SURVEY OF BILATERAL UPPER LIMB PROSTHETIC USERS

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

Unaffiliated

ABSTRACT

Bilateral upper limb loss (BiULL) is perhaps the greatest challenge for upper limb prosthetic care, now more than ever, as we witness the increase of sepsis as a major cause of multiple limb loss. This small-n survey has recruited 28 individuals with BiULL, 27 of whom are prosthesis wearers. 12 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. Secondary prosthetic use is also included, when the secondary prosthetic set was used for 10% or more of total activities.

The survey used person-to-person interviews to compile detailed data about how tasks are performed, how many tasks are performed, etc. A detailed picture is painted from this data, including the functionality and independence achieved by many in this population, and the needs expressed for improvements in their devices of choice, and the care they receive. For example, the indications for improvements needed emphasized greater dependability, and greater grip security. Ratings of prosthetic features illuminated shortcomings in training especially.

The information should be useful for clinical guidance, but also to help guide the development of future prosthetic devices, as well as set an example for how a small-scale study can collect useful data about the use of prosthetic devices, without a large grant or large institutional sponsorship.

A. BACKGROUND

The bilateral upper limb loss (BiULL) individual presents perhaps the greatest challenge in UL rehabilitation. Since there is a dearth of information in the literature about the actual needs of this small but important population, this small study hopes to contribute relevant knowledge towards both the clinical and development needs that exist. It is also expected that wearers with BiULL use their prostheses in the same ways as wearers with unilateral limb loss (LL), i.e., what is needed by the small group in this study is also going to be needed by the larger population with unilateral LL.

From previous experience with similar surveys[1,2] the in-depth information available from personal interviews with prosthesis users has been used successfully to focus on prosthetic needs. A large segment of the entire population of BiULL individuals may be nearly impossible to recruit, but gathering in-depth information from the 28 subjects in this small study provides a wealth of information (about the details of prosthetic use) that would be more difficult with a large-n study.

Methods: The data collected in this survey seeks to document all the ways that BiULL persons use their variety of prosthetic devices, and the ways they are still limited by those devices. Direct interviews with all subjects, either in person or by telephone, allows the open-ended discussion necessary to collect the breadth of information sought.

The simple assumptions, upon which the study is based include:

- No research grant, thus no delays for proposal writing and funding.
- No oversight by a large institution, thus less staff to coordinate, less "red tape", etc.
- The authors each have 30+ years' experience in the prosthetic field, working as therapist, prosthetic coordinator, and engineer/manager. The first author has conducted earlier surveys with published results.
- Data is collected directly from subjects within the population with BiULL, who are directly recruited.
- This project hopefully can set an example others could follow. The highest priority is to gather data from consumers – a priority recognized by the limb loss community as well, in the 2018 Amputee Coalition study[3] which cited the great need for outcomes reflecting the actual needs and priorities of the limb loss population.

Recruitment: Many (approximately half of the 28 subjects) were recruited at the Fifth Skills for Life (SFL5) Workshop, attended by over 70 persons with BiULL, held in Houston, TX, in October 2018.

Institutional Review Board (IRB): The protocols and informed consent form were reviewed by a certified private IRB (Ethical and Independent Review Services, Corte Madera, CA), and the study was judged to be exempt from IRB oversight, citing no risk to subjects. Subjects were not compensated.

RESULTS:

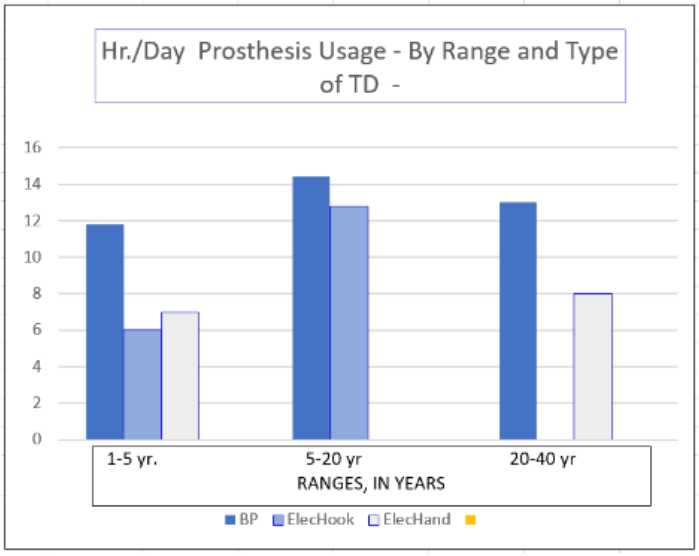

Figure 1 – Average daily usage reported by the subjects, in the three nearly equal ranges. Again, BP usage is on average very high, and only approached by Electric Hooks in the middle range.

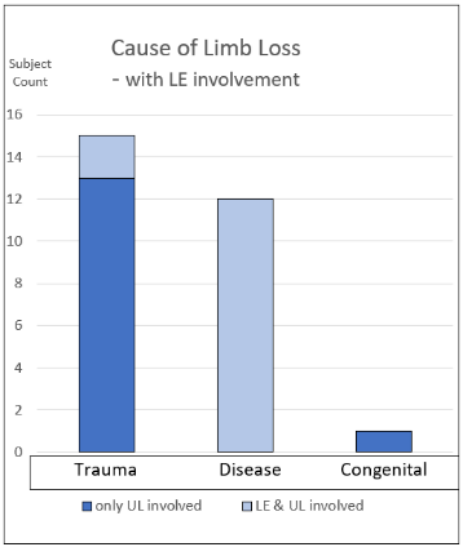

Figure 2 – Cause of limb loss, showing the significance of disease-caused limb loss (sepsis, in all cases, also causing LE loss).[4]

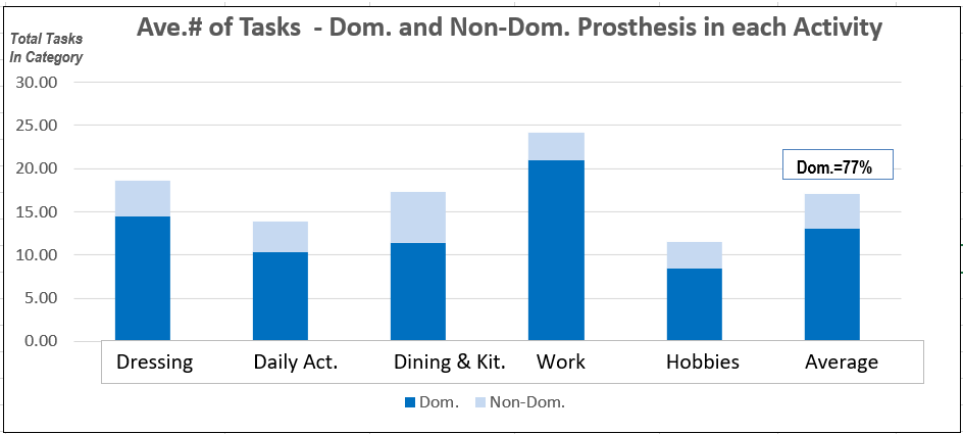

Figure 3 – Summing the total tasks performed in each of five categories, shows the dominant side consistently is the most heavily used - 77% on average . Data includes all TDs, all loss levels. On average 85 different tasks are performed, some many times each day, so total tasks are underestimated.

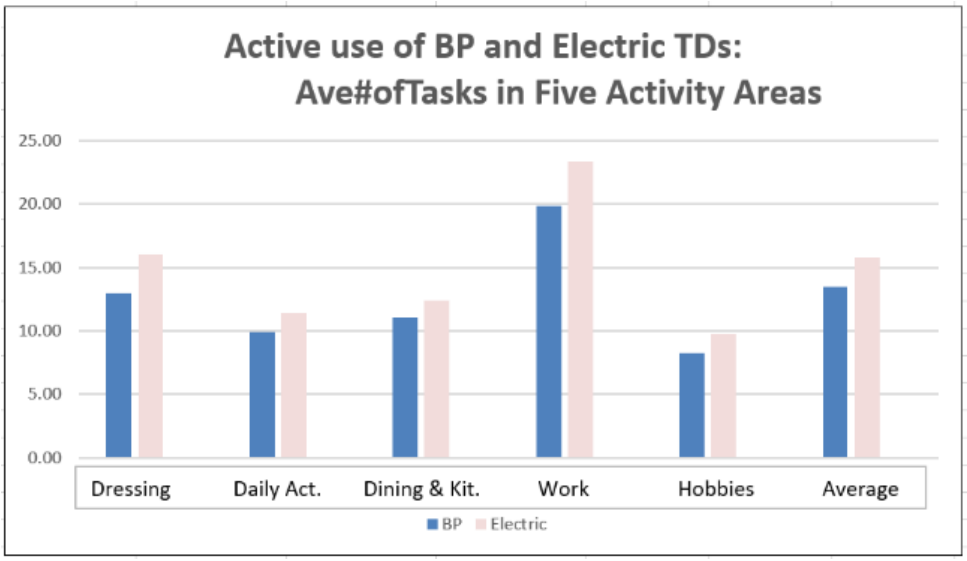

Figure 4 – The total number of tasks tallied in each of the categories, including the average of all five. In this case the electric TDs tasks (both hook and hand) are slightly higher, but the difference is not statistically significant.

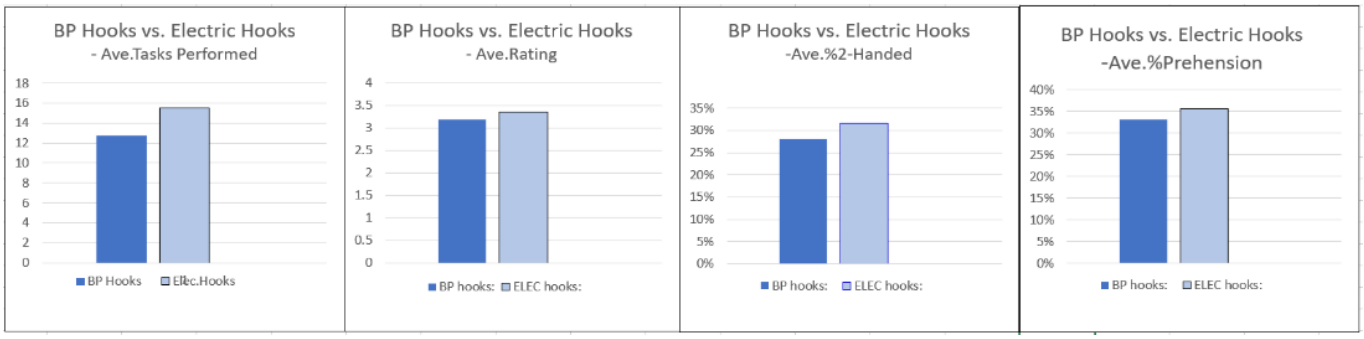

Figure 5 – Comparison of BP Hooks (n=16) vs. Electric Hooks(n=9). Data is average of five activities (for total tasks multiply by five) and includes both primary and secondary prostheses, if used. Charts are i to iv, left to right:

i. Tasks reported- Total tasks (repetitions of tasks not included) (ElecHooks +22% higher).
ii. Average rating, 4=A, 3=B, 2=C, 1=D, 0=F (ElecHooks +5% higher).
iii. Average percent of 2-handed tasks (ElecHooks +13% higher).
iv. Average percent of tasks using prehension (ElecHooks +8% higher).

Other survey results included the subjects' ratings of prostheses in specific features, which can help to explain some of the results presented in Figure 4 and 5, e.g., electric hooks were rated higher in grip security, which was a very high priority for all the surveyed group. "Improvements Desired" was solicited from subjects, and produced a high amount of data, listing 15 specific shortcomings of present devices, mostly centered on the terminal devices. The clear areas of most need could be generalized as: *Durability* (four distinct areas were cited), and *Grip Security* (including hand and hooks, electric and BP). "Impact of Training" was also graded. Electric prostheses graded their training a D+; BP prostheses graded training a C. In addition to the prosthetic devices used by subjects, 'Other Assistive Devices' (in 10 categories), were very important to nearly all subjects, and are used in many diverse activities, including: household activities, driving, bathing, eating, computer/phone functions, and sports.

Conclusions from the data

1. Functional capabilities of the surveyed group are on average very high – and notably, for all the

prosthetic choices: e.g., BP Hooks, Electric Hooks, and Electric Hands. The majority have chosen body-powered hook TDs, but for subjects whose experience is within the last 20 years, the group is nearly equally divided between electric and body-powered devices.

2. The functional needs expressed, considering all devices, are led by *better dependability* and *better grip security.* Other needs included better range of motion, water resistance, comfort, and lower weight. Generalizing, the surveyed group appreciates what they have accomplished, but they know improvements *could give them better function*- as long as the *dependability, versatility, and affordability* they value are not sacrificed. Choosing the right device for the individual need not be haphazard. Careful evaluation and trial fitting could give patients and caregivers better choices. [5,6]
3. Prosthetic use by this group shows: very high use of the *dominant side* prosthesis over the non-dominant side (75% vs. 25%), as well as very high use of *passive function,* over prehension functions (65% vs. 35%).
4. Other contributions to function:
    a. Additional assistive devices, of a wide variety from a home-made zipper holder to driving rings, and clothes pins (13 different categories are enumerated).
    b. Consumer electronics (phones, tablets, computers, etc.) and Automotive electronics aid this group immensely.

Indications for additional study about the BiULL population.

1. The priority for improvements in *dependability* and *grip security* were high in this survey of 28 persons with BiLL.
   Larger studies (or focused small studies) could *verify* these conclusions, and could also be more *specific in comparing types of hooks and hands*, control options, or the impacts of important variables such as *expert prosthetic care* and the *center-of-excellence* approach, *early fitting and training, mental health* services and other technologies.
2. *Training* clearly is an area of great potential- but exactly how to improve training must be studied seriously. A few possibilities include (but are not limited to):
    a. *Telehealth* shows potential for leveraging the impact of expert therapists to provide wider access to skilled therapy, custom training for clients, and training for therapists in specific skills.[7]
    b. Internet links such as You Tube video of skilled users, are widely accessed consumers, and could supplement training for therapists also.
3. Focused evaluation studies of specific prosthetic TDs would help consumers to understand the pros and cons of new (or old) devices, before making expensive choices. *Cost-benefit analysis* is difficult in prosthetics, but could be developed as a benefit to consumers, and prescribers as well.

REFERENCES

1. Sears H, Shaperman J; Proportional myoelectric hand control – an evaluation; *American Journal of Physical Medicine and Rehabilitation;* 1991;70, 20-30.
2. Sears H, Shaperman J; Electric wrist rotation in proportional-controlled systems. *Journal of Prosthetics and Orthotics,* 1998; 10 (4) 93-97.
3. Limb Loss Task Force/Amputee Coalition of America. Roadmap for improving patient-centered outcomes research and advocacy. Knoxville, Tennessee: ACA; 2019. Available at: amputee-coalition.org. Accessed September 15, 2019.
4. Hawiger J, Veach RA, and Zienkiewicz J; New paradigms in sepsis; *Journal of Thrombosis and Haemostasis*; 13:1743-56.
5. Sears H; Approaches to prescription of body-powered and myoelectric prostheses; *Physical Medicine and Rehabilitation Clinics of North America;* 1991:2,361-371.
6. Uellendahl JE, Heckathorne CW. Creative prosthetic solutions for bilateral upper extremity amputation. In: Meier, RH, Atkins, DJ; *Functional Restoration of Adults and Children with Upper Extremity Amputation;* New York, NY: Demos Medical Publishing, 2004.
7. Latour D. Unlimbited Wellness: Telehealth for adults with upper-limb difference. *Journal of Prosthetics and Orthotics.* 2019; 31(4):246-256.