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Research Paper

Priorities for the design and control of upper limb prostheses: A focus group study

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ABSTRACT

Background: Common prosthetic options do not allow for enough independent control signals to control all the movements of the arm. Invasive approaches to obtain prosthetic control signals are being developed to provide people with upper limb loss improved prosthetic control and feedback.
Objective/Hypothesis: This study explored the prosthetic qualities that are important to users and examined the factors that play into the decision to consider invasive prosthetic interfaces that allow for enhanced prosthetic control.
Methods: Individuals participated in semi-structured focus groups or in individual semi-structured interviews ($N = 11$). A semi-structured interview guide containing open-ended questions was used to learn about ideal prosthesis qualities and interest in prosthetic technology interfaces including targeted muscle reinnervation, peripheral nerve interface, and cortical interface. Qualitative content analysis with an inductive approach was used for transcript analysis.
Results: Participants were most interested in improving the dexterity and durability of prosthetic options. Recovery time, anticipated risk, medical co-morbidities, and baseline functional status influenced willingness to consider invasive prosthetic interfaces. Participants were interested in learning more about all three invasive interfaces but had the most concerns about cortical interfaces.
Conclusions: Attitudes toward invasive control interfaces vary. Further education on invasive control interfaces and additional conversations between prosthetic developers and people with limb loss will help to develop effective prosthetic devices that potential consumers will use.

Loss of an upper limb can have a catastrophic impact on a person, resulting in loss of function and affecting their ability to return to work.[1] While people with upper limb loss can gain some function with a prosthesis, many users report low satisfaction with training, function, and information about new prosthetic technology.[2] Estimated rates of upper extremity prosthesis use vary, from low to moderate levels of use,[3] with mean prosthesis abandonment rates in the literature of ~24% (range 0–75%).[4]

The three main categories of prostheses currently available to patients are: 1) cosmetic, which looks like an arm but does not provide any active degrees of freedom; 2) body-powered, which requires the user to harness shoulder movements to operate distal actions, such as opening and closing a terminal device[5,6]; and 3) myoelectric, which is externally powered and utilizes electromyographic signals from residual muscles to operate distal actions.[7–9] Myoelectric prostheses require the isolation of independent muscle signals for prosthetic control.[7–9] Recent advances with pattern recognition, or the combination of specific signal characteristics to control a prosthesis, has allowed for increased control.[10–13] Because these devices do not have enough independent control signals to control all the movements of the arm, research efforts have been directed at exploring invasive approaches to obtain control signals. These surgical options include targeted muscle reinnervation, peripheral nerve interfaces, and cortical interfaces.

Targeted muscle reinnervation is a procedure in which transected peripheral nerves are transferred to reinnervate more

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proximal muscle and skin.[14,15] Electromyographic signals from the reinnervated muscle are then used to control a prosthesis.[14,15] Peripheral nerve interface involves placement of electrodes on whole peripheral nerves or individual nerve fascicles.[16,17] A recent advancement with regenerative peripheral nerve interfaces, or partial muscle grafts reinnervated by a transected peripheral nerve branch with the electrode implanted on the muscle tissue, can both protect the nerve and also produce high-amplitude electromyographic activity from muscle contractions.[18,19] Finally, cortical interface uses neural signals captured directly from the motor cortex for the control of a prosthesis. This approach has not yet been used to control a prosthesis mounted on the body.[20,21]

Each of the control interfaces described have the potential to provide people with upper extremity amputation with improved prosthetic control and feedback. However, many of these approaches require invasive surgical procedures and, as such, come with increased risk. In an on-line survey, we previously explored whether people would be interested in these procedures to gain increased function despite the risk.[22] Of 104 participants who responded to the survey, most were interested in non-invasive myoelectric control (83%). However, the majority were also interested in having targeted muscle reinnervation (63%) and peripheral nerve interfaces (68%) and over a third (39%) were also interested in cortical interfaces.[22]

The on-line survey helped to determine how many people would be interested in this type of technology[22] and what potential demographic factors related to this interest,[23] but it did not allow full exploration of participants' thought processes that contributed to their decisions nor elucidate what current prosthetic users who have tried to adapt to their lifestyles still found lacking. To learn more about the factors that impact an individual's decision to consider surgery for enhanced prosthetic control, we conducted semi-structured interviews of people with upper limb loss. Such interviews are useful strategies for exploring the thinking patterns of the target population and discovering unanticipated findings.[24] We hope that the results of this study will contribute to future patient-centered developments in upper extremity prosthesis technology.

Methods

Study design

The study employed focus groups and interviews to understand the experiences and perspectives of individuals sustaining limb loss about prosthetic use. Initially, three focus groups were planned, each with six participants. However, many interested participants lived prohibitively far from the study center. Therefore, after the second focus group, the remaining five interviews were conducted by telephone. One-on-one interviews allowed for the participant and the interviewer to discuss topics in greater detail and in some cases mitigated shyness. By the fourth telephone interview, data saturation was reached for participants with unilateral limb loss. We conducted a fifth phone interview to include a participant with bilateral limb loss.

The study was approved by the local Institutional Review Board and all participants provided written informed consent.

Participants

Participants were current prosthetic users over 18 years of age with upper limb loss and who had or were receiving care from a large prosthetics center in Michigan. Potential participants were approached in person after their clinic visit or were contacted by one of the researchers via telephone after they had expressed interest in participating in research at previous clinic visits. Potential participants were excluded if it would not be possible for them to interact with the study staff or other members of the focus group (e.g. cognitive disorders that would limit their ability to communicate, or an inability to speak or understand English). All participants screened were eligible. Two were unable to attend their scheduled focus groups for personal reasons and 11 completed the study.

Data collection

Two focus groups, each with four participants, were held at an outpatient clinic and lasted approximately two hours. Each telephone interview lasted about an hour. All focus groups and phone interviews were conducted by the same investigator (J.Z.), a physician with clinical expertise in prosthetics and care of individuals sustaining limb loss and experience engaging individuals with complex medical conditions in semi-structured interviews. The interviewer had not provided clinical care to any of the participants in this study. All focus groups and phone interviews were audio-recorded and professionally transcribed verbatim for analysis.

After a brief introduction to the process (A.1), participants were asked to describe the qualities in their ideal prosthesis, limitations of current prostheses, and any additional thoughts they had on prosthetic technology and use based on their own experiences. Improvised probes were asked to obtain more detail about participant comments. In the second part of the interview, participants were presented with a survey question[22] regarding the importance of various customized prosthesis functions (A.2) such as dexterous actions and touch sensation. Additionally, we presented three separate prosthesis interface descriptions: targeted muscle reinnervation, peripheral nerve interfaces, and cortical interfaces.[22,23] The descriptions were intended to summarize the basic idea behind each interface since technical details continue to evolve with current research and included a caveat about lack of availability of the technology as none is available in the form presented or with all the functionality listed.

Printed descriptions of the different control procedures were handed to focus group participants or mailed to telephone interview participants. Participants were asked not to look at the document until instructed. We asked participants whether they understood the description, what else they wanted to know about each interface, and whether they would be interested in trying each interface. Improvised probes were again used to gather further information about participant comments.

Data analysis

Qualitative content analysis with an inductive approach was used to analyze the transcripts.[25−27] Excerpts were selected and coded using a thematic content analysis using Dedoose, a cloud based computing program.[25−27] Two researchers (J.Z. and M.L.) individually conducted readings of the transcripts to gain a sense of the overall data. Then, each reviewer individually coded the data and compared the coded transcripts at regular intervals to resolve discrepancies. The coding structure was iteratively developed throughout the application and reconciliation of coding. Once coding was completed, the coded excerpts were reviewed a last time to finalize the coding structure. To evaluate the potential effect of data collection mode (focus group vs. one-on-one interview), a matrix analysis was used for a visual representation of the data.

Results

The eleven participants had limb loss ranging from transmetacarpal to transhumeral (Table 1). Participants were mostly male (n = 9), with unilateral limb loss (n = 10), and ranged in age from 27 to 65 years. Two participants had congenital limb loss, while the others had acquired limb loss due to trauma or infection. At the time of the study, of the nine with acquired limb loss, four had had their limb loss for three years or less.

The qualitative analysis produced two major themes regarding prosthetic technology: 1) important prosthesis qualities and 2) personal characteristics and experiences influencing willingness to consider prostheses and invasive prosthetic interfaces. Thematic content did not differ between the focus groups and the phone interviews. While many prosthetic qualities were discussed, several prosthetic features were frequently mentioned by participants. These themes are described below:

Theme 1: important prosthesis qualities

Ability to provide increased dexterity

Participants frequently mentioned wanting a prosthesis to give them increased dexterity, or fine motor skills. They provided numerous examples of tasks that they could not perform due to the lack of fine motor function with their current prostheses. One mentioned that while certain myoelectric hands on the market are now able to provide increased finger movements and grip types through programming on a phone app, they were still limited in the number of actions that can be performed at once. Another participant discussed the difficulty he had with typing and holding nails.

"The one thing that I miss … is the fine motor skills of doing things that take a lot of control in a small space. You just don't have that with the prosthesis … Things like typing on a keyboard, I'm like this but I'm not real good at hitting the right one … I'm very inefficient compared to what I used to be and the thing with holding the nail, putting it into the wall, that's an art of fine motor skill of holding it in the right spot, too."

Other tasks where they felt limited by poor dexterity included writing, opening a soda can, cooking, folding clothes, working as a mechanic, and tying shoelaces.

Dexterity was also mentioned by a participant as a quality that he thought targeted muscle reinnervation or peripheral nerve interfaces could improve. He described his fingers being 'stuck' since his traumatic amputation because of entrapped nerves and that perhaps the surgery would allow them to be "opened up free to do what they need to do." Another felt that while dexterity was important, he had difficulty envisioning how any novel prosthesis or prosthetic interface could provide additional improvements.

Table 1
Participants in focus groups and phone interviews.

	Age	Gender	Level of limb loss	Cause of limb loss
Focus group 1	30	M	Transradial	Trauma
	65	M	Transradial	Trauma
	43	M	Elbow disarticulation	Congenital
Focus group 2	45	M	Transhumeral	Trauma
	63	M	Transradial	Trauma
	44	F	Transradial	Congenital
Phone interview 1	45	F	Wrist disarticulation	Trauma
Phone interview 2	27	M	Transradial	Trauma
Phone interview 3	48	M	Transradial	Trauma
Phone interview 4	65	M	Transmetacarpal	Thrombosis
Phone interview 5	56	M	Bilateral transradial	Infection

Durability and stability

Participants also frequently listed durability as an important quality to have in their ideal prosthesis. For some, durability was one of the reasons why they preferred a body-powered device over a myoelectric device; they did not think that increased dexterity and function were enough to make up for how easily their myoelectric prostheses were damaged.

"My one complaint because of my experience with it, with the [name redacted], was the durability. I would have continued to wear it for its different functions had I not broken it so frequently. Within minutes of getting it, I broke it and then I never really wore it for a 24-h period [laughs] without breaking it."

Overall, participants were concerned with their ability to use their prostheses for work and hobbies due to fear of breaking expensive devices. They wanted a prosthesis that would be useful not only for day-to-day activities, but also for physically demanding tasks and sports. Others learned ways to adapt their prosthesis to withstand certain activities, for example, using tape to keep the prosthesis together and attached to the arm when weight-lifting.

Discussion also extended to prosthetic interfaces. One participant expressed concern about the durability of a prosthesis with use of a peripheral nerve interface, stating that "it [the attachment of the prosthesis to the interface] has to be solid … So it can't come off." Another also wanted to know how often the wires of a peripheral nerve interface could break, as that would require repair and subsequent recovery time during which the prosthesis could not be worn.

Aesthetics

Most participants thought the look of a prosthetic was less important than other qualities such as dexterity and durability. Among those who mentioned aesthetics, participants had differing goals depending on how recently they had had limb loss. A participant who had limb loss eight months wanted a prosthesis that would look as realistic as possible, stating

> "I would want them [the designer] to know that it looking more realistic, like a regular arm, would be like one of the biggest things that they could do. I feel like even matching skin tone to somebody would be a big deal. I feel the more realistic it would look, the more normal someone would feel with it."

Several participants who were many years out from their amputation discussed that instead of attempting to make the prosthesis look more like a human arm, it would be worthwhile to make the prosthesis stand out and be something to "wear with pride." Different colors on a prosthesis could make a statement, to "celebrate life [rather] than feeling sorry."

The only time aesthetics was mentioned in discussion about prosthetic interfaces was by the only individual with a bilateral amputation. He thought it would look "funny" if one arm used a hook while another was connected to a novel prosthetic interface, stating "If I did one side I'd have to do the other."

Touch sensation

Most participants did not spontaneously bring up touch sensation and only commented on it once the interviewer asked whether this was something that they found important. It was a quality that for some was unfathomable and far beyond current technology. Some did not see a relationship between sensation and how it may help with function, stating it would be low on their priority list of important prosthetic qualities to have. As one stated, "I mean the touch sensation would be great and everything, but overall it'd be more about using the prosthetic than anything."

Others acknowledged that having touch would be helpful for performing household or vocational tasks that were currently difficult for them to do. While none spontaneously used the word "proprioception," several described wanting to accomplish tasks with their prosthesis without having to directly visualize the activity. For example, one said that "Touch would aid function … putting a nut on the bolt, and you're up inside the car hood and you can't see anything but if you can touch it, you could put stuff together." Another gave the example of difficulties fixing the inside of a vacuum without being able to see what he was doing. Participants also related the sense of touch with emotional responses and a feeling of completeness.

> "I think it'll round you out as a person … I think touch is emotional so to have that back is psychologically good and I think that it's such a huge thing that way."

Theme 2. personal characteristics and experiences influence willingness to consider prostheses and invasive prosthetic interfaces

The desire to have or to consider a prosthesis was influenced by the participants' characteristics (e.g., unilateral/bilateral limb loss, acquired/congenital limb loss) and experiences. Those who had acquired upper extremity amputations spoke of adapting to their loss and that this process influenced their expectations of what they could accomplish with their prostheses.

> "[As] a person with new limb loss, it's not so much what can't you do yet with your prosthesis. It's more what kind of activities have you done in the past that you would still like to continue doing." In contrast, a participant with a congenital limb deficiency said, "I don't know what I'm missing so I'm content."

One 57-year-old participant discussed the influence of age on his willingness to consider cortical interfaces: "I just am not real happy about somebody dealing with my brain. … But hey, if I was 19 again I'd try anything." Another expressed concern that at his older age, his nerves might not function the way they are expected to after an invasive procedure, making him a poor candidate for one of the invasive prosthetic interfaces.

Though many were interested in learning more about the invasive prosthetic interfaces, surgical risk and procedural complications were the most common concerns. A few stated that having gone through so many surgeries or hospitalizations during the time of their amputation made them leery to return for any additional procedures: "I'm not going under any surgery unless I'm dying. … I don't know if I'd even be able to take it again. I'd probably end up having a heart attack on the table." Due to the concerns over surgical risks (especially with cranial surgery) the majority expressed the highest interest in targeted muscle reinnervation and peripheral nerve interfaces. One participant, however, stated that he was open to hearing more about cortical interfaces as he had had brain surgery before, and it was "not that bad."

Some articulated that because they already had an amputation, what remained of their residual limb was a very important contributor to what they could functionally do with it. Therefore, participants had to carefully weigh the possibility of additional limb loss against potential benefits that the interface could provide (even if the interface gave users the prosthetic qualities they desired). Along a similar line, several noted that because of their reliance on their current residual limb and/or prosthesis in daily activities and vocational work, longer healing and training times posed significant concerns as to whether they would consider an interface. However, they were still interested in learning more about the interface even if they thought the healing or training times were long.

A less commonly mentioned factor that went into decision-making involved frequency of current prosthetic use. One user who wore his prosthesis infrequently had low interest in even his stated ideal interface. Another factor was whether participants had previously had a prosthesis that did not meet expectations. One who had experienced this was hesitant to try invasive interfaces. Finally, many participants had more specific questions about exactly how each of the interfaces worked and wanted more details than that provided in the brief survey descriptions. Several wanted to wait until the interfaces were out of research stages before considering it for themselves.

Discussion

This study examined the perspectives of individuals with upper limb loss on upper extremity prosthetic technology. The qualitative nature of the study allowed an understanding of which prosthetic qualities were valued, interests in invasive prosthetic interfaces, and why and how participants reached these conclusions. Each shared their own experiences regarding limb loss or bodily difference, which allowed for a multidimensional exploration into their decision-making process.

While many prosthetic qualities were mentioned by participants, here, we focused on the aspects of the device that were most appealing to them and to the features that would most impact their decision-making. This did not include other factors, such as cost, which may play into the decision-making process, but were not presented due to lack of available information.

Overall, the ability to provide improved dexterity and durability dominated as characteristics that users thought were important prosthetic qualities. While some had developed adaptive strategies or learned to live day-to-day without performing certain activities, advancements in dexterity were welcomed, especially if it could significantly improve prosthetic functionality and make daily activities possible. Although there are current technologies on the market that can improve dexterity, these were viewed as insufficient. Additionally, many worried about the durability of their prosthesis, which made some avoid using their device altogether for certain activities. The thoughts of this group of individuals were like those reported in.[4] They found that consumers desired body powered prostheses with increased durability and functional grip and wrist control, and passive and electric users wanted increased dexterity and fine motor skills.[4]

Several participants related touch sensation to emotion and associated it with the ability to establish human connections with loved ones. In addition, it was a quality that participants found added to their sense of feeling human rather than adding to prosthetic function. This idea of contributing to sense of identity is consistent with prior work that noted that participation in experiments with a prosthesis with sensory feedback allowed the user to experience the prosthesis as part of their bodies.[28] A few participants with unilateral upper limb loss surmised that touch may be a quality that bilateral upper extremity amputees find more important to have than them. Similarly, in a study that assessed forearm amputees' view of prosthesis use and sensory feedback, a participant also supposed that touch would be more important for someone with bilateral amputations.[28] Interestingly, the participant with bilateral upper extremity limb loss in this study did not find touch to be a quality that he desired. He felt that he was already highly functional with his current body-powered prosthesis and thus the addition of sensation was not important.

Participants persistently acknowledged functions that were still lacking in current prosthetics and most expressed interest in learning more about the three surgical options. Concerns regarding recovery time, training time, risks associated with the procedures, and their overall state of health and function impacted their interests. Participants were more drawn to peripheral nerve interfaces over targeted muscle reinnervation due to the decreased healing and training times expected in the former. While these specific healing and training times were estimates, it highlighted the participants' value of their current level of independence and fear of prolonged lack of functional independence with another surgery.

In our prior online survey work, time since amputation was a significant predictor for interest in targeted muscle reinnervation and peripheral nerve interfaces, but not for cortical interfaces.[23] Similarly, participants in this study found the surgical risks associated with cortical interface most concerning, no matter when they had their limb loss. In contrast, all participants expressed greater interest in peripheral nerve interfaces and targeted muscle reinnervation. Whether an individual has a unilateral or bilateral limb loss may also influence their risk aversion. Interestingly, the one participant in this study who had bilateral upper limb loss was not interested in any of the three interfaces. He worried he would not survive another operation after all the medical complications he already had experienced and because he was satisfied enough with his current function. The prior survey work also found that people with bilateral limb loss were less interested in all four interfaces (myoelectric, targeted muscle reinnervation, peripheral nerve interfaces, cortical interfaces) than those with unilateral limb loss.[23]

This study has several limitations. Due to evolving research on the different interfaces and lack of technical specifications, precise information on risks, benefits, functionality, cost, and other information was not presented. Therefore, the descriptions may have come across ambiguous to participants and resulted in inaccurate inferences about the interfaces. Additionally, detailed information on exact number and type of prostheses and terminal devices each participant had tried in the past was not gathered. While not a primary focus of this study, such information could be valuable in understanding the shortcomings in durability and dexterity and availability to adapt to their respective lifestyles.

While the qualitative nature of this study allowed for a detailed exploration of themes, the findings may not be generalizable to the entire population of persons with upper limb loss for several reasons. First, the participants recruited in this study openly volunteered their thoughts on prosthetic devices, and this may have resulted in a population who had strong opinions about prosthetic technologies. Second, participants were recruited from a prosthetic clinic and accordingly were all current prosthetic users. Thus, their opinions may not be reflective of the entire upper limb amputee population, many of whom do not use a prosthesis at all. Here, we cannot determine if those who have rejected prostheses would be more or less inclined to have surgery for improved control. However, novel technologies are frequently targeted to current prosthesis users and/or those who have used a variety of prostheses in the past. Third, most individuals who participated in this study were male, had unilateral limb deficiency, had traumatically acquired limb loss, and were many years out from the original event that resulted in limb loss. An effort was made to increase the number of participants with bilateral limb loss, but due to its rarity in the general population, there was only one in this study. Additional participants with bilateral limb loss may have added further insight.

Conclusions

As evidenced from the participants' stories, attitudes toward prostheses are dynamic and can vary depending on a variety of factors, including time since amputation, reason for bodily difference, medical co-morbidities, and self-assessments of current level of function and prior experiences with prostheses or the medical system. These same attitudes affect whether users are willing to consider emerging prosthetic control interfaces. While there was an overarching interest to learn more about prosthetic technologies, participants' responses underlie the need for more education about these topics. As the development of invasive control interfaces progresses, it is crucial that potential users have easy access to information about these options and that conversations between the developers and future users continue.

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Appendix A. Supplementary data

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