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Exploring user requirements for an exoskeleton arm

Insights from a user-centered study with people living with severe paralysis

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Abstract. It is recognised that assistive technology plays an active role in empowering individuals who live with severe paralysis. Exoskeleton (exo) technology is a promising emerging assistive technology—a wearable robot designed to support the functions of the human body. However, an exoskeleton is a complex technology, and the successful design of exoskeletons depends heavily on the ability to integrate this type of robot in the environments of future users. In this paper, we present insights into user requirements produced through a qualitative study involving adults living with one of the most severe forms of paralysis: tetraplegia, or paralysis from the neck down. The study is based on two iterations of interviews conducted in the homes of future users. The study identifies key user requirements and contextual factors that are important for user acceptance of future exo design. We discuss how to integrate these findings in the design of an exo prototype of an exoskeleton arm targeted at people living with tetraplegia.

Keywords: Exoskeleton, Participatory Design, Assistive Technologies, User-centered, Tetraplegia, Paralysis.

1 Introduction

In this paper, we present the results from a design of human-robot interaction involving an exoskeleton arm targeted at people living with a severe form of paralysis called tetraplegia. An exoskeleton is an assistive technology in the form of a wearable robot designed to support the functions of the human body [13]. Exoskeleton technology has a great potential to rehabilitate and empower individuals who live with some sort of paralysis and therefore depend on caregivers in their daily lives. In the US alone, it was estimated in 2013 that around about 1,7 percent of Americans live with sort of paralysis [1] adding up to around 5,5 million people currently. Tetraplegia is one of the most severe forms of paralysis in all four limbs; however, its victims are usually unaffected cognitively, retaining full potential for education and work if they are only able to, e.g.,

open doors, control elevators, use computers, eat and drink. A study on selected Activities of Daily Life (ADLs), such as eating and drinking, has shown that the need for assistance could be reduced by up to 41% with the use of an assistive robotic arm [11], and a survey study shows that 86% of disabled participants would consider buying an assistive robotic arm if they could [15]. Further, a study has shown that individuals with complete functional paralysis of the arms and legs are capable of controlling such an assistive robotic arm using the tongue [16].

We present findings on user requirements for assistive robotics. The results are gathered through two iterations of interviews conducted with a total of nine participants, all living with tetraplegia. The ambition is to find an optimal integration between users' visions for robot assistance in their everyday lives and technological opportunities for advancing exo technology. Related research on the design of exoskeletons is primarily technology-driven and based largely on information about future users from Activities of Daily Life. ADLs refer to a clinical list of basic activities of daily living developed based on insights from clinicians and physicians. Hence, future users are primarily included by proxy in the design of exoskeletons [2, 3, 8, 9, 12]. A literature study conducted on the occurrence of user perspectives in exoskeleton technology research in 2017 [6] identified that among 912 articles identified as concerning exoskeleton technologies, only nine papers reported on user perspectives on exoskeleton development —only as far, however, as to state the importance of understanding users. No papers reported on actual user involvement in the design. However, a scoping review found instances of research studies stating that they were either human- or user-centred. Some of these studies involved users by the use of questionnaires, though often without a clear distinction between caregiver and patient [8, 9] and some with a very broad target user group [4]. Additionally, some existing studies report the use of interviews, both with individuals and groups. However, they rarely do so with end users (i.e. people who are paralysed) but with experts (health care professionals) and their perspectives on users' needs [2, 12, 14]. While some papers do focus on the specific context of use and values of the users that are to be designed for [4, 5, 10], the daily lives of the individual end users and the existing technological ecologies employed by the users seem to get lost in previously ascertained notions of building for ADLs.

2 Methods

The recruitment of participants for this study was carried out in collaboration with the Spinal Cord Injury Centre of Western Denmark. The participants recruited for the study were between the ages of 32 and 77. All the participants lived with tetraplegia, albeit with differing degrees of paralysis. Two participants had partial control of their arms, and one was able to stand using a specialised support, though only for brief periods at a time. Because of these abilities, their paralysis is defined as incomplete, although functionally they are still unable to conduct activities requiring even little strength. All but one of the participants interviewed used specialised powered wheelchairs on which several different technologies were mounted. The housing situations

for the participants varied. Two of the participants lived in specialised disability housing that was designed for people with physical limitations. One participant lived in a first-floor apartment. The rest of the participants lived in standard housing that had been altered slightly to accommodate their needs. All participants had 24-hour personal caregiving, either entirely provided by their municipality or supported by spouses and family. However, all waking hours were covered by professional caregivers. The participants would never be left on their own and always have help available.

2.1 Home interviews

Two iterations of home interviews were conducted with the participants. The first interviews were based on design games and focused on attaining an understanding of the users' lives, experiences with paralysis, technologies employed and daily activities. The design game that was created for the interviews revolved around a list of activities that each participant would create and prioritise based on activities they carry out during a normal day. Each activity was mapped in relation to assistive technologies and caregivers before being reimagined by the participants to learn about their visions for future scenarios of everyday life with a fully functioning exo arm. The second iteration were based on feedback for a preliminary version of the tongue controlled exoskeleton arm, EXOTIC [17] and zoomed in on the activities prioritised by the participants in the first home interviews. Participants were asked to create timelines for the activities discussed, draw the space in which the activities were currently carried out, and list positive attributes that the arm should possess and negative aspects that should be considered in the design of a future exo arm. For a further explanation of the visual aids and the methodology used, see [7].

3 Results

During the interviews and the design games, a number of different activities ($n=45$), artefacts ($n=69$), assistants ($n=8$) and contextual factors ($n=54$) were identified. While the users identified a long list of activities, they agreed on six activities that should be prioritised most highly. These activities were consistently mentioned and prioritised throughout the different interviews. The six activities that the participants prioritised were eating, drinking, itching, reading, brushing teeth and shaving, each of which is described in the following.

Eating was described by the participants as an important activity. However, in contrast to general presentations of eating as an ADL, the participants in this study did not focus on the act of eating a meal as something they would like to have improved. Rather, they focused on the activity of eating as part of a cosy moment defining the activity of eating as being able to eat candy or other snacks over a longer period while, e.g., watching a movie. Independence was not related to being able to have a meal. As explained by one of the participants, "*A meal is on the plate as it is and is eaten in a specific tempo, but when you have a bowl of candy, then you will have to keep saying; one more, one more, one more, one more*". Another participant explained, "*It would be*

very nice if, at night, when sitting in front of the television, I could sit and nip at something on my own. That would be a great freedom, to not always have to call and ask for another piece of liquorice". One participant presented previous experience with an eating robot: "I think it could be hard. I mean it would be nice to be able to eat on my own, to be able to pick up the pieces, but that machine just grabbed it randomly and then it was cut into pieces like dog food, and that is not fun, that is not a good thing". Drinking was an equally important activity for the participants. Currently, only a few participants were able to drink by themselves, and they all emphasised that a future use of the exoskeleton arm should be focused on supporting users to be able to drink by themselves. For example, one participant presented the following: "...and then during the evening with a little glass of red wine so I can sip myself. Especially being with others, drinking, then it is nice to be able to drink on your own." Another participant described, "none of us will ever lift anything heavy, it is more to be able to grab a cup of coffee, eat and so on, to me at least, that is important".

The participants also stated that they were at times annoyed by the lack of ability to scratch themselves when itching. Some participants stated that they believed that they had more itching now than before suffering their paralysis, and that this could be due to medical side effects or imagined itching due to the inability to do anything to mediate it independently. As one participant stated, "Apparently there are some specific areas on the scalp that are very irritated, I do not know if it is because of medicine or damage to the nerves, but on the scalp it itches so much sometimes".

Reading was also an important activity that the participants wished could be changed for the better. The participants currently read with the help of their private caregivers, and conversations on possible futures identified a strong wish to not only be able to turn pages themselves, but also that they would be able to fetch some reading materials themselves. As one participant stated, "...I mean, it would be nice, or an advantage to be able to turn pages in books and newspapers, that is a big wish of mine so I don't have to say all the time: I would like to have the page turned, I would like to have the page turned". And further, "...I constantly have to have it fetched, it would be nice to have an arm so one could go over and fetch a magazine and place it".

An activity that several of the participants also prioritised was the act of grooming, where especially shaving and brushing one's teeth was mentioned. As both of these are activities in which most people have a specific preference as to how it should be done, most participants found it important, or at least desirable, to be able to do these actions by themselves. As one participant stated, "That with brushing teeth, I can acknowledge that, it is one of the hardest tasks for a caregiver. I have grown a full beard in the process because I realised that it was a challenge to get shaved. I mean I had my own way of shaving, and to have others do it, aaaaaaah, so in the end I gave up and thought that then I was past that problem. Of course, then you have to have it trimmed. But I believe that I have found the best solution for me." Another participant explains, "...you could say that those things are very basic things, they occur daily, you brush your teeth twice a day I mean. And it is not good when you have to have another person brushing your teeth and shaving you, because it will never be done the way you want it to be (...) the helpers do their best and it is not on purpose, but it would be nice to be able to do these things yourself".

In sum, the conversations about present and future activities and artefacts revealed that the participants imagined several activities that an exo arm solution could support them in for future independent living. However, they devoted strong attention to details with, e.g., cosy moments with snacks and wine, grooming, reading and being able to react to itching.

Several activities were discussed during the game but ultimately not deemed important or, at least, less prioritised by the participants as activities to be supported by the future exoskeleton solution. Some of those activities were brewing coffee, using a recreational tabletop bike, printing, opening doors and using a computer. Common to these activities was that most of them were not entirely doable autonomously in the future scenarios. That is, the users could not envision that a future exoskeleton solution would give them independence in completing the activities. Other activities were mentioned that, despite being highly desirable to the participants, could be solved by other existing technologies in a more meaningful or efficient manner, such as doors being opened by electronic door openers. The second round of interviews qualified the findings and gave insights into a deeper contextual understanding of users' design wishes and the use context for an exo arm. The attributes that the future users found important are listed in Table 1. Generally, the attributes that the users found to be important revolve around the look and feel of the future solution. Moreover, most of the mentioned attributes had either been discussed explicitly during the first round of interviews or had, at the very least, been mentioned earlier in the process. Thus, these findings qualified and deepened the results from the first iteration. However, the act of listing them—categorising and visualising the positives and negatives—brought forth some new attributes, such as sharp edges and a wish for the arm to be smaller around the wrist and forearm. In the following sections, the contextual insights and important attributes uncovered throughout the interviews are covered.

Table 1. List of positive and negative attributes that users identified as important to consider in the design of an exo arm

Positive attributes	Negative attributes
Flexibility	Noisy
Small	Robot-like movements
Light	Chunky looking
Smaller at wrist and forearm	Sharp edges
Fast mounting	Requires charge
Must work around the face	Effect on wheelchair battery
Usable in wheelchair	Can be uncomfortable
Can fit clothing underneath	Mounted on wheelchair
Harmonic movements	Should not only have one interfacing option
Can be cleaned	Over-steering
Secure grip	

The home interviews also identified contextual factors. These were especially related to the appearance and functionality of an exoskeleton arm. Regarding statements made by the participants about the design of the exoskeleton arm, most of the participants argued that the most important focus for the development of an exoskeleton arm is functionality. A few of the participants called for close attention to the aesthetics of the exoskeleton design. However, all participants highlighted that the arm should be designed in a manner that makes it as discrete as possible, i.e., none of the participants preferred a “chunky” arm or an arm that makes a lot of noise, as that would draw too much attention in public and make them feel stigmatised. Lastly, the participants stated that the arm should be simple, easily cleaned and require as little time as possible to mount. Due to changing caregivers and the long time spent on getting in and out of bed, this point was emphasised strongly.

Besides appearance and functionality, a lot of information surfaced about the users’ lives in general and how they manage a life that is different from that of most people during the home interviews. First and foremost, all the participants that were interviewed identified their own role within their context as that of a manager, employing, scheduling and managing employees in a manner similar to a small company. This was also apparent in the houses in which the users resided, where specific rooms—and in one case, the entire second floor—are dedicated as space for the employees to relax and rest. Secondly, we found that it is not just the wants and needs of the users that decide the success of an assistive technology; it is also a cost-effective assessment made by the municipality in which the users reside as to what technologies can lessen the cost of care. Some participants shared that they had made requests for economic support for electronic door openers that would allow them to move from one room to another on their own. This was denied in all cases, as the participants already had economic support for caregivers who could do this task. Thus, the independence provided by assistive technology like an exo arm will be an important part of the calculation for implementing this future technology in the homes of people living with tetraplegia.

4 Discussion

4.1 Six key activities

The analysis has outlined a larger set of activities, among which six activities stand out as user priorities for a future exoskeleton arm. Although activities such as drinking and eating are certainly basic activities of daily life and thereby affirm the choice of using ADLs as a platform upon which to design exoskeleton technologies—as they are sometimes seen in the literature [2, 3, 8, 9, 12]—entirely relying on ADLs would neglect some important insights that we discovered in this paper, such as the different notions and contextual insights into what eating entails. Further, this could mean that the design would not allow for activities such as itching and reading, both of which were highly prioritised by the participants of this study.

In all the prioritised activities, the overall motivation from the users was to attain agency and further their own autonomy and independence. They want to be able to shave in the manner that they prefer. They want to be able to brush their teeth in the manner that they find most comfortable, and perhaps most of all, they want to be able to do repetitive activities without having to ask for help repeatedly, such as eating candy when watching the television at night and reading on their own without having to ask for the pages to be turned. All the activities that were prioritised stood out, as they all entirely replaced the involvement of caregivers with the utility of an exoskeleton arm, indicating that the participants envisioned that the arm should, to the highest degree possible, enable them to independently conduct an activity rather than complement how it is completed today.

The majority of the activities mentioned during the interviews, including the ones that were chosen for further examination, are acted out in a workspace in close proximity to the face of the user. An implication of this is that special attention needs to be paid to the safety of the movements that the arm can make. Furthermore, the participants stated that the mounting of the arm should be both simple and require little time, which is important to the actual use of a future exoskeleton arm—if it is too complicated and time-consuming to mount, there is a strong risk that the arm will not be used, as caregivers will have to prioritise other tasks. Other important findings show that the participants in this study prioritised the functionality of the arm, with a secondary focus on the aesthetics of the final product. The participants want an exoskeleton arm that is as discreet as possible and where functionality and size is balanced towards being able to perform small activities rather than being able to lift heavy loads. Furthermore, emphasis was placed on a wish that the arm is to be as silent as possible and that it should be moving smoothly and as human-like as possible. As an implication of the insights produced, and building upon a users expressions in a previous study [16], it has become evident that careful considerations must be made in regards to meet users' expectations. Whilst the participants engaged in this study prioritised ADLs, the study expanded the understanding and nuances of the activities. An example is when designing for eating, this should be focused more on snacks that can be picked up independently rather than dinners. The prioritisation of ADLs that the users shared in the study is important, not only in the exo-design itself, but also in the design of clinical tests used for evaluation, in which one of the selected by our research team on the EXOTIC exoskeleton is to grasp plastic strawberries to test the capabilities of the arm.

4.2 Limitations and future research

This study was conducted in Denmark, which employs a tax-based and need-based health care and social welfare system. All participants in the study had 24 hours of support from this healthcare system, which is likely to have influenced the types of activities that they prioritised. Therefore, it is likely that similar user-centred research in other countries might give differing results. It is also important to note that the insights described in this paper are based on nine interviews, only one of which was with a woman, which might eliminate some gender-based insights that could have been extracted. Why we were unable to attain more female participants can only be speculated.

However, as the pool of potential participants that are eligible for the study was extremely limited, the issue has proven very tough to overcome. Additionally, the study did not include caregivers and family members, which we have learned to be instrumental in the participants' lives and the activities they carry out throughout the day. Further, as discussed in the analysis, decision makers in the public care system play a vital role in relation to the participants' technological possibilities. Their opinion is therefore relevant to understanding the larger ecology for an exo arm, i.e., the care systems requirements for an exoskeleton arm.

Lastly, during the interviews, some participants stated that they were anxious about the adoption of the exoskeleton arm, as this might decrease the amount of professional caregiving received by the municipality, which all participants stated that they would not be able to function without. This might have influenced the manner in which the participants thought of and prioritised tasks, which further adds to the notion that decision makers within the municipalities could have been included in the discussions.

5 Conclusion

This paper has presented insights gathered through two iterations of user involvement focused on investigating and integrating users' contextual expertise in the design of future exo technology to support people living with severe paralysis. The results highlight that users identify activities in which they can regain full autonomy and activities that they deemed to be frustrating or invasive. Although this paper does not give a conclusive answer to which activities exoskeleton developers should design for, it identified six situations from the participants' everyday lives that they prioritised as the most important, unfolding the contextual factors related to these activities and how we have worked with integrating these findings in the design of an exo prototype. The findings demonstrate that involving users, in this case individuals living with severe paralysis, and employing their contextual expertise when designing complex technical solutions such as exoskeleton technologies can help to ground the design in the actual context that is being designed for. Further, the paper presented a number of specific design decisions that should be regarded in relation to both the aesthetics and functionality of upper-body exoskeleton solutions. Details of importance are the identification of the facial area as the primary workspace for the interaction and that non-functional requirements, such as the aesthetics, mounting, sound and size of an exoskeleton arm, are key for user acceptance.

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