS

From experience performing similar surveys,[4–6] previous questionnaires were modified for bilateral UL prosthesis use (Appendix B, Supplemental Digital Content, http://links.lww.com/JPO/A74, shows the Questionnaire for Bilateral Prosthesis Use). The data were autofilled within the Excel version of the questionnaire when it was entered on a computer. Each subject was interviewed (by telephone, when necessary) to ensure uniform interpretation of each question for all subjects and consistent recording of the response data. Interviews lasted from 1 to 2 hrs, averaging approximately 90 minutes. Initially, five pilot interviews were conducted, resulting in additions or clarifications to the instrument. Follow-up calls with pilot subjects ensured that all questions were asked of all subjects. After the pilot interviews, all were performed with two interviewers whenever possible, and afterward, the handwritten data set was compared with the digital record to ensure completeness of the digital version.

SECTION 1: DATA COLLECTED

- Age
- Sex
- Date of limb loss and date of subjects' start of prosthetic use (over 1 year's use was required)
- Level of limb loss for dominant and nondominant sides. “Dominant” side was self-described by each subject, although a few subjects described both sides as dominant. For data analysis, the dominant side was designated as the side performing the greater number of tasks.
- Prosthetic components for both primary and secondary prosthetic sets. Without any precedent to cite, the authors designated the threshold for a “secondary prosthetic component” as one used for at least 10% of tasks performed with a prosthesis. Many prosthetic and assistive devices are used effectively for

less than 10% of tasks performed—these were recorded in the Assistive Device section.
- A brief work history and present status was recorded.
- Lower-limb absence if it affected UL prosthetic use.

SECTION 2: TASKS PERFORMED

The tasks performed was the largest section of the questionnaire and included dressing and grooming, daily activities, hobbies, work, and eating and cooking. A general list of tasks was the starting point, although the list was open-ended. The categories of tasks performed provided a structure to the interview and helped the subjects to report on specific use patterns.

Each task was noted if performed two-handed (i.e., with two prostheses), and with prehension or passive function of the TD. The perceived disadvantages of the prosthetic devices were noted and recorded as functions needed. For subjects who used a secondary prosthesis, a second listing of tasks was recorded. Other assistive devices, if used, were noted for each task.

In this way, all tasks recalled using the prostheses were recorded as well as how they were performed and the functions felt lacking. Inevitably, some tasks were duplicated in more than one category, for example, opening a door might have been listed in several categories, but was recorded only once.

At the end of each category, the subject was asked to rate the usefulness of his or her prosthesis in that category. The subjects grade the prosthesis A, B, C, D, or F (ranked from best to worst), which was converted to 4, 3, 2, 1, or 0, for the digital entries.

SECTION 3: FEATURE RATINGS

The details of tasks performed provided the minutiae of the data but do not completely describe the global features of the prosthesis. For this reason, ratings of the broader features of the prosthesis and training were added. Section 3 recorded the ratings and comments for the following 12 features for both the primary and secondary prostheses:

1. Overall satisfaction with the primary and secondary sets
2. Dependability of the prosthesis (and the repairs recalled)
3. Quickness rating in task performance
4. Comfort while wearing the prosthesis
5. Control of the prosthesis
6. Security of grasp
7. Noise of the prosthesis, that is, its acceptability
8. Appearance
9. Ease of donning and doffing the prosthesis
10. Contribution of the prosthetic training, if provided
11. Affordability of the prosthesis, including repairs
12. Self-estimate of the amount of assistance required from other people

RESULTS

DESCRIPTIVE DATA

The group recruited for this survey was consisted of 28 adults older than 21 years with Bil UL Loss (see Figure 1). Sex totals were 61% male and 39% female. The majority in the BP group were both male and female prosthesis wearers, although ElecHook and ElecHand were represented in both sex groups.

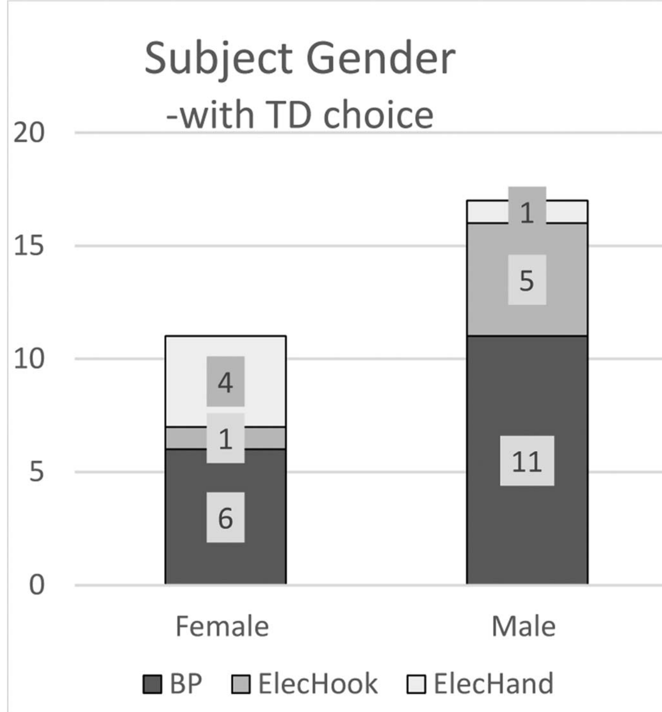

Figure 1. Sex totals are 61% male, 39% female. The “TD choice” is the dominant side terminal device for each prosthesis user. Electric hook and hand represent 39% of the total.

Explanation of Group Labels

The subgroups within most of the charts were defined by the dominant side TD and the general level of limb loss. The categories are as follows:

- BP devices, with one exception, were mechanical devices providing active grasp and release. The cable and harness-operated split hooks are termed voluntary opening (VO), because the wearer's pull on the cable opens the device (all were Hosmer 555 or 5X models). Among the broader UL loss population, voluntary closing (VC) BP TDs are an option, especially among unilateral BP wearers. However, in this study group, no subjects used VC devices nor BP hands. Therefore, BP hook designation also implies a VO device. Included in the BP group is one passive (i.e., without active grasp) mechanical tool holder, a Texas Assistive Devices (TAD) N-Abler[7] system used with a partial hand-level loss.
- ElecHook-labeled data were all motorized electric hooks (ETD1 model, Motion Control,[8] available since 2005).
- ElecHand-labeled data were either one degree of freedom (1-DOF) electric hands (OttoBock SensorHand Speed[9] and Motion Control ProHand[8]) or a multiarticulated (M-A) hand (Touch Bionic iLimb[10]). This category included two 1-DOF users and one M-A user.
- TR includes transradial level and all levels below the elbow.

- TH includes transhumeral and all levels above the elbow.

Three ranges were chosen to create the three nearly equal groupings in the survey (see Figure 2). Thus the 1- to 5-year use period had about the same number of respondents as the midrange and long-term use group.

Twelve of 28 subjects (43%) had worked since limb loss, some for decades (see Table 1).

DEMOGRAPHIC AND OTHER DATA

- This sampling of persons with Bil UL Loss was mature—only three subjects were younger than 35 years of age; two-thirds of the group had over 5 years of experience with their prostheses (Figures 2 and 3).
- The data of Figures 1 and 2 show that BP prostheses were well represented across both sexes and all ranges of years of use. Electric hooks have gained in use, compared with the TIRR (1996) sampling, in which electric prostheses were used by approximately 20% of that group.[11]
- As shown in Table 1, 12 of the 28 had worked since injury (six of them full time), and nine reported they were presently working. Careers of working subjects included engineer, geologist, social worker, and student. This was not counting the mothers and fathers raising children and many performing volunteer work.
- Average daily use was high, 10+ hrs per day (see Figure 4), which is similar to that reported in a recent large study of veterans' prosthetic care.[12] Most subjects reported all-day everyday use, but daily use for some was limited due to other factors, for example, fatigue, irritation, pain, or scar tissue. BP average daily use is very high in this sample of persons with Bil UL Loss, although BP and electric hook average daily use are approximately equal in the midrange use group (Figure 4).
- Historically, the majority of ULL has been the result of trauma, especially electrical accidents (see Figure 5), whereas dysvascular etiologies cause the majority of lower-limb loss in the United States.[13] However, the rise of sepsis, particularly as a cause of quadrimembral loss, has been alarming.[14] (As a point of reference, deaths from sepsis in the United States alone are predicted to pass 2 million in the year 2020, up from 387,330 in 1996). Sepsis did not change the age profile significantly in this group. The average age for trauma-caused subjects was 52; average age for disease-caused subjects was 51.

Table 1. A small-scale survey of bilateral LL prosthetic use November 4, 2019

Since loss of limbs, have you worked?	No. of Subjects
Have not worked:	16
Have worked half-time:	6
Have worked full-time:	6

The number of subjects who have worked, either half-time or full-time, since their limb loss. Twelve of 28 subjects (43%) have worked since limb loss, some for decades.

DOMINANT VERSUS NONDOMINANT SIDE USE

Summing the total tasks performed in each of five categories shows the dominant side as by far the most heavily used (Figure 6). These data include all types of TD and all lengths. Difference between dominant and nondominant utilization is significant, to $P = 0.05$ level of confidence. The result of the analysis presented in Figure 6 shows that dominant side prosthesis use, on average, was used to accomplish three times as many tasks as the nondominant side. The non–limb loss population also use the dominant side for many more tasks, of course.[15] In any data analysis that follows, for example, comparisons between hand and hook prostheses, only the data for dominant side devices of each prosthesis were considered. In fact, three subjects (with much shorter residual limb on the nondominant side) used only a single prosthesis, performing tasks without aid of the nondominant side.

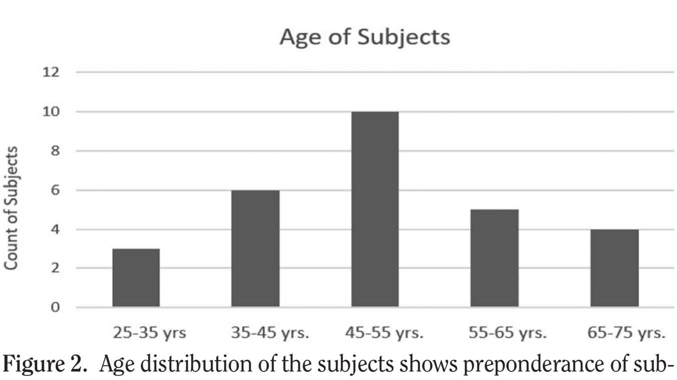

Figure 2. Age distribution of the subjects shows preponderance of subjects were within 35–65 years of age, with only three younger and four older.

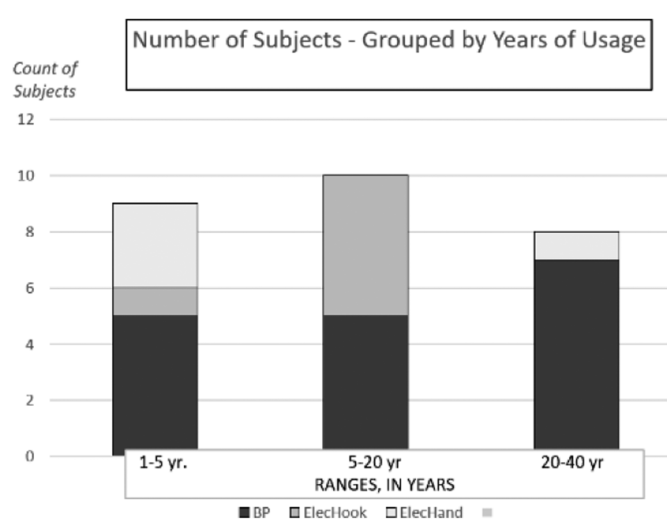

Figure 3. Subjects fall into one of three ranges with nearly equal numbers in our survey. Nearly two-thirds have 5–40 years of prosthesis use. Body-powered representation is high in all groups.

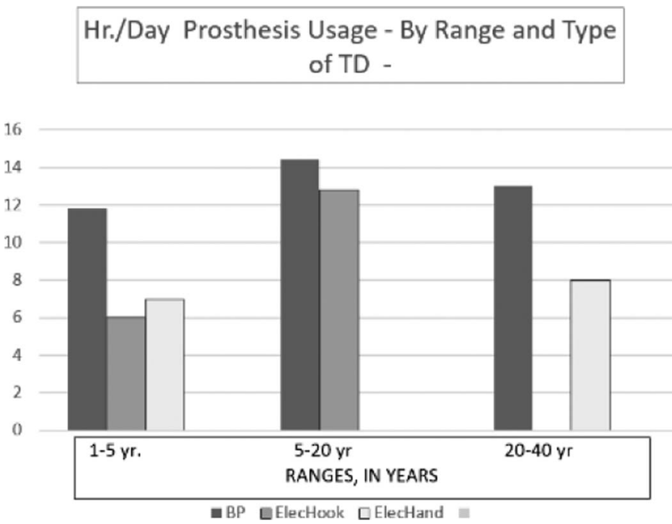

Figure 4. Average daily use reported by the subjects in the three nearly equal ranges. Again, body-powered use is on average very high and only approached by electric hook in the middle range.

SECONDARY PROSTHESIS DATA

As with the primary prosthesis, only the dominant side use for secondary devices was considered. It should be said also that nearly all subjects had backup prostheses, but of the same componentry as the primary set, thus were not considered secondary.

TRANSHUMERAL SUBJECTS

Prosthesis wearers in this study were predominantly in the TR group, with only a few in the TH group (see Figure 7). The data for TH wearers were not remarkably different from TR use, in this study, so TH versus TR groups were not compared. TH wearers all used BP elbow components (on the dominant side only) with one subject using an electric hook TD in a hybrid combination.

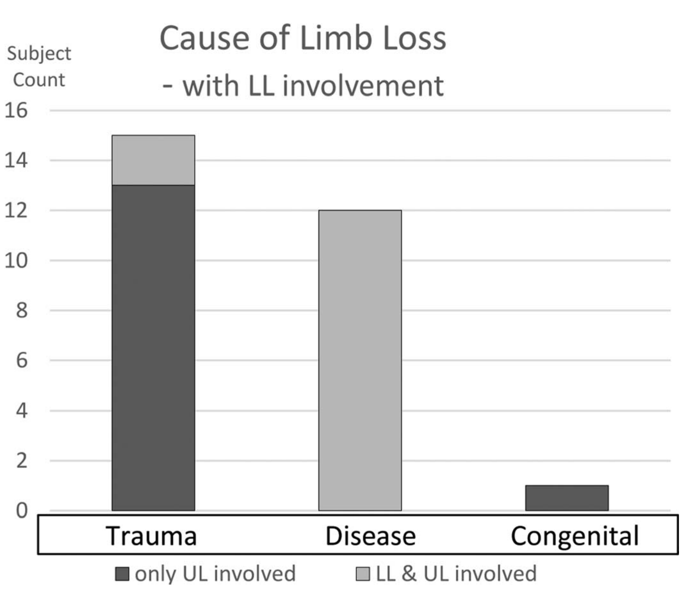

Figure 5. Cause of limb loss, showing the significance of disease-caused limb loss (sepsis, in all cases). Note also, the lower-limb involvement that accompanies sepsis (no subject without lower-limb involvement).

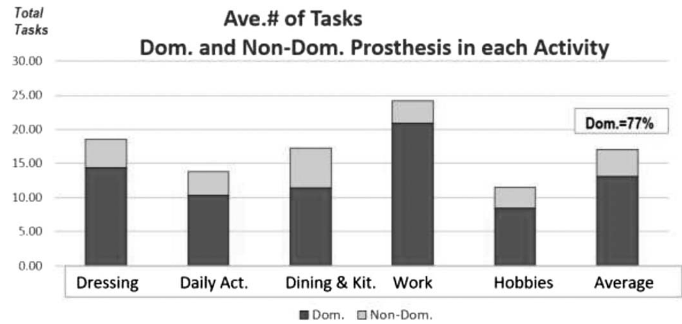

Figure 6. Summing the total tasks performed in each of five categories clearly shows the dominant side as the most heavily used by far—77% on average. Data include all terminal devices, all loss levels. Difference between dominant and nondominant utilization is significant to $P = 0.05$ level of confidence.

BP AND ELECTRIC TD COMPARISON

DISTRIBUTION

Examining dominant side TD use (including primary and secondary devices), the two significant groups were as follows:

- BP TDs (n = 16, all hook TDs, no hands),
- Electric TDs (n = 12 TDs total, nine ElecHook, three ElecHand).

Comparing the overall benefits of BP TDs (all BP subjects used hooks) with electric TDs (of both hook and hand) presented a challenge, because there is no universally accepted measure of "goodness" of a prosthetic device. This study evaluated the data using several performance measures including the following:

- The number of tasks performed, in each of five different categories of each subjects' usual activities (dressing, daily activities, eating and kitchen, work, and hobbies). Displayed as "number of tasks."

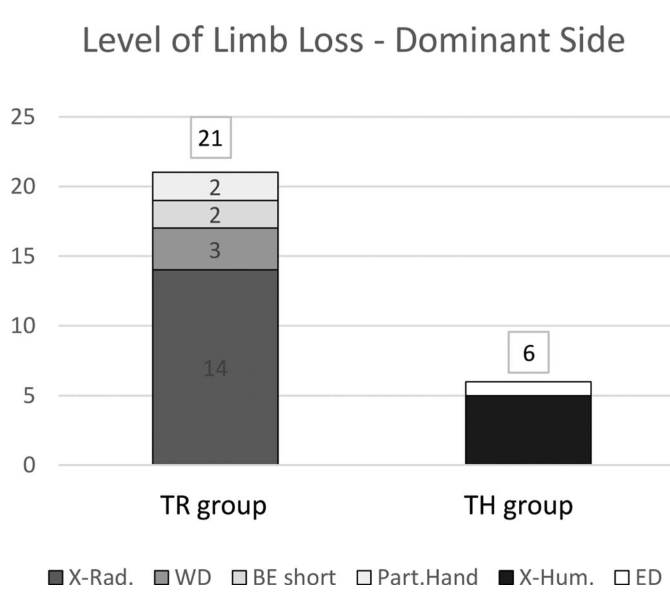

Figure 7. Level of limb loss categories are small, so 'TR group' combines all levels from wrist to elbow joint. "TH group" consolidates all subjects with loss above the elbow.

- The extent of use of two-handed tasks in the performance of those tasks. Displayed as "% of two-handed" task performance.
- The extent of use of prehension by the TD as a percent of total TD function. The variable was labeled "Ave.% prehension," that is, the percent of all tasks performed using prehension.
- The ratings of the usefulness of the prosthesis, collected for each category of activities as well as overall.
- The feature ratings (in 11 categories): the feature ratings were relevant measures of prosthesis function and provided distinguishing differences between various types of TDs.

Figure 8 shows the total number of tasks recorded for BP and all electric TD groups. In this case, the electric hook and hand tasks reported are slightly higher, although not statistically significant.

The comparison of BP and electric TD may be seen as skewed, because the electric TDs included both hooks and hands, and no BP hands were used by any subjects. For a more consistent comparison of only hook TDs, Figures 9A to D compare BP hooks versus electric hooks, using four measures available from the questionnaire data, which shows a similar relationship for all measures, with electric hooks scoring higher (noting that none of the differences were significant to a $P = 0.05$ level).

To help explain the slightly higher electric hook results by these measures, the Feature Ratings (see Figure 10) give more specific data:

- Electric hooks and hands showed a higher quickness rating, and higher average grip security rating, perhaps due to higher pinch force. All other functional categories only showed only small differences between TDs.
- In contrast, BP hooks scored higher in noise (acceptability), lower in comfort, and higher in affordability compared with electric hooks.

OTHER RATINGS: FEATURES AND TRAINING

In section 3, feature ratings and comments from the subjects supplement the other measures. Discussions of each feature rating are listed from lowest to highest.

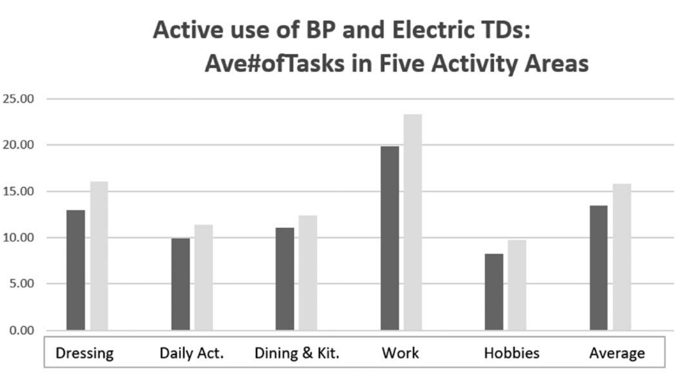

Figure 8. The total number of tasks tallied in each of the categories, including the average of all five. In this case, the electric terminal devices (both hook and hand) are slightly higher, but the t-test of significance did not yield a 0.05 level of confidence, as expected for small-n data sets.

TRAINING

Each subject was asked to rate "the contribution of their prosthetic training." The score was 0 if there was no training at all, which was true for 35% of the individuals using prostheses. The average rating was 1.7 (a C grade), and a typical comment in the interviews was, "I learned the most about using my prostheses from my own experience through trial and error." Many subjects also credited learning from other prosthesis users and videos (most now available online). Appendix A, Supplemental Digital Content, http://links.lww.com/JPO/A73, lists several online sources, most created by experienced wearers themselves. Another common comment was, "I felt like I was the training class for my therapist, due to their inexperience with a bilateral prosthesis user." Clearly, this is a challenge and opportunity for improvement in the future.

AFFORDABILITY

The question asked was, "How acceptable is the expense of your prosthesis, including repairs?" Many subjects expressed mixed feelings for this question, because everyone who used a prosthesis had a third-party payer who reimbursed the original prostheses and subsequent repairs, so many rated 4 (an A grade). However, some complained of time delays for their third-party payer to preauthorize repairs or a new prosthesis. A few subjects, out of sympathy for people paying out-of-pocket, rated 1 or 2 (a D or C grade), although their own prostheses were covered by insurance. On average, the ElecHook group rated affordability 0.8 points lower than the BP group.

GRIP SECURITY

BP hook wearers rated grip security 2.4 (a B grade), and the average rating by electric hand and hook wearers was 3.6, (an A grade). In the summations of Improvements Desired (see below), grip security was the most mentioned by BP subjects.

APPEARANCE

The average of all groups was a consistent 3.2 (B grade) for appearance. Anecdotally, a few mentioned they would appreciate a more cosmetic look to their prosthetic devices.

COMFORT

Surprisingly, the average ratings are high, given the comfort challenge inherent in all-day prosthesis use and the well-documented role of discomfort in device abandonment.[16] Heat buildup was a complaint as well. The BP group was the lowest rated, at just above 3.0 (a B grade), whereas the electric hook and hand groups were just above 3.5 (A grade).

DEPENDABILITY

The high ratings, 3.3 to 3.5 (B+ grade), show that the surveyed group was tolerant of the dependability of their prosthesis of choice, whereas emphasizing that improvement was desired in this area (see Improvements Desired below).

OVERALL

Stated as "overall, rate your satisfaction with the prosthetic system." The average was close to 3.5 (B+ grade) for the three types of systems.

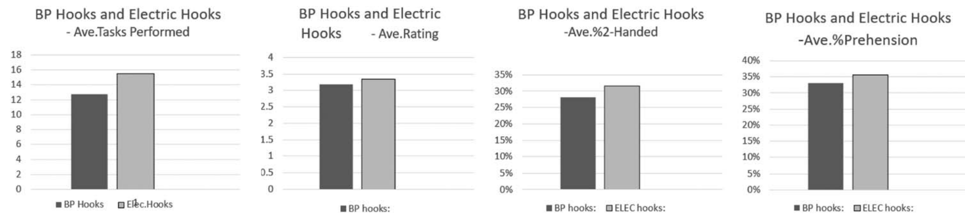

Figure 9. Comparison of body-powered hooks versus electric hooks—the average of all subjects in five activity categories: (A) tasks reported average of five categories (ElecHooks +22% higher); (B) average rating in five categories, 4 = A, 3 = B, 2 = C, 1 = D, 0 = F (ElecHooks +5% higher); (C) average percent of two-handed tasks (ElecHooks +13% higher); and (D) average percent of tasks using prehension (ElecHooks +8% higher).

NOISE (ACCEPTABILITY)

The average ratings were high, 3.5 (B+ grade), with ElecHand rated the lowest of the TD types, 3.0 (B grade). The electric systems generate audible motor noise, thus having room for improvement. Anecdotally, noises in BP systems were mentioned, including clicking of cables and other metal parts and air expulsions from sockets moving on the residual limb during use.

QUICKNESS

BP and ElecHook were rated 3.5 (B+ grade) and ElecHand even higher at 4.0 (A grade). Few problems were mentioned.

CONTROL

All groups were rated 3.5 or slightly higher. Anecdotally, there were mentions of lack of control creating problems with grip security, especially while learning to master the prosthesis.

DONNING AND DOFFING

All groups were rated 3.5 or higher. Self-suspending sockets are not commonly used with this group's prostheses, because they may require assistance in donning.

IMPROVEMENTS DESIRED

The importance of subjects' perceived needs and priorities led to eliciting improvements desired at several points in the questionnaire.

Figure 11 displays the compilation of all suggested improvements, summarized in 16 categories. Grip security had the highest mentions, especially from BP wearers. Because the durability category was so varied, Figure 12 displays five subcategories: cables (for BP devices), electronics (for electric devices), mechanical components, rubber, and glove materials.

The two areas of grip security and durability both exceeded 30 mentions. As explained by the subjects, grip security was compromised when the rubber grip surface is worn—it loses friction and the edges become ragged. Also, BP wearers usually have only approximately one-third of the pinch force of electric hooks, so for VO hooks, the lower friction cannot be compensated by simply increasing pinch force. The BP wearers surveyed were not inclined to increase the pinch force by adding rubber bands, because it also would increase cable resistance and discomfort. VC hooks can potentially generate higher pinch forces, but are seldom selected by Bil UL Loss wearers, because of the

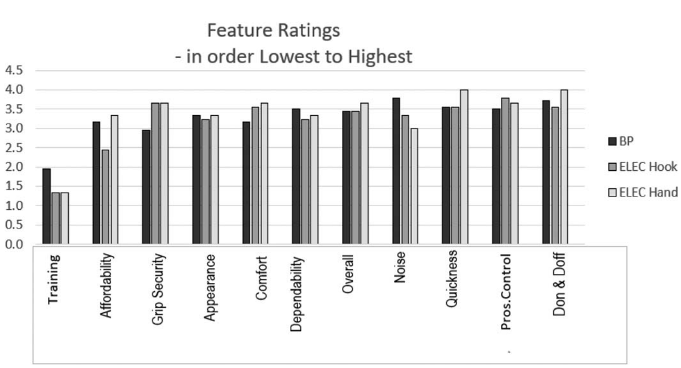

Figure 10. The features are rated on a school-type A, B, C, D, and F scale, numerically represented as 4, 3, 2, 1, and 0. Training, specifically stated as "rate the contribution of your prosthetic training," was clearly the category with the greatest potential for improvement.

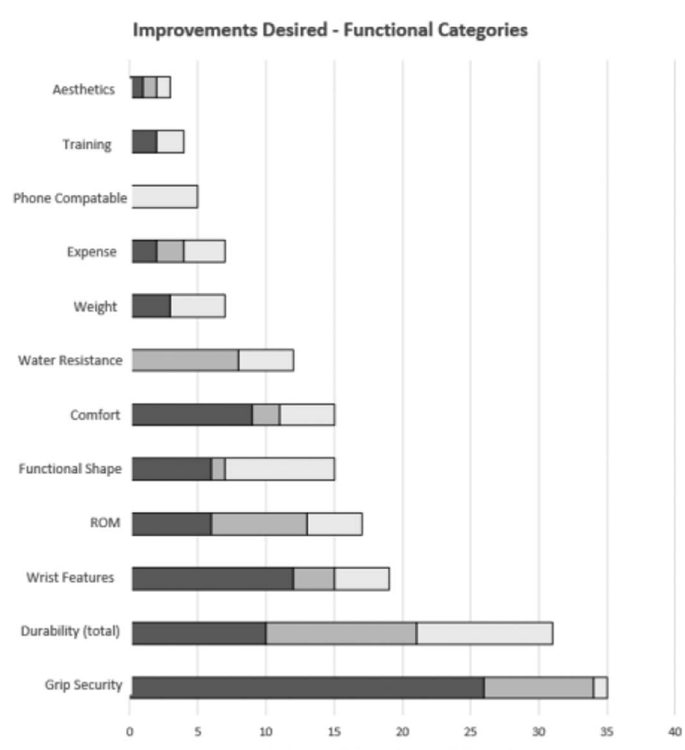

Figure 11. Compilation of all improvements desired. Clearly, among all features, grip security and durability were the highest priorities. Electric hook users also mentioned improvements in range of motion and water resistance; electric hand wearers in addition also stressed better wrist features, lower weight, and phone compatibility (for touch screens).

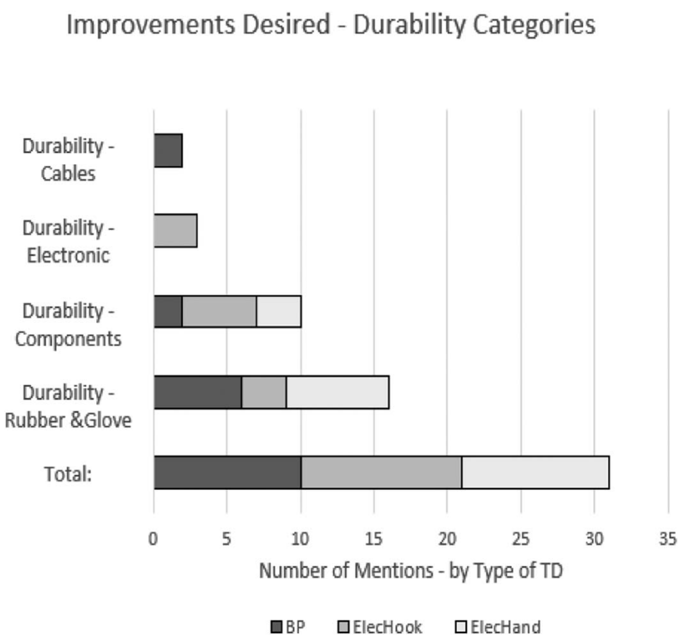

Figure 12. Durability categories are shown in four areas: cables, electronics, components, and rubber coatings (for hooks) and gloves (for hands). The total shows durability to be as important as the highest functional category, grip security.

additional complication of two control cables, each requiring the wearer to maintain tension.

Other improvement areas mentioned included wrist features, that is, locking the wrist position, security against accidental release, and ease of repair: for BP hook wearers—comfort, range of motion, and better wrist positioning; for the ElecHook and ElecHand groups—better water resistance was desired; for ElecHand wearers—desired improvements included better functional shapes (e.g., flat palm shape, finer tip pinch, pocket compatibility, phone compatibility). The BP hook group desired more versatility in grip shapes and hook compatibility with touch screens on phones and tablets.

In Figure 12, the durability total shows that durability was as important as the highest functional category, grip security. BP wearers' desire for better rubber hook coating and better control cables stand out as do their anecdotal comments, such as, "Cables (failures) are problematic—and they always wear out in the same place!"

For the ElecHand group, glove durability was the largest problem mentioned. The ElecHook subjects cite the durability of their components (grip control, ease of repair, wrist quick disconnect improvement) and electronics (interference issues, electrode contact, and sweat problems) as problems.

REPAIRS REPORTED BY SUBJECTS

The actual repairs required for the subjects' prostheses was another way to discover targets for potential improvements. One limitation was that subjects may have only recalled a subset of the total repairs. Manufacturer's and prosthetist's service records would be necessary for a complete listing.

Reducing repairs was especially important to this group because the loss of prosthesis function affected the wearers' independence and perhaps their livelihood. For the majority of subjects, a backup (or the secondary prosthesis) prevented a total loss of prosthetic function during repairs to the primary set.

In Figure 13, the repair data were categorized by the type of TD used and was the summation of dominant and nondominant sides, as well as primary and secondary prosthesis sets. The most repairs reported were for BP devices, although ElecHook and ElecHand were also represented in every group.

Discussion of repair categories:

- Cable repairs were mentioned nearly as often by BP subjects as any other type of repair. As reported, cables often break in the same place at the terminations near the TD.
- Rubber coating on hooks (both BP and Electric) and glove replacement for hands was worthy of a separate category. Hook surfaces and gloves were not always replaceable by consumers and often created delays to order a new part or send the device to the manufacturer.

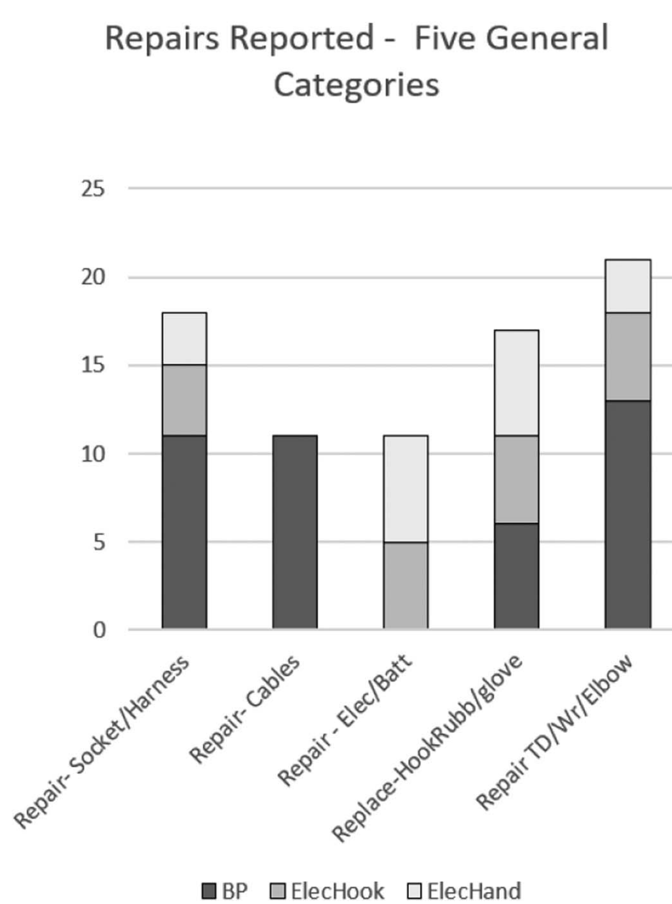

Figure 13. The repair data are categorized by the type of terminal device used and is the summation of dominant and nondominant sides, as well as primary and secondary prosthesis sets. The most repairs reported were for body-powered devices (n = 16), although electric hook (n = 10) and electric hand (n = 8) were also represented in every group. Of course, cable repairs (control cables) are only reported from body-powered use, and electronic and battery repairs are only reported from electric use.

- Socket and harness repairs were common to both BP and Electric devices. Also, even small weight gain or loss could affect socket comfort and prosthesis function and required modification or replacement.
- "Repairs TD/wrist /elbow" includes all parts of these components, including broken fingers, or hooks, wrist and quick disconnect failures, and elbow lock failures.

ASSISTANCE FROM OTHERS

Beyond their prosthetic devices, the subjects used assistive devices and assistance from people, usually family members. The question was phrased, "estimate the percent of your daily tasks for which you require some assistance." The self-reported independence demonstrated was remarkable: seven subjects estimated 0 or 1% and a total of 13 subjects estimated 5% or less. Twenty-two subjects (all but four reporting) estimated 30% or below (see Figure 14). Not measured was the state of health of the subjects, and for some, the tasks requiring assistance represented essential activities. Without spouses and daily caregivers, many said essentially, "I simply could not get along."

OTHER ASSISTIVE DEVICES

Assistive devices were frequently used by the subjects in the survey and include both commercially available devices, modified everyday tools, and homemade devices demonstrating creative solutions (see Figure 15).

The categories are listed from highest to lowest number of mentions:

a. Household—Making the home as accessible as possible was a common theme for using these additional devices, including aids for heavy lifting (hand truck, heavy straps, and human assistance), modified handles on household tools, for example, brooms, brushes, vacuum cleaner, riding mowers, and garden tools for yard chores. TAD special-purpose garden tools were often used (with a quick-connect system built into the socket). Limited reach overhead often required lower shelves. A special purpose modified "zipper holder" is shown in Figure 16, which was clamped on a counter or shelf to help with a variety of needs.

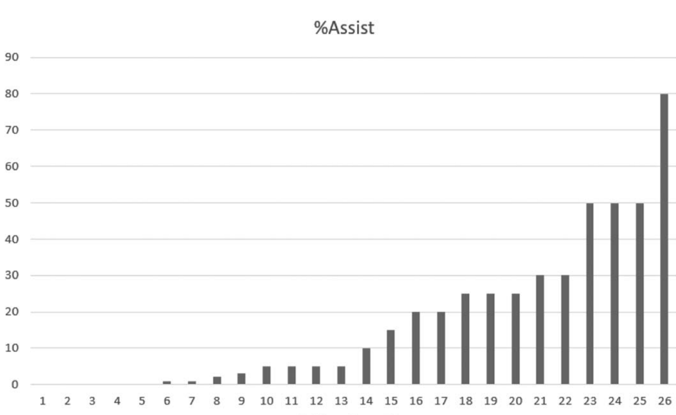

Figure 14. The percent of assistance required for all activities, as estimated by 26 subjects responding. There is a wide range of assistance required, from 0% to 80%; however, 13 of 26 reported 5% or less, and 20 of 26 (65%) reported 25% or less.

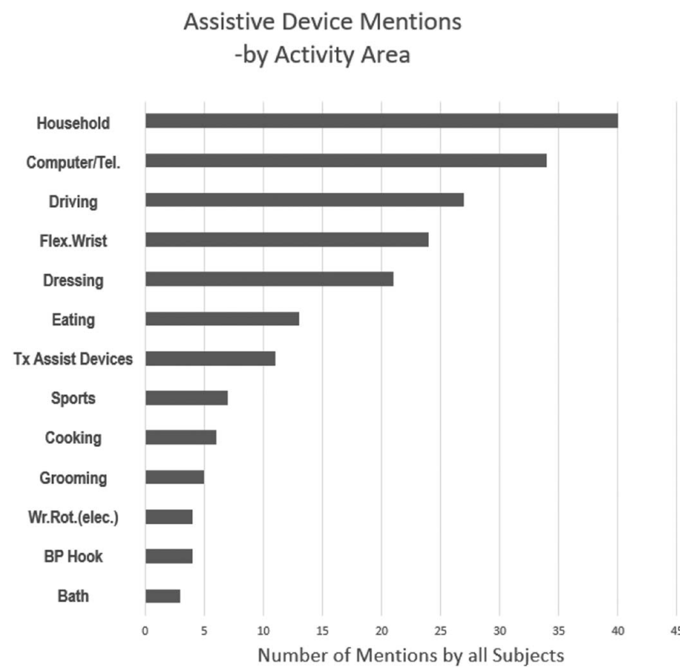

Figure 15. Assistive devices needed and used by Bil UL Loss individuals in our survey are many and very diverse. They are categorized into 13 areas, with household devices being the largest, followed closely by computer/phone/touch screen and driving. Several prosthetic components are included because their use is not specifically recorded elsewhere: flexion wrist, Texas Assistive Devices brand specific–function tools, and electric wrist rotation.

A common modification to BP hooks was the addition of silicone or plastic tubing, which is slipped over a hook finger to improve grip friction. The tubing used varied from ordinary flexible silicone tubing to tough high-temp silicone (e.g., Du-Bro Exhaust Deflector).

a. Computer/phone/touch screen category—Modern computers and portable devices were used by the majority of individuals in the survey. Several technical features were particularly helpful:

- Voice recognition—For tablets and phones, voice commands were widely used, like Siri (for Apple's iOS) or Google Assistant (for Android). Photograph taking and other phone functions were simplified by audible shutter commands. PC-based commercial software Dragon 13 was used by a few subjects for voice control of PC functions.
- Touch screens—A simple and affordable stylus was an easy way to use nearly any touch screen, but smart phones by Samsung (and some other brands, including newer Apple phones) were adopted by many subjects because they featured a more sensitive touch screen, usable by the tap of a metal hook. ElecHand wearers still require a stylus because touch screen–sensitive gloves were reported to be inadequate. Through these means, text messaging,

Figure 16. Two ways to handle credit card readers at self-serve gas stations: (A) using extension wrist position with electric hook; (B) a small key ring through a hole punched in the card allows most hook (or hand) models to pull the card out.

photograph taking and sharing, Internet searches, and so on, were more accessible to persons with Bil UL Loss.

b. Driving—Voice-controlled door locks, keyless ignition, and automatic controls made hands-free operation of a modern vehicle much more possible. Low-tech door levers were also commonplace, and a driving ring attached to the steering wheel was a frequent modification. Pumping gas was mastered by many with adept use of hook or hand TDs. More simply, many subjects simply patronize gas stations where "full service" was available. Figure 17 shows two methods for meeting the challenge of inserting credit cards into a self-service gas pump. A simple clothes pin or alligator clip was also frequently used.
c. Flexion wrist, wrist rotation—Flexion wrist, an optional mechanical component integrated into both BP and electric TDs, was adopted by 23 of the 27 prosthesis wearers. All the flexion wrist versions used had a mechanical lock with up to four flexion and extension positions (BP versions do not extend). Wrist rotation (electric) was used by nearly half the electric TD wearers (5 of 11). Its wider adoption is limited by the additional weight and additional space required within the prosthesis and, for some, inadequate myoelectric control of the wrist.
d. Cooking—Independence in the kitchen is a high priority to many, especially those without domestic partners. Devices used were often electric (can and jar openers, beaters). Manual devices included several TAD utensils for cutting, stirring, or grasping in the kitchen. Simple adaptive aids were frequently mentioned, for example, adaptive cutting boards and Dycem mats, curved blade knives (Ulu knife), and even a simple elastic forearm strap to aid in holding a spoon or fork without a prosthesis. Lowered counters were helpful for a few subjects who sit for kitchen work.
e. Eating—Adaptive utensils were often used for eating as well as cooking, especially for cutting meat, although many requested their meat to be cut for them, both at home and dining out in restaurants. Use of adaptive utensils was not favored by some subjects, who preferred not to depend upon special-purpose devices. Attitudes varied,

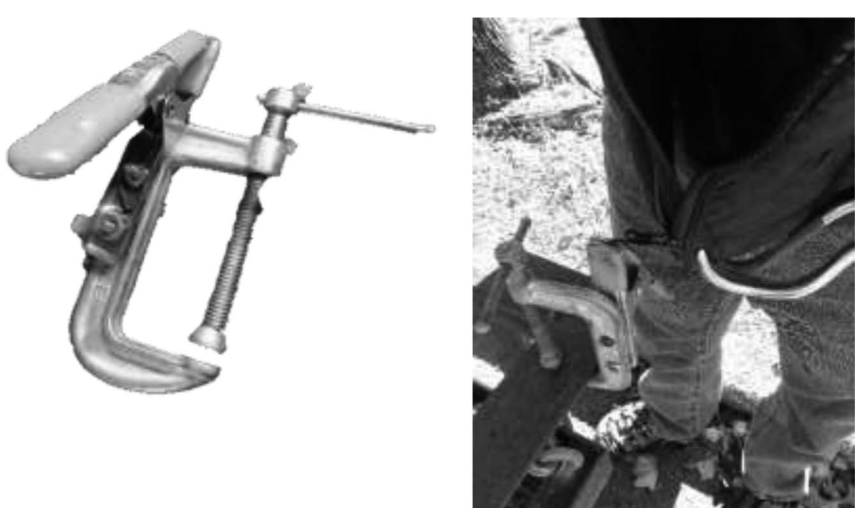

Figure 17. A, A homemade "extra hand/zipper holder" is attached with the carpenter's clamp onto a countertop or other sturdy object; then the strong clamp can be used to pinch onto whatever needs to be pinched. B, A zipper pull is gripped while the terminal device pulls the garment down (photograph courtesy John Krenzel).

and some adopted a "fanny pack" or similar holder in which to carry personal items and/or adaptive utensils, such as keys, billfold, drinking straw, clothes pin, or alligator clip, and so on.

f. TAD[7]—Eleven mentions were made of these special-purpose tools, which are available in a wide variety for cooking, as well as carpentry, recreational, and mechanic-type tasks.
g. Sports devices—Special-purpose sport TDs were mentioned for several activities, usually utilizing a Therapeutic Recreation Systems (TRS)[17] activity-specific device for basketball, skiing, paddling, and weightlifting.
h. Grooming and bath—Electric consumer products were mentioned often, especially electric shaver, hair dryers, and bidets. To reduce the need for manipulation, some use fixed mounts, that is, a dressing tree, a permanent holder for appliances, comb or brush, shampoo dispenser. Innovative towel modifications such as sewn-in pockets for residual limbs allowed independent drying.
i. Alternative TDs—Heavy-duty TDs (usually a steel BP hook) were used by four subjects for specific tasks, for example, chopping and stacking firewood, fishing, or gym workouts.

DISCUSSION

INDICATIONS FROM THE DATA

1. Reviewing the data for the entire study reveals an interesting dichotomy. Functional capabilities and average overall ratings were high (for all prosthetic choices represented). Many subjects have decades of successful prosthetic use, and most were highly independent.

It contrasts this apparent success story with the improvements desired listing (for all prosthetic choices again), which showed high needs for better dependability and grip security and significant needs in 12 other categories.

2. Prosthetic use by this group showed very high use of the dominant side prosthesis over the nondominant side, as well as high use of passive function—not surprising, considering that nondisabled hand use is very similar.[15] However, these data would emphasize two prosthetic lessons:

i. The function, the fit, and durability of both prosthetic sides are very important, with awareness of the high use of the dominant side.
ii. For nearly every bilateral wearer, secure grip in prehension as well as passive function are highly used, and both require high maintenance of friction surfaces and, when space allows, components allowing wrist positioning.

3. Other prosthetic and nonprosthetic contributions to function were demonstrated to add important function for specific tasks.

a. Assistive devices of a wide variety from home-made zipper holders to driving rings and clothes pins leveraged prosthesis function.
b. Supplemental prosthetic wrist components for flexion wrist and wrist rotation added functional degrees of freedom. Special-purpose TDs were essential for many activities not possible for the subjects' usual TD.
c. Consumer electronics (phones, tablets, computers, autoelectronics, etc.) were adopted very widely, to significant benefit.

AREAS FOR ADDITIONAL STUDY

1. Both electric and BP devices had high ratings for overall satisfaction, and for both groups, hooks were chosen over hands typically. However, all subjects had evaluated their alternatives and arrived at their own choice.

Clinically, this speaks for thorough evaluation of all alternatives, matching individuals with their own best option. Trial fitting[18] (or prototype fitting[1]) is one method to allow each individual to experience his or her options first-hand, so the pros and cons of each can be matched with his or her own use patterns. Validation of this approach or others would be of benefit for future Bil UL Loss patients.

2. The study group's highest mentions for improvements desired were for dependability and grip security. Other areas for improvement included increased range of motion, water resistance, comfort, and lower weight.

Larger studies (or more focused small studies) could investigate these topics and others, and could be more specific in comparing for instance, types of hooks and hands, control options, or the impact of more intensive training.

3. Training in prosthetic use (and skills for independence) had been unevenly provided but has great potential for improvement of care for this population. Training in prosthesis use was often challenging and discouraging for subjects in the study, and for their therapists, a lack of experience with Bil UL Loss patients was a challenge. The problem will not be easily solved but some suggestions (for therapists and prosthetists) have included the following:

a. Telehealth is a growing use of technology to provide access to skilled therapists (or others) via Internet (with video) links.[19]
b. Internet links with well-experienced therapists and other professionals might become a training resource for occupational therapists (OTs) and others before or while working with Bil UL Loss patients. (Appendix A, Supplemental Digital Content, http://links.lww.com/JPO/A73, has links to two earlier teaching videos for OTs [for BP and Electric TDs], now on YouTube without fee.)
c. Increased and improved training for OTs and others working with ULL patients might be developed at universities and centers of excellence in ULL and Bil UL Loss. Short-term courses might be an option for this specialized

training. Also, resources (online or other) could help consumers to seek out therapists and prosthetists with experience in Bil UL Loss care, perhaps with recommendations from professional and/or consumer groups.

4. Online resources for peer teaching for new or even experienced Bil UL Loss individuals may be better used. Appendix A, Supplemental Digital Content, http://links.lww.com/JPO/A73, lists a number of online sources of prosthetic use by Bil UL Loss mentors, although they do not include all prostheses nor all activity areas. A curated group of video examples for the full range of prosthetic as well as assistive devices would be very useful if compiled and made available via YouTube or other Internet sites.
5. Cost-benefit analysis has been challenging in this area, but consumers and caregivers would benefit from more information about the features and their value of the useful types of prosthetic and assistive devices available.
6. Small-scale surveys like this one could focus on other specific issues in the understudied world of Bil UL Loss, or wider prosthetic topics. For instance, evaluation of TDs, socket-fitting techniques, comparison of new TD technologies with existing options, details of wrist function, the pros and cons of center-of-excellence clinics, impact of specialized OT, mental health services, prosthetic caregivers, and so on.

LESSONS FOR FUTURE INVESTIGATIONS

1. The in-person interviews, with an in-depth questionnaire, are capable of gathering a great deal of useful data. Estimating the total activity of a subject by the number of tasks performed is an approximate but unbiased estimate of the subject's breadth of activities, especially because of the open-ended nature of the questionnaire.
2. Subjects' mentions of improvements desired gathered a wealth of information about functional shortcomings of each prosthesis. Reporting of prehension or passive use and two-handed task also gave wider information about task performance.
3. Size of the study: the final sample size of 28 is small, but perhaps not considering that the total population with Bil UL Loss people in the United States has been estimated as small as 462,[20] and that much of the information has never before been gathered about this population. Again, more data are needed, and hopefully more accurate UL population sizes, and other data will be contributed by the new Limb Loss Registry for the UL population.[21]
4. Statistically significant comparisons were not the most important goals of the study. The indications of the needs and priorities of this group do not have to be statistically significant to be relevant to improvement of clinical care for patients with limb loss, be they bilateral or unilateral individuals. This survey's results can demonstrate the breadth of information possible from small studies, conducted by a few highly interested people, with little funding, as long as there is some access to the specific population to be studied.

FINAL THOUGHTS

The data showed that this group was overall very functional, with high use and high independence. However, the group also expressed a high need for improvement to their prostheses and their training, that is, they could do even better with well-directed improvements. The caveat is that improvements are needed, but without sacrificing the dependability, versatility, and affordability they value so highly, that is, "do not throw the baby out with the bathwater."

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