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Bringing Context Into Exoskeleton Design

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USER PERSPECTIVES ON ASSISTIVE TECHNOLOGIES

BRINGING CONTEXT INTO EXOSKELETON DESIGN

BY
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DISSERTATION SUBMITTED 2022

AALBORG UNIVERSITY
DENMARK

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by

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Dissertation submitted

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CV

Frederik Victor Kobbelgaard, a former fireman, has bachelor's a degree in Information Studies and a master's degree in Information Studies which he finished in 2017 at Aalborg University. Having finished his degrees, he worked as a research assistant for a year primarily focusing on Learning Analytics and co-design of student-facing learning analytics for improved group collaboration in a problem-based study setting. In 2018 Frederik started as a PhD Student at the Department of Planning and Design, in the Techno-anthropology & Participation group. As part of his work Frederik has become affiliated with The Danish Center for Health informatics, as well as Center for Rehabilitation Robotics at Aalborg University. Frederik research interest are mainly the inclusion and work with non-traditional user groups in design processes be that cognitive or physically disabled participants or perhaps just participants that in a traditional sense might be overlooked in a development process. This interest stems from Frederik's upbringings with a brother who is cognitively disabled as well as a mother who both professionally and in her spare time has worked with and fought for the rights of disabled children and young adults in Denmark. Both in his research on Learning Analytics and during his PhD work, he has worked with bridging gaps between knowledge domains and facilitating processes in which participants can achieve agency in the design of complex systems that would otherwise be very difficult for them to give inputs to. Frederik has published papers on learning analytics and exoskeleton robotics where he has had a main focus on the methodological considerations and reflections. In the following thesis, Frederik presents his work on including people who live with tetraplegia in the design process of an assistive exoskeleton arm.

ENGLISH SUMMARY

In this thesis, a study is presented in which people living with tetraplegia have been involved in the design of an upper-limb exoskeleton. The thesis is part of a larger interdisciplinary research project with four PhDs and a Postdoc that spans the disciplines of participatory design, mechanical engineering, interface design, computer vision and computer science. The thesis is paper based and the three research papers form the basis for the development of a design game, use of theory to involve users in the design process and how insights into the users' lives have influenced the design of the exoskeleton arm. Summaries of the papers are presented in the thesis and the thesis unfold and elaborate the findings and presents a unifying discussion and conclusion.

The thesis presents a study focused on researching user involvement in design of an exoskeleton and contribute with theory and methods in form of design games created using an activity theoretical model as its basis, namely the Human-Artefact Model (HAM). Inspired by HAM, the study was divided into three phases of inquiry of the use context, each focused on a level of an activity hierarchy. The phases concerned the motivational, instrumental, and operational levels of activity, starting with specific activities important to the users and then exploring them in depth. Two different design games are created as cooperative artefacts to be used during the first and second phase of interviews and a total of 20 interviews with participants living with tetraplegia were conducted during the three phases.

The empirical results presented in the thesis contribute a number of recommendations in terms of what should be considered when designing an exoskeleton arm for tetraplegic users. First and foremost, the thesis presents six activities that the participants have prioritized as the most important to support. Secondly, the thesis presents a number of contextual considerations that must be made in terms of functionality, aesthetics of the arm and the sounds it produced. Third, the thesis presents a number of findings that are closer tied to the users' experiences of living with tetraplegia. These considerations include aspects such as being compatible with the caregiving that is available to them, understanding the environment they live in as well as the routines of the participants, as part of these results recommendations are made to sanitary concerns and how easily and timely the design should mountable. Finally, the thesis presents specific implications that the participants insights had on the final design of the exoskeleton arm.

The discussion unifies methods, theory and empirical results asking questions to the use of theory as a basis for design games, how employing an activity theorical model has affected the insights produced, how the understanding of the users' lives and aspirations has changed and how this has affected the results and finally the limitations of the study.

On this basis the thesis answers the research questions and conclude on the findings. The conclusion revolves around the successful involvement of the participants of the study and how the gap in technical knowledge was overcome. Secondly the thesis concludes on the importance of the local context and the existing artifact ecology in the understanding of the situation that is to be designed for, and lastly the paper concludes on the importance of setting aside one’s own assumptions when working with participants that are so radically different as have been the case in this study

DANSK RESUME

I denne afhandling er et studie præsenteret hvori borgere der lever med tetraplegi har været inddraget i designet af et eksoskelet til en arm. Afhandlingen er en af at et stort interdisciplinært forskningsprojekt der involverer fire Ph.d.er og en Post.doc. arbejdende indenfor felterne participatory design, mechanical engineering, interface design, computer vision og computer science. Afhandlingen er artikel-baseret og bygger ovenpå tre artikler der omhandler tilblivelsen af et design spil, brug af teori i inddragelsen af brugere i en design proces og hvorledes indsigt i brugeres hverdag har haft indflydelse på designet af eksoskelet-armen. Resumeer af artiklerne er præsenteret i afhandlingen og afhandlingen bygger ovenpå og elaborerer på det der er fundet ud af, samt præsentere en samlende diskussion og konklusion.

Afhandlingen præsenterer et studie som er fokuseret på at forske i brugerinvolvering ved design af eksoskeletter og bidrager med teori og metode i form af et design spil der skabt ved brug af en aktivitetsteoretisk model som fundament, specifikt Human-Artefact modellen (HAM). Inspireret af HAM er studiet inddelt i tre faser hvori brugskonteksten undersøges, hver med et fokus på et abstraktionsniveau fra et aktivitetshierarki iboende i teorien der er brugt. Faserne omhandler motivationelle, instrumentelle og operationelle niveauer af aktivitet, startende med specifikke aktiviteter som er vigtige for brugere og derefter en tilbundsgående undersøgelse af disse. To forskellige design spil er blevet skabt som samarbejdsfordrende artefakter og bliver brugt i den første og anden fase af studiet. Sammenlagt er der udført 20 interview med deltagere der lever med tetraplegi.

De empiriske resultater som er præsentere i afhandlingen, bidrager med en række anbefalinger i forhold til hvad man bør overveje når man designer en eksoskeletarm til brugere med tetraplegi. Først og fremmest præsenteres der seks aktiviteter som deltagerne har prioriteret som de vigtigste at understøtte. Derudover præsentere afhandlingen en række kontekstuelle overvejelser som bør gøres i forhold til funktionalitet, æstetik og lydmæssige aspekter. Derefter præsenteres der en række fund der er tæt forbundet med brugeres oplevelse af at leve med tetraplegi. Disse fund inkluderer aspekter såsom kompatibilitet med nuværende hjælp i hjemmet, forståelse for det rum og hjem som de lever i, samt hvilke rutiner som designet skal passe ind i. Som en del af disse fund er der også præsenteret aspekter såsom hvordan der bør tænkes på hygiejne og hvorledes armen kan monteres samt hvor lang tid dette må tage. Til sidst præsenterer afhandlingen hvorledes der er ydet en indsats for at imødekomme de ønsker og overvejelser som deltagerne har bragt ind i processen.

I diskussionen sammenkobles metode, teori empiriske resultater ved at stille sig kritisk overfor brugen af teori som basis for design spillet og hvordan brugen af en aktivitetsteoretisk model har haft indflydelse på de indsigter der er skabt. Derudover diskuteres det hvordan forståelsen for deltagernes liv har ændret sig og hvorledes det

har haft indflydelse på studiet. Til sidste præsenteres en række begrænsninger som der har været i forbindelse med studiet.

På baggrund af det som er præsenteret i afhandlingen besvares studiets forskningsspørgsmål og der konkluderes på de fund der er lavet. Konklusionen drejer sig om den succesfulde involvering af deltagerne i studiet og hvorledes det er lykkes at overkomme store forskelle i teknisk viden. Derefter konkluderes der på vigtigheden af forståelse af den lokale kontekst og den eksisterende økologi af artefakter som et design skal arbejde ind i. Til sidste konkludere afhandlingen på hvorledes det er vigtigt at tilsidesætte sig selv i arbejdet med deltagere der er så radikalt anderledes end en selv og som lever under helt andre forudsætninger.

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The biggest thanks that I want to give in these acknowledgements go to the participants of my study. I have been awestruck by the enthusiasm, the tenacity and willingness that the participants of the study have had in sharing their lives, dreams and aspirations with me. Even at times when corona was raging and their lives were quite literally at stake, they trusted us so implicitly that they travelled across the country to meet us and partake in the clinical trials. If it had not been for the participants, this study would not have been a success.

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At the Department of Planning, I became part of a wonderful small research group named **Techno-Anthropology and Participation** spread across the two campuses of Aalborg and Copenhagen. I would very much like to extend my gratitude to all the colleagues that I have collaborated with over the past four years. Being part of the group has been a great mix of collegial support and academic furtherment. I would not have been without the breadth of knowledge that is available to anyone who seek it at TAPAR.

One of the greatest parts of becoming part of the group at Aalborg University has been the fact that it has allowed be to get to know and befriend a group of wonderful fellow PhD students and assistant researchers. I have had a wonderful time with the others in TAPARisk ungdom! I would like to thank **Jeppe Eriksen** for being such a massive support throughout my PhD and for the great academic discussions that we have had. **Ditte Weber** I would like to thank for being such a wonderful person! Without your cheery support and supportive personality I am not certain I would have gotten though this ordeal. **Mette Møller Jeppesen** I would like to thank for all the support she has offered throughout my PhD, I still think back to the great talks we had around the lake at Emdrup campus. **Casper Knudsen** I would like to thank for all the great political discussions that we have had and all the beer that you have offered, I might just take you up on the offer now! **Kristina Tornbjerg** I would like to thank for the great times that we have had discussing old times and all the laughs that we shared, I would also like to thank you on behalf of all of us for getting Jeppe to settle down. Lastly, I would like to thank our two newest additions to our little collective. **Lasse Krejberg Møller** and **Helena Amalie Haxvig** it has been a wonderful time working with you guys, you are fantastic both as people, as academics and as cake-givers!

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CHAPTER 1. INTRODUCTION

1.1. THE EXOTIC PROJECT

The development of exoskeletons is not a new discipline, and a lot of research has been conducted over the years in how exoskeletons can be developed, controlled, what they can be used for and how they fit into the overall field of research that is robotics in general. However, exoskeleton research has recently become less of a novelty and more of a genuine solution to problems that are identified within different areas of application, such as, industrial, medical and personal use (Gull et al., 2020). This change of usefulness can be attributed to a number of different factors but can generally be ascribed to advances within the technologies such as the actuators used and innovative thinking as to how humans and technologies can coexist and contribute to joint optimization and advance technically as well as advance the use context. Whilst exoskeletons have been quite prominent and marveled at in popular culture with examples such as Iron Mans suit or the exoskeleton that is used by Ripley to fight of the Alien in the iconic scenes from the first Alien movie. However, reality is that modern exoskeletons are much more specialized and developed to conduct specific actions and have very little to do with the fictitious counterparts which, ironically, is often what people imagine to be reality when imagining what an exoskeleton is. When designing exoskeletons afforded by current technological advances, tradeoffs and compromises must constantly be made in order to ensure that the final solution deliver both the functionality that is needed in order to solve a specific problem, yet still remain within reason as to the weight, rigidity, noise and size of the exoskeleton. To exemplify this, one can look at the Guardian XO exoskeleton produced by Sarcos (*Guardian® XO® Full-Body Powered Exoskeleton*, n.d.). The exoskeleton that Sarcos has managed to develop is an engineer’s wet dream and boasts amplification of the operator’s strength by up to a factor of twenty times, has an eye watering 24 degrees of freedom, hot-swappable batteries and can be entered in a mere 30 seconds. These are truly remarkable feats of engineering, but they come at hefty price, namely the size, movement, and rather limited use-cases for the exoskeleton, being the lifting of heavy objects. With the arm extended, the Guarding XO can compensate for 44 kilos of weight, which is truly remarkable given the state of current exoskeletons, but at the price of any usefulness besides industrial and logistical tasks, the exoskeleton exemplifies not only that modern exoskeletons can be designed to, and actually overcome problems of the current era, but also that the design of exoskeletons should be carefully considered in relation to the problem at hand.

This thesis presents research on exoskeleton arm designed is for personal use in everyday life for people living with severe paralysis i.e., should be usable in any sort of location that the user wishes to use it in. This means that an important part of research in the design of the exoskeleton is an understanding of not just the location and parameters of usage, but the users themselves, what their aspirations are and the activities and context that the exoskeleton needs to be incorporated into to meet user acceptance and contribute to advance exoskeleton technology as well as use practice.

1.2. LIVING WITH TETRAPLEGIA

Tetraplegia, which is also known as quadriplegia, is the term used for paralysis of all for limbs of the body as opposed to paraplegia which refers to paralysis in lower torso and down. Tetraplegia can be caused be either damage to the brain or the spinal cord. In this project a focus is placed on traumatic injuries to the spinal cord, why the other cause will not be discussed. There are many different ways in which a person can attain a spinal cord injury that causes tetraplegia. Most commonly the trauma is incurred by a physical injury such as a traffic accident or for example diving into shallow water, but other causes can also be disease, muscular dystrophy and as a result of surgeries.

Tetraplegia is usually defined by the position of the injury onto the spinal cord (see figure 1 (VectorMine, 2018)). Overall, the injuries are separated into high injuries which occurs from the c1-c4 vertebra and low injuries which occurs from the c5-c7 vertebra. An injury that occurs on the upper part of the spine will often incur more issues with paralysis in the arms and may often result in respiratory problems which might necessitate the use of an oxygen mask or a transportable respirator. However, apart from being defined by the position in which the injury occurs, tetraplegia is also defined as either complete or incomplete, both in sensory and motor paralysis. Usually an American Spinal Injury Association (ASIA) classification is made to assess the extent of an injury, which classifies the injury from A to D. The classifications range as follows:

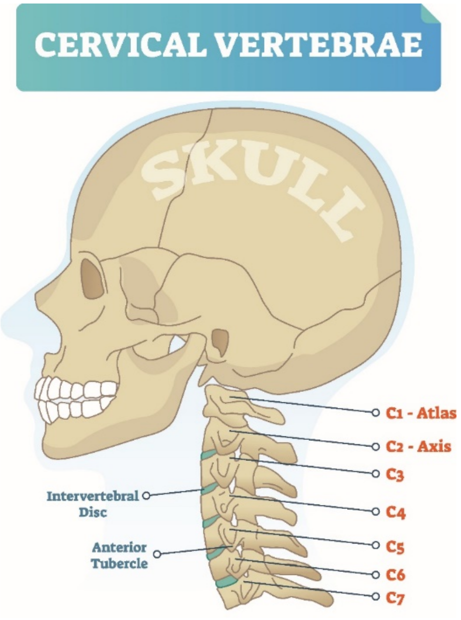

Figure 1 – Picture that shows the cervical vertebrae

- A refers to a complete injury in which both motor and sensory function is paralyzed
- B refers to an injury in which the motor function is paralyzed but the sensory function remains

- C refers to an injury in which more than half of the motor function has been lost
- D refers to an injury in which less than half of the motor function has been lost

Understanding what it means to live with tetraplegia can be very hard, not because there has not been a lot of research conducted into understanding what it means to have tetraplegia, how to classify it, how it is treatable and what measures can be taken in order to mediate the effects of living with tetraplegia, but because how tetraplegia manifests itself and how it is perceived by citizen can vary wildly and often changes over time. Whilst some citizens with for example an c2-ASIA B injuries might have need of a respirator a lot do not, and the level of respiration need from the individual can also vary which changes how fast the person is fatigued and how much caregiving is needed. A person with full respiration needs will always need to have a caregiver present to observe for obstructions in the system, whilst a person that does not need a respirator can often sit comfortably on their own for long periods of time, given that they have a way to signal for help. Further, when a tetraplegic injury occurs it will often manifest the strongest right after the injury occurs. Within the first year of having the injury, given proper treatment and rehabilitation, many people will regain some of the function previously lost, but it is never truly a given how so. Some people regain speech, some people start on a ventilator but become able to function without over time, and some might even regain the ability to stand and even walk for a while. How much rehabilitation a citizen can achieve is almost impossible to ascertain, but for most they will generally experience an increased amount of function over time – mostly so during the first year of rehabilitation, but some experience improvements for the remainder of their lives.

1.3. UNDERSTANDING THE PARTICIPANTS

Understanding tetraplegia is a useful basis for understanding the circumstances of the lives of the participants in this study. However, understanding the diagnosis does not mean that one can understand who the participants are or how they conduct activities in their daily lives. People are not their diagnosis; they live with it. Trying to define a person based on tetraplegia would be as futile as defining a person based on religion or level of education. It certainly permits some assumptions about aspects of a person's life, but it could never account for the way that people choose to live. The notion of not defining a person by his or her disability is nothing new. There is a multitude of examples in the literature, from Vygotsky's theories on defectology (Bøttcher & Dammeyer, 2012) to modern classifications made by the World Health Organization (World Health Organization, 2001). WHO proposes that a distinction should be made in how we classify disabilities, and it proposes three distinctions: impairment, activity limitation and participation restriction. Impairment refers to limitations in bodily function; activity limitation refers to problems engaging in an activity; and participation restriction refers to limitations that might arise when engaging in social life. Furthermore, it is important to note that disability is dynamic in the sense that an impairment might reduce a person's ability to conduct an activity in one's environment but not in another. Moreover, it might depend on the level of stress, tiredness or confusion that the person is experiencing (Pullin, 2009). For example, a person might use noise to tell when to turn off a kettle. However, if the volume of the other sounds in the room is high, it might not be possible to hear the kettle, and this would create an issue.

Work for this thesis showed that participants with seemingly similar diagnoses differed in autonomy, self-management and level of independence. These differences can be based on which municipality they reside in, how open they are to using and appropriating technologies to facilitate their actions, what kinds of accommodations they have and many other variables. One participant may be passionate about driving in nature and experiencing the outdoors, while another prefers to stay indoors and use a computer as his pastime. Some of the participants have invented devices such as toothbrush-holding-braces so they can brush their teeth themselves, sticks with rubber thimbles to turn the pages of a newspaper and customizable thigh-trays to facilitate reading and carrying liquids. Each participant in the study created a situation for themselves that uniquely suits their needs and supports the activities and pastimes they find important and valuable.

This level of uniqueness creates both opportunities and issues when designing a suitable technology for such users. The solution must be safe and useful, adaptable to the particular user and able to address issues common to people with tetraplegia. It has to fit with a multitude of technologies that might already be used in the homes of different users, while having a function that is defined enough for the engineering PhDs of the project to be able to design its functionality.

1.4. RESEARCH QUESTIONS

In order to facilitate a fruitful collaboration with the potential users of the exoskeleton arm that was developed, the project must establish a footing in the context of those users. This is especially true given the complexity and diversity of the target population. To do this, it is important to bridge the gap that exists between the engineering PhDs technical domain and the knowledge that the participants have about their own lives, situations and contexts. Furthermore, it is important that the insights produced in collaboration with potential users can be analysed and represented in such a manner that the engineers can incorporate them into the system. Lastly, it is important to recognize that to truly state a partnership with the participants, they must also be engaged not just in developing the solution but also in evaluating it to trace whether their contributions are evident in the final product. This leads to the three research questions on which this thesis is based.

1. Given the complex nature of the design task, how can participants be included and given the agency to participate in the design process in a meaningful way that allows for informed contributions to exoskeleton design?

2. What is the context for which the arm is being designed, and how can it be represented and analysed so that it makes a meaningful impact on the design of the exoskeleton solution?

3. What are the challenges of working with participants living with tetraplegia, and what recommendations can be made about involving paralysed participants in the design process?

CHAPTER 2. THESIS OUTLINE

The thesis presents the study investigating the above research questions and communicates an iterative design process in ten chapters presenting related work, theoretical framework, design methods, findings, discussion, and conclusions. The results from the research have been communicated in research papers during the process and the thesis is based on these papers with chapters that elaborate, unfold, and unifies the results. Research papers are as follows

2.1. ARTICLE 1: DESIGNING A GAME TO EXPLORE HUMAN ARTEFACT ECOLOGIES FOR ASSISTIVE ROBOTICS: BASING DESIGN GAMES ON AN ACTIVITY THEORETICAL FRAMEWORK

This article was written in collaboration with Susanne Bødker and Anne Marie Kanstrup. The paper was published as part of the NordiCHI20 proceedings (Kobbelgaard et al., 2020).

The paper concerns the creation of the design games that were conducted as part of the study of this thesis. The paper presents important literature on design games and activity theory before explaining how the two design games were created. The paper then proceed to present and reflect on the overall findings made using the design games. Having presented the findings, these are reflected upon based on the how the use of theory-based design games has impacted them. The paper concludes on the user of the Human-artefact model as a theoretical frame for building design games.

2.1.1. CONTRIBUTION AND REFLECTIONS

The paper presents findings that are central to this thesis. First and foremost, it describes the creation of the design games and how the design process of the study was split into three phases, each representing a level op abstraction inspired from the activity theoretical model on which the games are build. The paper contributes the thesis by outlining how each of the games specifically relate to the three levels and how the findings reflect as much. Lastly the paper reflects on the impact that using an iterative and theoretical approach as had on the imperial findings.

Whilst the findings presented in the paper are thorough and concisely describes the creation of the games and the findings that were made. Whilst the reflections made in the paper about how the use of HAM has had both positive and negative effect on the creation of the design games, it lacks proper inclusion of artefact ecologies.

2.2. ARTICLE 2: EXPLORING USER REQUIREMENTS FOR AN EXOSKELETON ARM: INSIGHTS FROM A USER-CENTERED STUDY WITH PEOPLE LIVING WITH SEVERE PARALYSIS

This article was written in collaboration with Anne Marie Kanstrup and Lotte N. S. Andreasen Struijk. The paper was published as part of the proceedings for INTERACT 2021 (Kobbelgaard et al., 2021).

This paper present key empirical findings from the first and second phase of the study. The paper starts by introducing to what tetraplegia and gives an overview of literature written on the design of exoskeleton robotics. The paper then proceeds to a brief methodological description before going on to the empirical findings. The findings are split into findings from the first and second phase. The paper then presents a discussion concerning first the empirical findings and then limitations and future research.

2.2.1. CONTRIBUTIONS AND REFLECTIONS

The main contribution of the paper are the empirical findings. The paper presents them split into the first and second phase. During the presentation of the findings from the first phase, transcript excerpts are used to emphasize the points made. The presentation of the empirical findings from the second phase focuses on a list of positives and negatives made in collaboration with the participants.

Whilst the paper presents important insights that are central to the thesis, it does not include the evaluative insights produced in the third phase of the study. Likewise, it does not make include reflections on how the different levels of abstraction shaped the findings and therefore does not connect them. Whilst there are some grievances, the paper presents the findings in a concise manner and manages to make recommendations for future design as well as future work that has value both to the thesis and the field. Lastly, the discussion of the findings expresses the need for a contextual understanding to properly acknowledge the actual needs of the participants.

2.3. ARTICLE 3: EXOTIC – A DISCREET USER-BASED 5 DOF UPPER-LIMB EXOSKELETON FOR INDIVIDUALS WITH TETRAPLEGIA

This article was written in collaboration with the other partners of EXOTIC. The co-authors of the paper are Mikkel Thøgersen, Muhamad Ahsan Gull, Mostafa Mohammadi, Stefan Hein Bengtson and Lotte N. S. Andreasen Struijk. The paper was written as part of the proceedings for the 3rd International Conference on Mechatronics, Robotics and Automation (Thøgersen et al., 2020).

The paper summarizes findings made throughout the project and presents them collectively. The paper starts by summarizing some of the key challenges that currently face exoskeleton design in terms of functionality, weight, bulk and degrees of freedom. The paper then presents the key findings made during the first interviews and how these relate to the design of exoskeleton as well as which biomechanical and clinical considerations that are necessary to take into consideration. The paper then proceeds to introduce to the exoskeleton design that was created as well as how the participants are to interface with it. Finally, the paper presents the initial analysis and testing as well as concludes on the work done.

2.3.1. CONTRIBUTION AND REFLECTIONS

The main contribution of the paper is the design of the exoskeleton arm as well as the proof of concept as to the size vs functionality. The paper presents the rationale behind the design in terms of inputs from the users, biomechanical considerations as well as the actuation and control of the exoskeleton arm. While the paper manages to present its findings it a concise manner, the relative briefness within which it presents multiple findings results in a slight simplification of the results presented

CHAPTER 3. RELATED WORKS

3.1. PARTICIPATORY DESIGN

In the study that forms the basis for this thesis, the focus has been on engaging potential users directly in the research. The aim is to attain a proper understanding of the context in which the technology developed must function. To include users in a manner that made sense to the participants of the study and to produce the insights needed to further the design of the exoskeleton solution, the ideals, and methods of participatory design (PD) were used. The following areas of study formed the basis for this work.

At the core of participatory design is the notion of democratizing the design. This is based on the assumption that design is inherently better or perhaps better suited to its intended purpose when the stakeholders for whom the design is targeted are included (Gerrard & Sosa, 2014). Participatory design as a field of study is not new. It took hold in the 1990s where PDC (The Participatory Design Conference) became a conference for discussing different aspects of participation and as a platform for researchers to discuss their findings with others who hold the same ideals about including users in research (Basballe et al., 2016; Smith et al., 2017). The main ideals that hold true from then to now can be organized into five categories: politics, people, context, product and methods (Basballe et al., 2016).

Politics refers to the notion that any person who is affected by a design, either directly or indirectly, should be included in the decision-making and planning for any such design.

The category of *people* revolves around the notion that individuals are experts in their own lives and context and therefore they can and should play important roles in a design process.

Context refers to the proposition that the basis for any design should be based on situations in which the product is used, arguing that context is a fundamental part of the understanding needed to create good designs.

The *product* of a participatory design study should revolve around making the state of things better and improving participants' lives in a manner that is meaningful for future use of a proposed design.

The last category, named *methods*, refers to the notion that any approach to participatory research should allow for the proper inclusion of the users, maximizing the participants' influence in accordance with the goals of the research.

In the literature on participatory design, the manner and extent of citizens' participation varies from project to project. Some researchers have found a lack of actual participation by and acknowledgement of the user. For instance, Buskens (2016) said that participants 'often remain unacknowledged, unnamed and unknown in all their complexity and fluidity' (2016, p. 103). Others simply state that the scope of participation must be carefully considered and weighed against the intended outcome. One example of this is Jon Whittle (2014), who argued that 'in a noble desire to involve participants as much as possible, PD practices can be over-designed and take the lion's share of the resources that are available.' (2014, p. 129).

It is important to note that this is not a new discussion but one that has been consistent throughout the history of participatory design literature. For instance, Sherry Arnstein (1969) discussed levels of participation in terms of the potential users' power over the final product. To simplify different levels of participation, she created the participation ladder, which has three levels: nonparticipation, tokenism and citizen power. Nonparticipation refers to situations in which users are included, but rather than being involved directly, become the objects of change through the assertion of power through manipulation or therapy. Tokenism revolves around studies in which participants are included by being repositories for information, by being consulted or simply by being placated. Lastly, citizen power refers to studies in which the participants have a large voice, either through a partnership with the project, by delegating power to the participants or in extreme cases by granting the citizens partial or perhaps even full control of the design process. Arnstein's ladder has been cited over 26,000 times and it is widely used both in and out of PD. While Arnstein's ladder might seem rather simplified in its categorisation, it can serve as a useful guide in asserting and evaluating the degree to which participants have been included in a project. Perhaps it can even make it possible to increase the amount of power that the participants hold, making their contributions useful for PD. Bratteteig and Wagner (2016) say such participants 'aim to strengthen the position of the "weak party" through artefacts (and associated practices)' (2016, p. 143).

3.2. USER-CENTRED EXOSKELETON DESIGN

At the beginning of the study, a scoping review was conducted to assess the degree to which exoskeleton research for tetraplegia has been user-centred and whether other projects included participants directly in the development of their exoskeleton designs. The review used a search string that incorporated different spellings and terms used for different user-centred approaches. With the assistance of a university librarian with knowledge of the domain, a number of databases were identified as relevant for the study: ProQuest, Scopus, Web of Science, EBSCOhost, Springerlink, PubMed and ACM Digital Library. The following is an example of a string used. In some databases, the string had to be altered slightly.

Exoskeleton AND (‘human-centered design’ OR ‘human centered design’ OR ‘human centred design’ OR ‘human-centred design’ OR ‘patient-centered design’ OR ‘patient centered design’ OR ‘participatory design’ OR ‘user centered design’ OR ‘user-centered design’ OR ‘user centred design’ OR ‘user-centred design’)

The searches identified 34 articles for review. Of these, 28 were chosen for reading. A conscious choice was made to include PhD dissertations and one grey paper because of the low number of journal articles found. In this reading, the perspectives found in the literature on PD were used to analyse user participation in related research.

The short review showed that users were mostly included by proxy through intermediaries like doctors, physicians and other medical professionals. The actual end users were rarely included (Beckerle, 2014; Christ & Beckerle, 2016; Krishnaswamy, 2017; Krishnaswamy et al., 2017; Pedrocchi et al., 2013). In addition, it showed that exoskeleton designs for assistive purposes were often based on activities of daily living (ADLs), which are considered basic for the care of oneself (Edemekong et al., 2022). This makes ADLs useful for assessing caregiving needs. In general, six primary ADLS are discussed: the ability to move oneself, the ability to eat independently, the ability to take care of one’s own hygiene, the ability to control one’s own bladder and bowel movements, the ability to go to the toilet and the ability to dress oneself (Edemekong et al., 2022).

While most studies included users only by proxy, some involved them through questionnaires, though often without clearly distinguishing between caregivers and patients (Krishnaswamy, 2017; Krishnaswamy et al., 2017). Some questionnaires had very broad target user groups (Christ et al., 2012). Other studies used interviews of individuals and groups, but rarely with end users (i.e. people who were paralysed). They mostly included experts (health care professionals) and their perspectives on users’ needs (Beckerle, 2014; Pedrocchi et al., 2013; Power et al., 2016). In a recent case study on assistive robots, an individual with tetraplegia expressed a strong desire to bring a robot arm to her home. She wanted to use the robotic arm to take her own clothes out of the closet, eat and drink by herself, play social games with her family and hold hands with her grandchildren. She claimed that a robot arm would allow her to open doors and, because of this, she could spend time on her own, potentially reducing the need for help and increasing her independence. (Struijk et al., 2017). Research like this highlights the insights that users can contribute to the design of exo-technology. It expands ADLs with understandings and challenging visions for independent and social lives.

I have found that research based on participatory and user-centred approaches to exoskeleton design (as defined in the first sections of this chapter) has increased our understanding of end users and their requirements for different aspects of exoskeleton design. Examples include developing personas to inform design (Amirabdollahian et al., 2014), using technology acceptance models to anticipate factors in use, acceptance and design (Shore et al., 2018), and assessing ownership and user-acceptance of prosthetic limbs (Caspar et al., 2015). Still others have used psychological tests to ascertain embodiment across different prosthetics (Beckerle et al., 2012). While some papers focused on the specific context of use and the values of the users that are to be designed for (Christ et al., 2012; Ding et al., 2007; Lynn et al., 2017), the daily lives of individual end users and the existing technological ecologies they employ seem to get lost in the previously ascertained notion of building for ADLs and complying with user-acceptance norms.

In another aspect of the literature review, Hill et al. (2017) set out to ascertain how often user perspectives were taken into account. They identified 912 articles of interest, but they discarded the vast majority based on abstracts alone. As a result, only 19 remained after the initial culling of papers, and only 9 included perspectives on user involvement. Although a lack of user perspectives can be identified in the literature, the willingness to include them certainly seems evident. Many researchers noted the importance of user-centred design (Bates et al., 1993; Demain et al., 2013; Kiesler & Hinds, 2004; McMillen & Söderberg, 2002), and they called for future studies to include users in the design (Brown-Triolo et al., 2002; Hill et al., 2017; Louise-Bender et al., 2002). In 2017, in the *Journal of Robotics and Autonomous Systems*, Beckerle et al. (2017) stated, '*Since the devices incorporate and closely interact with human users, research activities and real-world applications require human-oriented approaches'*. Further, they said that '*devices that satisfy human demands and fulfil technical requirements would greatly benefit from multidisciplinary collaboration of engineering, computer science, and human sciences'* (2017, p. 238).

Different calls have been made to include users in the development of exoskeleton design, and many have been quite specific about the aspects that should be furthered. The most common call was related to the conceptualisation of exoskeleton technologies. It is of utmost importance when designing in collaboration with users to make sure that the manner in which the users and the engineers conceptualize the exoskeleton is compatible with solutions that truly suit the users' lives. An example is walking speeds when designing exoskeletons for the lower body (Hill et al., 2017). The average walking speed of an exoskeleton solution is 0.03 to 0.05 metres per second. This is dramatically slower than the average walking speed of an adult, which is approximately 1.35 metres per second. Therefore, if the exoskeleton is designed to enable the user to walk again in the same manner as an able-bodied adult, the user is certain not only to be disappointed and disheartened with its performance but quite possibly also with the design process as a whole.

Further, calls have been made to understand how assistive technologies, exoskeletons included, alter the way in which users view themselves and the meanings they ascribe to their surroundings (Louise-Bender et al., 2002). This, in line with the previous call, also means that an understanding of how the technology might alter the current lives and surroundings of the users must be established to understand the users' visions. This is supported by the literature on designing for disabilities. For example, in 'Design Meets Disability', Graham Pullin (2009) stated that '*changing environmental factors and social contexts make disability contextual, even dynamic, for each individual*' and *'our abilities change depending on the context. Environments themselves may render us more or less capable, but so may activities or states of mind*' (2009, p. 91). Lastly, calls have been made to learn how users see technology in terms of functionality versus aesthetics. For instance, Brown-Triolo et al. (2002) stated that attention should be paid to whether exoskeletons induce a feeling of stigma in potential users. They have shown that this could be a reason why users disapprove of certain designs. Other researchers found that users were very aware of the potential functional advantages of the solutions and they put less value on the functional opinions of healthcare professionals and the promises of the manufacturer (McMillen & Söderberg, 2002; Shah et al., 2009).

These examples highlight both the importance and the challenge of balancing user visions with technological constraints and opportunities. Against this background, I conducted a user-centred design process so that individuals with tetraplegia could contribute insights on that complex balance in the design of an exoskeleton arm for people with severe paralysis. In this thesis, I present this process carried out in the specific design case of an exoskeleton arm. The study explored dilemmas related to balancing the advancement of human practices and exoskeleton technology, with specific attention to understanding user visions for future uses and how a common conceptual understanding of exoskeleton design can be established and benefit the design.

CHAPTER 4. RECRUITMENT

Finding participants was a constant effort throughout the study. One of the project's external partners, the Spinal Cord Injury Centre of Western Denmark, works directly with patients. Therefore, at first, participants were directly recruited there. To ensure that prospective participants fit the scope of the project, a number of requirements were made. First, the participants were to have a high-level C1–C4 injury and be finished with their initial treatment at the centre, which usually lasts for around a year. The second requirement was to ensure that the participants had experience dealing with their condition and had an established technological ecology that could be observed. Recruitment was conducted in three ways. First, when relevant patients came in for a check-up, the nurses would ask them if they would like to participate in the project. Second, flyers were placed at the centre with information about the study and expectations for participation in the project. Third, a presentation was held at the centre to inform patients about the project. Unfortunately, there were misunderstandings about the division of labour and a lack of relevant patients living at the centre at the time. Therefore, the first period of recruitment was unfruitful. After several months, it was decided that recruitment would have to change to attract enough participants.

At this time, contact was established with the head nurse at the centre, who was able to look through the medical journals that were present at the centre and contact participants directly in regard to participation. This process resulted in a number of possible participants who were contacted and informed of what their commitment would entail and ultimately recruited for the study. This concluded the first round of recruitment, which resulted in recruiting seven participants for the study.

Therefore, two more rounds of recruitment were carried out, using the same method of contacting possible participants directly while also asking current participants to think of possible candidates. During the second round of recruitment, two more participants were identified. However, other participants left the study, so the total number fell to five. During the last round of recruitment, a greater number of participants was seen as essential, as the evaluation was about to begin. Therefore, the requirements for participation were reduced to include more bodily functionality and to invite patients who were still hospitalized as part of their initial treatment. The evaluation included 10 participants, none of whom had participated in the earlier stages of the study. Table 1 shows a list of the interviewees who participated throughout the study.

Table 1 - Participants in the Study

Participant Number	Gender	Phase
1	**Female**	**1**
2	**Male**	**1**
3	**Male**	**1**
4	**Male**	**1**
5	**Male**	**1**
6	**Male**	**2**
7	**Male**	**2**
8	**Male**	**2**
9	**Male**	**2**
10	**Male**	**2**
11	**Male**	**3**
12	**Female**	**3**
13	**Male**	**3**
14	**Male**	**3**
15	**Male**	**3**
16	**Male**	**3**
17	**Male**	**3**
18	**Male**	**3**
19	**Male**	**3**
20	**Male**	**3**

Because of the lowered inclusion criteria, several participants did not yet reside in individual housing. For this reason, and because the evaluations were conducted at a secondary location, the focus on the participants' homes was excluded, so those details are not in the table.

CHAPTER 5. THEORY

This chapter presents the theoretical underpinnings and methodology of the thesis. As part of the research on tetraplegia and how people overcome the challenges associated with living with tetraplegia, a number of magazines and websites aimed at informing the public and newly diagnosed people were looked into. One notable piece of information that arose was the fact that a big emphasis has been placed on tools that can help people in their everyday lives. There were articles on such things as electric wheelchairs, cars customized for disabilities, eating machines and respirators. In addition, during an initial conversation and tour of the partner's rehabilitation facilities, a focus was placed on the different tools that were available to the people living there and how they were trained to use the tools in different contexts. The focus on artefacts that seemed to be very prevalent in the community led to the idea that a reasonable theoretical foundation for the project could be activity theory coupled with notions from artefact ecologies as a way to represent the wide range of artefacts used by the participants.

Activity theory began in Russian sociocultural research in the 1960s and 1970s, and it is often credited to Leontiev (Leontiev, 1978; 1981) who built on the theories of Vygotsky (1962). This theory emerged from a wish to reflect on the interaction between a person and the world around them or – in other terms – between a subject and an object. Activity theory proposed that such interaction was mediated by an activity that could be analysed. Building on Leontiev's theoretical framework, activity theory has become one of the most influential theoretical bases of modern Human Computer Interaction (HCI), and it has been appropriated by several notable and influential figures in the field. One such figure is Engeström (1987), who adapted the theory to make it more useful for modern software development. Whereas Leontiev's activity theory focused on individuals or individual groups as the subjects, Engeström's model could take multiple subjects into account. This introduced the notion of community as part of an activity so that rather than the activity occurring between a subject and an object, Engeström said that the activity between the subject and object was mediated by a community. Engeström added the means of mediation to the model, stating that rules mediate the

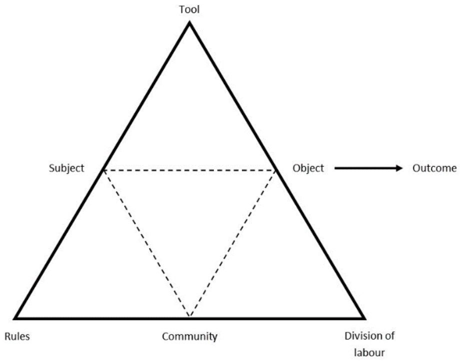

Figure 2 - The activity theory triangle

relationship between the subject and the community, divisions of labour mediate the relationship between community and the object, and tools mediate the relationship between the subject and the object. Engeström’s model of activity theory is often described as a triangle (see Figure (2)).

Initially, the plan was to use activity theory as proposed by Engeström (2000) with a focus on the relationships between the subject, object, instruments, rules, community and division of labour. As a matter of fact, the first iteration of the design game, described later, originated directly from Engeström's triangular model. However, a further look into artefact ecologies revealed a model that would allow for a more dialectical understanding of the relationships between the activities being explored and the artefacts at play. It is called the human–artefact model (HAM). Before going on to that, however, there is an overview of how artefact ecologies are understood in this project.

5.1. ARTEFACT ECOLOGIES

Looking at how an individual interacts with a given artefact or technology can, in itself, be valuable. Yet, it is acknowledged that the use of an artefact can rarely be isolated to a single individual or context. Most of the time, it is part of a larger assemblage or indeed the ecology of different artefacts and actors. Looking at artefacts as part of an ecology and attaining a holistic understanding of their use in correlation with the cultural dimensions within which they are embedded stems from research conducted in the 1980s and 1990s. Thus, the notion of ecologies is widely used and has a very important place in HCI research. In a literature review, Peter Lyle et al. (2020) showed that the concept of ecologies had become somewhat fragmented. They divided it into four traditions of use, or concepts: information ecologies, artefact ecologies, device ecologies and communicative ecologies. This thesis focuses on artefact ecologies, or the relationships between practices and artefacts and how they dialectically change each other.

Work on artefact ecologies can be divided into three levels of study: macro, meso and micro. At the macro-level, the focus is on organizations and figuring out how ecologies of artefacts change practice at the organizational level. At the meso-level, artefact ecologies are viewed in terms of their relationships to collaborative practices and communities. Lastly, at the micro-level, artefact ecologies are viewed in relation to how they affect and are affected by the practices of single individuals or with a focus on a single individual in the ecology. The work conducted in this thesis focused on a micro-level analysis of the artefact ecology of the participants. This means that the focus is on the individual participant and how a practice is changed by introducing a single artefact into the ecology, namely, the exoskeleton arm.

5.2. THE HUMAN-ARTEFACT MODEL

The human–artifact model (HAM) is grounded in activity theory. Developed by Bødker and Klokmose (2011), it is a 'framework that helps addressing the analysis of individual interactive artifacts, while embracing that they are part of a larger ecology of artifacts' (2011, p. 315). In other words, the HAM maintains that the artefact cannot be viewed in isolation. Instead, it uses basic activity and theoretical principles, together with notions from artefact ecologies, to make it possible to analyse an activity and focus on its practice while acknowledging the multitude of artefacts that surround us whenever we interact with the world. It offers a theoretical lens to view relationships between humans and artefacts at three levels: motivational, goal-oriented and functional. In the model, these are determined by answering the questions; why, what and how (Bødker & Klokmose, 2011).

5.2.1. ACTIVITY HIERARCHY

A vital part of using the HAM involves an activity hierarchy. At the core, the hierarchy splits an activity into three levels of abstraction that can be used to view it from different angles. The first level is the motivational level or aspect, which concerns the why of an activity: What is the purpose of the activity, and what is the motivation for spending time and effort discussing it? As the HAM prioritises the relationship between humans and artefacts, this level also concerns the motivation for using a specific tool. For example, while creating a table for a family, to ensure that the children do not get hurt, sandpaper is used to round down the edges.

The second level of abstraction is the instrumental or goal-oriented aspect. At this level, the activity is viewed in finer granularity to determine exactly what is happening. This level uses what questions to guide the analysis. In the example of the table, planks must be cut to similar lengths as a means of getting the table finished. At the instrumental level, questions could be raised as to which saw would be best for the action – one that can create a very clean cut or perhaps one that is efficient.

The last level of abstraction views the activity with very fine granularity. This level asks how an artefact is used. It looks at how the tool is being handled – what is required to conduct the activity – and how tools are adapted to ensure a successful result.

While the three levels can be viewed independently, they cannot exist as such. To understand why an activity occurs, there must be some understanding of what is being conducted and how it could be carried out. Otherwise, important aspects, such as why one activity is chosen over another that might achieve the intended result. A plank of wood can be divided with a multitude of tools ranging from the body itself snapping the plank to hammers breaking the plank with brute force or perhaps an axe chopping the plank into two. These are all possible scenarios that have been used to achieve results, so to understand why a person might want to use a saw, there must be an understanding of what the person intents to do with the plank, what previous experiences are the basis for the person’s decision and perhaps what conventions or expectations the person is subscribing to.

CHAPTER 6. THE RESEARCH PROCESS

To describe the process of understanding who the users are, what their aspirations are and how to support them in a proficient manner, it is important to understand how the study was organized and how it was aimed at answering the calls by other researchers noted in the literature review.

As presented in Chapter 3, the HAM was chosen as an overall framework for the study and as a theoretical basis for understanding the insights derived. Based on the three abstractions proposed in the theory, the study was divided into three distinct phases. The first phase concerned the motivational aspects of the participants' activities. The purpose of this phase was to explore which activities were important to the users and why they prioritized specific activities over others. During this phase, an understanding of what is happening during an activity began to develop as well.

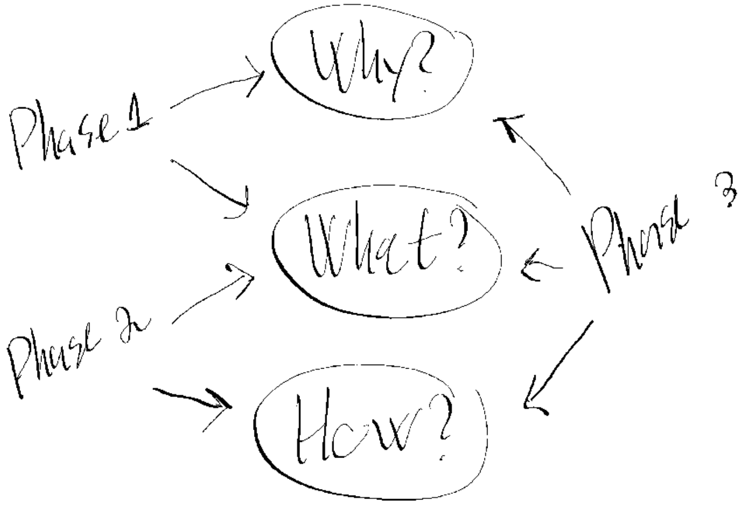

Figure 3 - Overview of study

The second phase of the study revolved around the activities that were prioritized during the first phase. During this phase, each activity was studied to understand *what* happens when activities are carried out in more granular detail than during the first phase. It was also aimed at attaining a further understanding of the time, space and artefacts used to carry out the activity – *how* the activity is carried out. The last phase concerns the evaluation of the arm, with a focus on tracing back the insights produced in the first two phases of the design. During this phase, all three levels of abstraction are touched upon.

To support user involvement, the concept of the ‘third space’ was used as a premise for methods design. As described in Chapter 2 on related research, a large part of being participatory means enabling the participants to engage on an equal footing with the researchers, designers or technical experts of the project. Designing exoskeleton technology is an extremely complex undertaking, one that the future users of a given study are unlikely to be familiar with or, for that matter, be confident enough to engage in. To ensure that future users can be engaged in the process and make informed decisions for both the design of the exoskeleton and in relation to their own contextual expertise, it is important to develop a space for user participation that supports a shared investigation of user visions and how these can be balanced with technological constraints and opportunities.

The ways in which this is possible have been exhaustively explored in PD research (Smith et al., 2017). For the design of this study, I drew on the notion of a ‘third space’ as coined by Muller and Druin (Muller & Druin, 2012). As presented by these authors, a successful participatory process can find a space between the two knowledge domains of the experts, in this case, the technical knowledge of the engineering team and the knowledge of potential users. They hold expert knowledge about daily living with tetraplegia, have experience with assistive technology and aspire for assistance that can make their living more independent.

To ensure that a third space is created, Muller and Druin described different aspects that must be considered: the setting and the narrative structures of the design process. For this study, there were two possible settings in which the participants could be involved – their homes or a third-party site between their homes and the university. This was because the university was too far from the participants’ homes and because of their limited mobility. To consider the users’ everyday living situations, I conducted interviews at their homes. Moreover, since they relied on 24-hour care, this decision was taken to make sure that the participants were comfortable in the situation, had access to their daily help and in general were in a setting that could strengthen their feeling of ownership and their contributions to the design from their own experiences. Second, following Muller and Druin, the interviews were supported by scenario-based design games to focus attention on situations of actual use (vs. technical functionality). Scenario-based games help to tie the design inputs directly to the activities and context of the participants, and the interviews were developed to bridge the gap between the two knowledge domains so that the users could make informed decisions about the design based on their own expertise.

The design games formed the basis for developing cooperative materials to facilitate a third space in the meetings with users. Design games as a method have a long history in the fields of participatory and collaborative design, with early notable concepts published by Habraken and Gross (Habraken & Gross, 1987). Later, many expanded the notion of design games (Brandt, 2006, 2014; Brandt et al., 2008; Ehn & Sjögren, 1991; Simonsen & Robertson, 2012), and today there are many versions and ideas about what design games are and how they can be used (Vaajakallio & Mattelmäki, 2014). In a nutshell, design games are developed to facilitate the exploration of a certain subject, such as a design, a research question or perhaps something else entirely. Design games can have different purposes, such as conceptualising designs, exchanging perspectives, understanding practices and creating scenarios (Brandt, 2006; Vaajakallio & Mattelmäki, 2014). The commonality across these purposes is that design games provide visual tangible artefacts that participants can manipulate to work with the subject matter at hand (Kanstrup & Bertelsen, 2011; Kanstrup & Nøhr, 2009). For this thesis, design games were used to create and explore scenarios. As described earlier, the main reason for using scenario-based games was to ensure that the discussions were tied to the expertise of the users, namely their own lives. Apart from that, scenarios also offer opportunities to explore the participants' current practices in a manner in which the flexibility of the scenario (Carroll, 2000) offers the bird's eye perspective (Brandt et al., 2008) needed to reflect on the practices of the participants. This, in turn, helps them develop a future vision (Löwgren & Stolterman, 2007).

The following sections describe the activities in each of the three design phases, including the presentation of the protocols and materials.

6.1. PHASE ONE – MOTIVATION

The purpose of the first phase of interviews was to discover the activities the participants carried out during their daily lives and what the motivational aspects of these activities were. To attain that knowledge, a design game and an interview protocol were developed. The protocol explained the different phases of the interview and the expected outcomes of each. The interview was semi-structured, and it started with a written statement. The protocol and statement are presented next, followed by a description of the design game and how it was played.

6.1.1. THE PROTOCOL

'In the following interview, I will ask you about your daily life. A focus is placed on the help that you have available and the tools and technologies that you use. You can at any time stop the interview if you no longer want to participate and please say if there is something that is hard to do or that you do not wish to answer. The interview will be recorded with the intent of further analysis, but it will not be shared with anyone outside the project. Furthermore, it will be stored safely and encrypted to ensure that no one has access to it. As the interview will last between an hour and an hour and a half, please tell me if you get tired or need a small break.'

Table 2 – Protocol from the first phase

Task with time	**What is to happen?**	**Purpose**	**Outome**
10min- Introduction	The participant is presented with the project and the statement of consent	The introduction sets the boundaries for the interview and ensure administrative formalities	Signed statement of consent
10min- Get to know	Initial questions about the participants situation, experience with tetraplegia and so on.	The participant is asked general questions for some background information and in order to ensure that the conversation is "opened"	Information of the participants circumstances, to be used in contextualizing the insights gathered.
10min– Presentation of game	The gameboard as well as the playing cards are presented	The participant gets an understanding of what is about to take place and how the game is played.	A collective understanding of the game and its purpose is attained.
30min- Playing	The game is played with the participant, at least three scenarios should be explored.	Through playing the game, the daily activities of the participant are explored, as well as an envisioned future given the introduction of an arm.	An understanding of the participants daily live, challenges and envisioned changes in praxis is established.
10min – The three scenarios are summarized	The three scenarios explored in the	Through discussion a further understanding of the individual	A further understanding of the prioritized scenarios is established as well

	game are discussed.	scenarios is established, a focus should be on tacit knowledge – Ask the “stupid” questions.	as tacit knowledge about the same.
10min – The attributes of the arm are discussed	A conversation about the exoskeleton arm.	Questions are posed with the purpose of understanding aesthetical, practical, and unspoken wishes of the participant.	A common understanding of what an exoskeleton arm is and how it could be designed is established.
10min – Finalizing remarks and future collaboration	Future followup is agreed upon and the participant is informed of the future of the project.	Through informal agreements a common understanding of the coming process is established.	A common understanding of the coming process is established. Any wishes from the participant concerning contact or participation is uncovered.

6.1.2. THE GAME DESIGN

The goal of the first design game was mainly to attain an understanding of the motivational level of an activity. This means that the goal of the game was to understand which activities the participants conduct their daily lives and why those activities are important to them. Thus, the game had two rounds. In the first round, the current state of activities was explored, and in the second round, the participants were asked to envision activities they wanted to carry out in the future if they had a functioning exoskeleton arm to help them. The materials for the game are as follows (see Figure (4)).

- A game board consisting of five areas, each labelled according to its use. In the middle, a playing area is used for the main activities of the game and surrounding it are four areas on which filled-out cards can be placed.

- Activity, artefact and assistance cards, some of which are filled out prior to the game with examples of each of the categories. Each type of card has a headline indicating what should be written on the card.

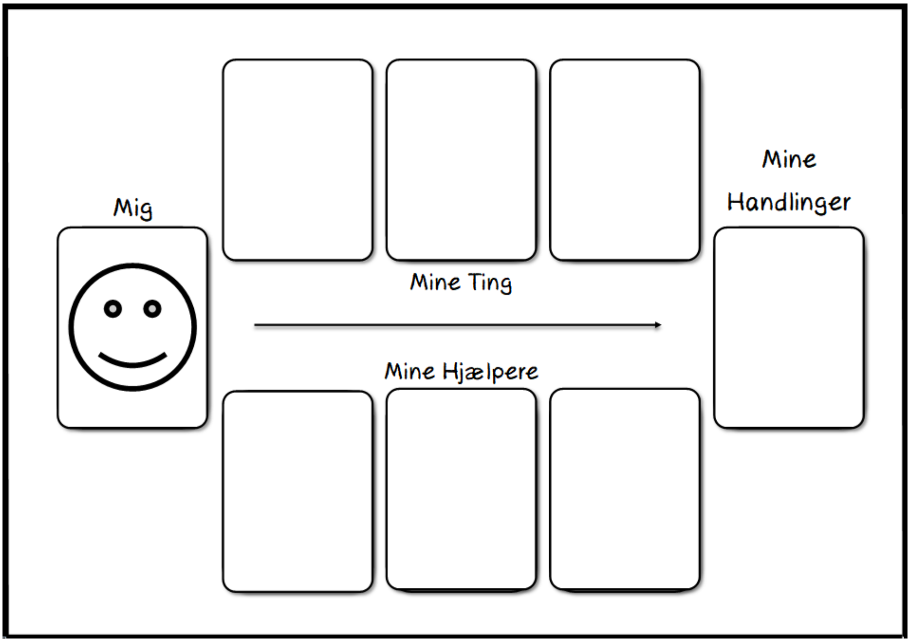

Figure 4 - The First Design Game

6.1.3. PLAYING THE GAME

The interviews that were part of the first design game were divided into 7 phases of 10–30 minutes. Before playing the game, the user was introduced to the project and how the interview would be carried out. The user gave consent to record the remainder of the interview. This was followed up by a ‘get to know you’ phase, in which the participant was asked about their current life situation, experience with paralysis and living arrangements. The third phase of the interview was an introduction to the three phases of the game.

During the first phase, the player was to fill out different cards, as follows:

- First, the player filled out the activity cards by describing what they did during a day. The activities could include, but were not limited to, ones that are frustrating, enjoyable or not currently being carried out.

- Second, the player filled out the different artefacts used to conduct the activities in the first round. (More artefacts could be added later in the game, if need be.)
- Third, the player listed and filled out the assistance card with the people who helped him or her during the day. (These could include people who assisted only occasionally.)

During the second phase of the game, the player explored three different activities that were listed as they were being conducted.

- The player was asked to identify the task that he or she found most important or that he or she wished could be changed.
- Each activity was discussed, and artefacts and assistance cards were placed on the game board in accordance with the discussion.

In the third phase of the game, the player was asked to do the following:

- Imagine the activities that were just discussed 'as is', as if the player now had a single fully functioning arm with which to carry out the activity.
- During this phase, cards were added and discarded according to the imagined scenarios that were discussed.

After the game, the player was asked to summarise the three scenarios that had been explored in the game. Then, the properties and aesthetics of the proposed exoskeleton solution were discussed. When the interview was wrapped up, the participant was informed of future activities and opportunities to contribute to the exoskeleton design.

6.2. PHASE TWO – OPERATIONALISATION

The second phase concerned how to make the activities discussed during the first phase happen. Like the first phase of the study, the interviews were held at the participants' homes, and each lasted for about an hour. A semi-structured protocol was created to ensure that adequate information was obtained from the participants.

6.2.1. THE PROTOCOL

Table 3 – Protocol from the second phase

Task with time	What happens?	Purpose	Outcome

10min – Introduction of arm and project	The current prototype is presented via pictures, as well as the current trajectory of development	The introduction frames the interview so that there is a common understanding of the arm.	The participant become sufficiently informed of the development to participate in the discussion.
10min – Presentation of game	The posters are presented	Understanding of the purpose of the game is established.	A common understanding of the interviews purpose is established.
30min - Playing	The posters are filled out	Scenarios are discussed and a common understanding of how the arm can be part of the activities is established.	An detailed understanding of the participants activities is established as well as recommendation for future design.
10min – Summary	The discussion is summarized	Through discussion a further understanding is established	A further understanding of the detailed descriptions of activities as well as how the arm fits into it is established
20min – Discussion of arm	The current prototype is discussed as well as positive and negative attributes that it should possess.	A common understanding of how the development should proceed is established.	A common understanding for future development is established as well as the participants wishes for the arm.
10min – Discussion and prioritization of attributes that the arm should possess.	Attributes are prioritized and the most important are discussed.	Through discussion a common understanding of the most important aspects of the arm is established	A short list of important aspects is produced.

6.2.2. THE DESIGN GAME

The second design game (See Figure (5)) was created to develop a deeper understanding of the different insights produced in the first round. This game also was scenario-based. However, instead of constructing the scenario through speech and writing, this time sketches would be used to uncover their special aspects. Individual playing boards were created for each activity uncovered during the analysis. That is, a game board was made for eating, drinking, scratching an itch, reading, brushing teeth and shaving. Each board contained three areas on which different aspects were explored in dialogue with the participant.

At the bottom of the board, a timeline was filled out to understand the timing of each activity being explored

Above the timeline, there was a large blank square for the participant to fill in with either a drawing or a detailed description of the space in which the explored activity took place.

On either side of the square were two lists. The list on the left was to be filled out with positive attributes that the arm must encapsulate to be appealing to the participant. The list to the right was for imagined negative aspects of the arm that developers should stay clear of.

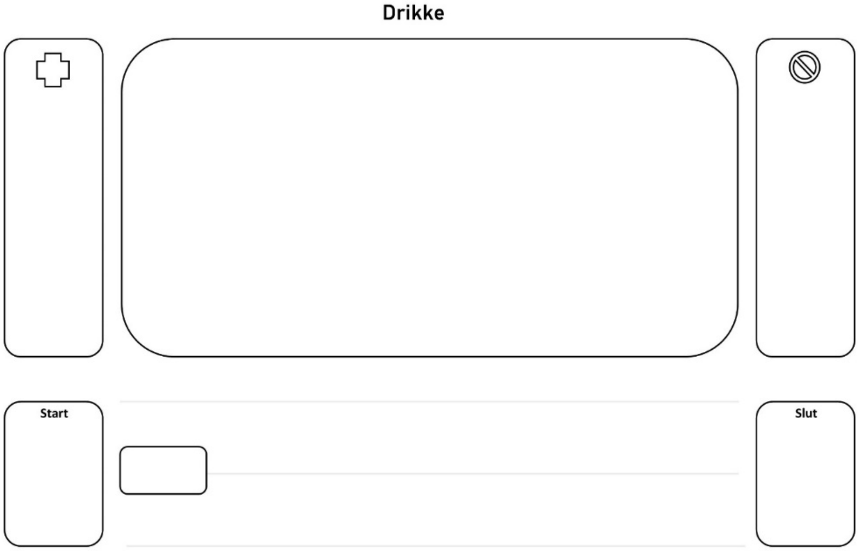

Figure 5 - The Second Design Game

6.3. PHASE THREE - EVALUATION

The third phase of interviews was an extension of the clinical trials that were part of evaluating the prototype that had been designed for the project. The overall clinical trials lasted 3 days, roughly 4–5 hours in length. Throughout the day, the participants were acquainted with the tongue interface, and they completed increasingly complex tasks. The tasks ranged from computer-simulated challenges in which they were to pick up simple objects, and they ended with complex tasks involving multiple actions, such as picking up items and placing them in hard-to-reach areas, simulating drinking from a bottle and picking up and simulating eating a strawberry. At the end of the third day, the participants were interviewed. The interview was designed to explore how the participants experienced using the arm and the tongue interface and to evaluate the design of the solution based on whether they felt secure, how the solutions fit their current artefact ecology, and what they thought of the design. The interview was semi-structured, with a scripted beginning to ensure that every participant was given the same information. I created the protocol, and it was reviewed and revised in collaboration with the project leader to ensure that the questions covered all the information needed. The following are the opening statement and the protocol. Both have been translated from Danish, in which they were originally written.

6.3.1. THE PROTOCOL

‘In the following interview, I will ask you about your experience testing our first version of the exoskeleton arm. During the interview, you will be asked how you experience the arm, if you think it could be useful to you in your everyday life and how you think the arm could be changed or improved to better fit your needs. You can stop the interview at any time if you no longer want to participate, and please say if there is something that is hard to do or that you do not wish to answer. The interview will be recorded with the intent of further analysis, but it will not be shared with anyone outside the project. Furthermore, it will be stored safely and encrypted to ensure that no one has access to it. As the interview might last up to an hour, please tell me if you get tired or need a small break.’

Table 4 – Protocol from the third phase

Area of inquiry	**Research question**	**Possible questions**
Experience of the clinical trials	How did the participant experience the prototype?	• How did you experience using the arm today? • What did you think of the functionality?
Future improvements	Kan the design be improved to better fit the needs of the users in their everyday lives?	• Could you imagine integrating the a future version of the arm in your everyday life? • What aspects of what the arm offers do you imagine could improve your everyday? • What aspects of how the arm works do you think could work against a good everyday?
Current artefact ecology	Will the design conflict with any of the artefacts currently employed by the participant?	• Do you imagine that using the arm would change how you use other technologies in your everyday? – How? • Do you imagine that the arm could be hard to use with any of your current tools? - How?

	How do the participants' current artefact affect their daily lives?	• Are you satisfied with the technologies and tools you have available at the moment? • How have you been able to improve your daily live with the tools you have at your disposal? • Do you think that you have to many or to few tools in your daily live? Are their any you want to get?
Design	What is important to the users in regards to design, aestethics & functionality?	• What do you think we should prioritize when we continue our work with the arm? – why? • Do you have any wishes about how the arm should look? • What do you prioritize highest, functionality or aestethics?
	Was the level of noise produced by the exoskeleton arm acceptable to the user?	• Do you have any opinion about the level of noise that the arm produced when used? • Would the current level of noise be disruptive to any activites in your daily live?
Security	Did the user at any point feel insecure when using the prototype?	• Where you at any point during the tests in doubt about your safety? • Could you imagine using the arm without any other people around?
Etc.	Other questions	• Is there anything that you think we should be aware of, anything that we have missed/not thought about? • Do you have any questions in relation to what we have spoken

		about just know, or to the tests over the past days?

6.4. ANALYSIS

Throughout the project, in line with the three phases of enquiry, three separate instances of coding and analysis occurred. To code the data and extract knowledge from them, each interview was transcribed. To choose a feasible manner of transcription, a few different techniques were reviewed. Transcription is a method for converting one medium into something codable, so it has a long history in the social sciences and plenty of literature and advice exist. The main considerations when choosing a manner of transcription are the degree of granularity that is needed, the readability needed for future work and the context of the medium that is being transcribed (Cowan, 2014). For this study, a high granularity of detail was not deemed important. First, what was said is the subject of analysis rather than how it was said. Second, high granularity might affect the reading of the data, as participants that were interviewed often spoke differently than the average interviewee, given that they might use respirators, have conversations with their caregivers in the middle of a sentence or simply be talking more slowly than was usual because of fatigue. The transcription technique that was used was the Jefferson notation system (Jefferson, 2004), chosen though in a pared-down version that would not include elements such as notations of overlap and lengths of pauses. The following excerpt exemplifies how the transcription was done.

257 Participant: Yes, read and turn pages.

258 *Phone rings*

259 Participant: It looks like an ingoing call; I just need to

260 Interviewer: You need to swipe. Should we do that?

261 Participant: No, I have it so that I can answer it. What? Is not Wednesday today; he must be impatient. He probably does not know if he should come today. I just need to go find the latest calls, latest calls.

262 *the participant interacts with the phones and makes a call*

263 Second interviewer: Look, it is like a mouse.

264 Interviewer: Yes.

265 Second interviewer: Oh, so **that** controls the arrow.

266 Participant: Yes, then it controls the arrow so that I can use the keyboard.

The excerpt shows three distinct characteristics of the transcription. First, each line was numbered as a way to refer to it during coding. Second, some words were written in bold to signify that the word was emphasised. Third, the text was made readable by removing redundancies and pauses caused when the interviewee stumbled over words or needed breaks to gather strength. The excerpt was translated from Danish to English to improve the readability of the report.

Having transcribed the interviews in each of the three phases, each transcription was coded using a schema and then analysed. During the second and thirds phase of analysis, inspiration was drawn from Thematic analysis as a means of structuring the code and keeping a organised overview (Braun & Clarke, 2006). In essence this means that the codes were divided into three distinct levels of themes. Activities were set as global themes to which other themes could be connected. The instrumental aspects of action was set as organising themes and the elements that constitute how an action unfolds were set as basic themes. The following presents the three analyses in the order in which they were carried out.

6.4.1. PHASE ONE

As previously mentioned, the first round of interviews was conducted in two phases. First, the everyday activities of the participants were discussed in terms of how they were being conducted at the time, then as future envisioned scenarios. This affected the coding schema, which was divided into current and future segments. Moreover, each of the three kinds of cards became a code in and of itself, meaning that a code was made for activities, artefacts and assistance. Lastly, during the transcription process, it became evident that many of the insights offered would not fall under one of the planned categories, so they got their own code, which was names ‘contextual’. The coding schema is shown in table (5).

Table 5 – Coding schema from first phase

Interview number					
Context					
Current			Future		
Activities	Artefacts	Assistance	Activities	Artefacts	Assistance

Each interview was inserted into the schema and reviewed meticulously to ensure that each insight was represented. The full coding schema for interview one is shown in Table (6).

Table 6 – Coding schema from first phase filled out

Interview 1
Context
2,5 years since injury (see line: 30-31)
Injury from riding accident (see line: 37-38)
House was rebuild to facilitate tetraplegia (see line: 50-55)
The participant states that she has, from the beginning accepted her circumstances (see line: 73-76)
The participant lives an active live outside her home (see line: 83-85, 278) This has sometimes had an effect on what she can manage at ome (see line: 85)
Has private help from 7-23 each day (see line: 108-109) And an alarm to get help the remaining hours of the day (see line: 110-114, 190-191)
Open to new technologies (see line: 210-216)
RSCV has a focus on physical rehabilitation (see line: 211)
Is conscious of her seating position and switching it up to prevent pressure-sores (see line: 330-334)
Has some problems getting new technologies as the municipality denies her requisitions (see line: 352-354)

Prefers the Exoskeleton arm to be constructed in a “soft” material (see line: 374-380)					
Has doubts about the possibility of turning pages qua experiences with a machine that was supposed to do that but could not (see line: 396)					
The arm should be as discreet as possible, as to not make the user “look like a robot” (see line: 401, 405)					
Would prefer the arm to be mounted on the chair (see line: 403, 405)					
Does not mind the look of electronics, though edges should be rounded and shaped organically (see line: 411)					
Should be easy to dismount by the private caregiver when going out, and require no more than 10 minutes (see line: 414, 425-427)					
Preference should be placed on doing practical everyday activites such as drinking as turning pages in a book (see line: 414, 434)					
The participant has a Tongue control system but is unhappy with its performance (see line: 133-136,)					
Before			***After***		
Activites	**Artefacts**	**Assistance**	**Activites**	**Artefacts**	**Assistance**
Going to other locations to work, holiday and socialize (see line: 91-93, 98-107)	Disability vehicle (see line: 95-96) Ipad (see line: 204)	Private caregiver (see line: 192-195, 198-204)	¤	¤	¤
Scrathing (see line: 124-127, 226-230)	Hair-brush (see line: 230, 237-240)	Private caregiver (see line: 226-230)	Scrathing (see line: 246-253)	Exoskeleton arm (see line: 246-247)	¤

				Hair-brush (see line: 248-251) A cloth (see line: 253)	
Take and make calls (see line: 154-158, 258-268)	Android Phone (see line: 129-130, 154-158) Chin joystick (see line: 260-267)	Private caregiver (see line: 156)	¤	¤	¤
¤	Tongue control (see line: 132-135, 164)	¤	¤	¤	¤
¤	Chin joystick (see line: 147-148, 168)	¤	¤	¤	¤
¤	Wheelchair (see line: 152-154)	¤	¤	¤	¤
Open Doors (see line:352)	¤	Private caregiver (see line: 359-360)	Open Doors remotely (see line:352-360)	Electronic door-opener (see line: 352-358)	¤
Drink (see line:314-327)	Tongue control does not inhibit	Private caregiver	Drink	Cup-stand (see line: 337)	Private caregiver

	drinking (see line:174-175) Cup-stand (see line: 314-317, 337) Straw (see line: 337) Straw-clip (see line: 341)	(see line:327)		Straw (see line: 337) Straw-clip (see line: 341)	(see line: 337-338)
Eat (see line: 160-163, 361-370)	Cannot eat with tongue control (see line: 172)	Private caregiver (see line:365-370)	Eat	Does not want eating machine (see line: 162-163)	Private caregiver (see line: 366)
Listen to radio (see line: 179-181)	Voice control (alexa) (see line: 179)	¤	¤	¤	¤
¤	¤	¤	Control exoskeleton	Voice control (see line: 183)	¤
Reading (newspaper, magazines, books) (see line: 186-189, 270) Turning pages (see line: 257)	Reading table (see line: 187, 271-272) Internet (see line: 187)	Private caregiver & Husband (see line: 281-282, 308)	Reading (newspaper, magazines, books) (see line: 255)	Exoskeleton arm (see line: 187, 312-314) Reading table (see line: 311-312)	¤

	Audiobooks (see line: 188-189) Alexa (lights) (see line: 274-276)				
Call for help during the night (see line: 110)	Iphone (see line: 216)	Municipality Caregiver (see line: 190-191)	¤	¤	¤
¤	Ipad (see line: 24, 206-207)	¤	¤	¤	¤
Call for help at Hospital	Iphone (see line: 216-224)	¤	¤	¤	¤
Wipe nose (see line: 236)	¤	Private caregiver	¤	¤	¤
Turning on lights (bedroom and reading table) (see line: 274-276, 288-290)	Alexa (lights) (see line: 274-276, 288-290)	¤	¤	¤	¤
¤	¤	¤	Turn on computer (see line: 291-292)	¤	¤
Turn on television (see line:	Android Phone (see line: 294)	Grand-child (see line: 300)	¤	¤	¤

177-179, 293-294)					
¤	¤	¤	Pour red wine (see line: 314)	Exoskeleton arm (see line: 314)	Private caregiver (see line: 337-338)
Going to bed, and being in bed (see line:113, 325, 330)	¤	Municipality caregiver (see line: 110-113) Private caregiver	¤	¤	¤

First, the schema shows a number of contextual insights that were produced during the interview for that schema. The contextual information is the utterings that did not fit into the remainder of the schema, and it concerns subjects, such as information about the cause of injury or the interviewee's housing. Each line in the excerpt represents an activity that was explored during the interview. Not every activity explored was discussed in terms of both current and future visions, as the participants were asked to focus on activities they found especially interesting or important. If we consider the second activity in the schema, scratching an itch, the schema shows that it was discussed both in terms of how it is currently being conducted and how it could be improved or changed. The activity is currently being performed with the use of a hairbrush and with the help of a caregiver. In a future scenario, the caregiver is not needed and an exoskeleton arm uses the brush. Lastly, each item added to the schema had a number that indicated its placement in the transcript.

6.4.2. PHASE TWO

During the second round of interviews, the focus was on furthering the understanding of a set of activities extracted during the first phase. When designing the posters that were used as visual prompts during the interviews, a number of themes were identified for which the engineering staff needed more detailed information. These themes were related to the notions of time, location, current artefacts and design attributes. During the coding, further themes emerged, such as price and interfacing. The insights turned out to divide neatly into either activity-specific or more general in nature, so two such categories were created. As in the coding of the first phase, a separate category named 'contextual' was created for items that were not direct information about the conduct of the activity or the general design of the exoskeleton arm. Table (7) shows the schema that was used to code the data. As in the first phase, items entered into the schema were given a line number to indicate where they could be found.

Table 7 – Coding schema from second phase

Interview number			
Context			
Activity specific			
Time	Location	Artifacts	Attributes
General			
Price	Interface	Artefacts	Attributes

6.4.3. PHASE THREE

As in the two previous phases, the data gathered in the third phase of the project were transcribed and then coded to extract the insights produced. The schema that was created for the process of coding (see Table (8)) was based on the interview protocol that was created for the interviews, and it had five organizing themes: experience, improvements, compatibility, security and contextual. The experience theme contained utterings concerning the participants' experience during the clinical trials. The improvements theme contained any insights about how to make the arm better. The compatibility theme concerned artefacts that the participants were currently using and whether there could be any conflict with them. Security concerned the participants' perceptions of their safety while using the developed exoskeleton, and contextual concerned insights that did not fit into the other categories. As before, items added to the schema were given line numbers to indicate where they could be found.

Table 8 – Coding schema from third phase

Interview number
Experience
Improvements
Compatibility
Security
Contextual

CHAPTER 7. RESULTS

This chapter presents the results of the three iterations of user studies that were conducted. The second and third iterations built on the previous one(s), so the results are not presented with respect to the process, i.e. dividing the findings by the three phases. The results are presented in the main analytic categories, which provide a perspective on the knowledge created through the studies. The categories are main activities, context of use and implications for design.

7.1. MAIN ACTIVITIES

In the first round of interviews, the participants were asked to name as many activities as possible in their everyday lives. Then, they were asked to prioritize the ones that were especially interesting or important to them. Throughout the interviews, six activities were regularly mentioned and prioritized: eating, drinking, scratching an itch, shaving, brushing teeth and reading. It is important to note that these six activities were not the only ones mentioned during the interviews, nor were they the only ones that the participants found important. However, common to the six activities is that they were mentioned in multiple, if not all, interviews, were regularly prioritized and were discussed in terms of future improvement. Other activities of note that were not among the six were using computers, using phones, shopping, opening doors and turning on lights.

7.1.1. DRINKING

One activity that the participants kept saying was important was the act of drinking. They said that drinking happened many times a day – often at times when it would be nice not to have to stop doing something else to drink. For example, one participant stated:

'*..in the morning when I read mails then I can have a coffee and then when it becomes evening, then a glass of red wine that I can drink on my own. Especially when being with others and having a drink, then it is nice to be able to drink on my own'*.

Some participants had solutions, such as attaching a cupholder or a small table to the wheelchair so they could drink using a straw. However, the participants said this created a barrier in front of them that was disturbing.

Besides the enjoyment of being able to drink on their own and not disturbing conversations or other activities, the participants gave other reasons that being able to drink was important. Most of the participants take medicine to ensure their health, so they are advised to drink a certain amount of water each day to stay hydrated. A few of the participants noted that it was sometimes difficult to drink that much liquid, as it was a nuisance to keep asking for a glass water. The participants envisioned that this problem could be partly solved by being able to drink on their own. However, most agreed that the focus should be placed on drinking rather than pouring, as they envisioned a way in which a caretaker would not be needed to give them their drinks. Moreover, some might not feel secure pouring hot liquids, which could cause complications. One participant stated:

I mean, if I get boiling water onto me, that could be a real problem. I mean, I would not be able to feel it. I know people who sat with hot liquids and then spilt on themselves. They were hospitalized with burn wounds because it would not heal and they could not feel it.

7.1.2. EATING

Another activity that the participants prioritized very highly was eating. However, what this meant was a matter of debate during the interviews. There was a consensus that the focus should be on snacking. One participant put it this way:

"It would be very nice if I could place a bowl of candy in front of me and then take pieces myself. At night, when I sit in front of the television, if I then could take pieces, that would really give me freedom as I would not have to call for my caregiver all the time asking for a piece of liquorice."

This quotation exemplifies a common notion that snacking involved repeatedly asking a caregiver for another piece over longer periods of time. At the same time, it shows another thing that was emphasised, namely that being able to snack by oneself also allows the participant to sit by themselves for a while. Rather than just talking about candy, the participants also spoke of the possibility of eating fruit as a means of healthy snacking during the day.

Some users said that they would like to be able to eat meals on their own. Others thought that the current way of eating meals was better, and still others stated that, based on their experience of being assisted by robots at dinner, they would prefer a caregiver to feed them. As one participant stated:

I don't think you can have enough control with a knife and fork to cut a vegetable or the like. … There are a lot of complicated processes in it, to get a piece and get sauce on it, then it drips on the cloth. I think the aesthetics and quality of eating is more important than just getting it in your mouth.

7.1.3. SCRATCHING AN ITCH

The third activity emphasized by the participants was the act of scratching an itch. This activity, together with eating and drinking, came up in every interview, and it was emphasised as very important by almost all the participants. Many of them spoke about itching on the scalp, around the face and on the nose and other places that would be nice to be able to scratch. Furthermore, some participants noted that their medicine could increase the amount of itching, and it could be severely debilitating not to be able to do something about it themselves. As one person said:

Especially some areas on the scalp can be irritated. I don't know if it is the medicine or the nerves acting up, but on the scalp, it can itch somewhat crazy sometimes. And then sometimes when you lie on your side on the pillow, then you can get an area with decreased blood circulation, I think that is what makes it itch like crazy.

As seen in this quotation, rather than just around the face, participants noted the areas of the body on which they lie, the upper back and the arms as places where they would itch. It is important to note that none of the participants knew for sure that it was medicine that increased their itching, but they thought this was the case because of the correlation between changing medicines and having increased amounts of itching.

7.1.4. BRUSHING TEETH

Shaving, brushing teeth and reading were the last three prioritized activities. All three were prioritised multiple times, and they were emphasised by the people who found them important.

Several participants said that having another person brushing one's teeth could be very intimidating. Most of them had had their teeth brushed by caregivers for 10 years or more, and they were still not used to it. The participants noted that maintaining proper dental hygiene as a tetraplegic can be very difficult for various reasons. First, it is hard to ensure that the caregivers are sufficiently thorough when brushing their teeth. Also, as some of the participants found it quite uncomfortable, they tended to skip brushing altogether. A few of the participants could tell stories of other tetraplegics that had extremely bad dental hygiene and, as a result, had become ill or had issues eating properly.

7.1.5. READING

The second-to-last activity prioritized was reading magazines or books. While the participants were quite used to reading on tablets and/or on their phones, they emphasised a wish to be able to read physical media, as this had a calming quality. It was also seen as a relaxing activity that could be done autonomously if the participants could just turn the pages on their own. Lastly, most of the participants were engaged in some sort of community of common interest, such as The Danish Football Association or nature-centred communities; they noted that these communities often had physical magazines that would be sent to their members.

7.1.6. SHAVING

Lastly, the activity of shaving was emphasised as very important by some of the participants. This was stated most often by participants who had become tetraplegic relatively recently, so it was at the bottom of the list of emphasised activities. The participants who prioritized this activity noted that they used to find shaving calming, but it had become a source of conflict, as caregivers were rarely able to do it just the right way.

7.2. CONTEXT OF USE

The interviews produced a number of insights concerning contextual factors and specific areas of concern to consider. In the following sections, I present the knowledge that was attained specifically with regard to the specific contextual conditions of the participants. As in the previous section, some insights were discarded, not for being imprecise but because they lacked generality or importance to the design process at hand. These included trauma that caused the paralysis and civil status.

7.2.1. LIVING CONDITIONS

Generally, the participants continued to live where they had lived before the trauma in which they had become tetraplegic. Most had altered their housing to accommodate their new living conditions, and some had chosen to use the second floor as living quarters for their caregivers. For some participants, it was not possible to stay where they had lived before, either because they did not own that housing or because it could not feasibly be arranged for their new situation. However, regardless of whether they stayed where they used to live – all the participants were in housing that suited their needs. When a participant has had trauma because of an injury or as a result of an operation, they spend the first 6 to 12 months at a spinal cord injury institution where they take part in rehabilitation, learning about possible assistive tools at their disposal and settling into their new, and very different, lives. Most participants start with very little physical capability and spend the time at the institution developing new skills, to a point where the medical staff determine that they no longer need the constant assistance of the staff. At that point, they start to become acclimatized to living outside the institution. Some of the participants that I visited had chosen to hide the assistive tools that were installed in their homes as much as possible, such as hiding a lift behind a wooded beam. Others did not seem to care about appearance and focused on functionality. All the participants in this study had electric wheelchairs with which they interfaced in different manners. One interviewee had enough wrist control to use a joystick to drive the wheelchair around. Most participants used a chin control. This is an interfacing device that attaches to the wheelchair and sits in front of the participant's head, so the participant uses the chin to interface with the wheelchair and other technologies linked to the device. Most of the participants had little or no function in the arm, and the few who had some ability left had a tenodesis grasp. This is a way to make the hand grasp chronically in a certain manner by restraining the tendons in the forearm for an extended period. This grip would allow the participants to lift certain objects and interact with their surroundings. However, when living with tetraplegia, not using the arms and legs often tightens the tendons and muscles, so the person must have periodic injections of Botox to loosen the muscles. This also means that certain movements might cause cramps, which tighten the muscles further.

7.2.2. OWNING THE SITUATION

Part of having tetraplegia is that you must start owning your own situation. Most people with tetraplegia in Denmark are responsible for hiring and managing their own crew of caregivers. In certain circumstances, the municipality in which they reside deems them incapable of such a commitment. In some municipalities, participants can choose whether they want to take care of hiring the staff or register the work hours for each caregiver, then the municipality takes care of the ones they do not choose. However, in most municipalities, the participants are left to manage their caregivers on their own, so in a sense, becoming tetraplegic also means becoming a project manager of one's own life. A few of the participants openly talked about their fear of losing the current level of caregiving from the municipality and stated that under no circumstances would they consider using the exoskeleton arm if that was the result. One participant told a story of how every year he would have to fight for his right to have a caregiver overnight, even though the participant suffered from severe sleep apnea. This ailment is common in people with tetraplegia, and they often need assistance during the night. The participants also spoke of very long waiting periods for assistive tools, which meant that they were unlikely to even try lowering the amount of help they received, as upgrades to such a device could be very time consuming.

7.2.3. FINDING A RHYTHM

All the participants that I interviewed for this thesis had rather settled routines during the day. This was partly because of the large group of activities that needed doing every day and partly because it made it easier for the caregivers to know what to do and when. The most evident routines occurred in the morning and evening. When a person is paralysed, a lift is needed to get them out of bed. This means that the participant is often transferred directly from the bed onto their wheelchair, again onto a shower stool or perhaps onto a toilet and then back onto the chair. This process is rather time consuming and is further lengthened by the fact that the participants must be checked for bed sores, washed, clothed and so on. For most participants, their routines are needed to organise their everyday lives, but also so they can plan what else they can do during the day. Living with tetraplegia not only means that there are many things that must be done every day, but it also means that every activity uses more of the energy that is available for the given day. Therefore, the participants were quite conscious of what they decided to spend their energy doing. On a day when I visited for a couple of hours to do an interview, some participants were not able to do anything else that required more than a minimum of energy. Some required a nap to make it through the rest of the day. The amount of energy available was of course not the same for each participant and it differed across the months. One participant might have more energy during the summer when less energy was needed to keep warm or perhaps deal with rashes that come with winter and dry skin. Others might have a need for a respirator, which means that a lot of energy is expended by the mere act of breathing and talking.

7.3. IMPLICATIONS FOR DESIGN

From the findings from the three phases of enquiry, several design inputs were produced by both direct and indirect uttering about the wishes of the users. In the following sections, these findings and their implications for design requirements are presented. They are separated into aesthetic and functional implications. It is important to note that the interviewees in the study found that both aesthetics and functionality were hugely important for the solution to be acceptable to them. However, there was a general consensus that functionality was more important. Some participants pointed out that they already had a lot of technology and they did not think that adding more would make much of a difference.

7.3.1. AESTHETICS

In this section, the aesthetical wishes and utterings of the participants are presented. Aesthetics in this case concerned both visual and auditive aesthetics. They should therefore not be regarded only as the appearance of the solution, but whether they were compatible with their physical surroundings as a whole.

During the interviews, it became clear that the activities and situations that the users often wanted to improve involved being less disturbing or disruptive to their environment, a conversation or other activities like watching television. For example, one possible use for the exoskeleton solution that was discussed often was the act of snacking, which could take place in front of the television, while in conversation, or perhaps while enjoying nature in the garden. In all these situations, the level of noise that the exoskeleton produced was important, as it might negatively affect the activity that the participant is performing. In the case of the television, a loud arm might ruin the auditive experience; in a conversation, it might interrupt the person they are talking to, and in nature it might drown out the calls of birds, the wind in the trees or perhaps the babblings of a creek.

Regarding the visual design of the arm, the participants wanted the arm to be as discreet as possible. This was not just in relation to its size, but also in relation to how it moves and what the exterior looks like. Multiple participants noted that they would like an arm that moves in a natural, biological manner rather than seeming robotic. The participants described a natural movement as something that flowed, rather than happening in small intervals. For the exterior of the arm, the participants said that it would be nice if the arm looked like a normal arm as much as possible, not necessarily in its colour but rather in its shape. Wires, gears and motors should, to the extent possible, be covered up so that the arm does not stand out as something robotic, but rather as a natural extension to the body.

7.3.2. FUNCTIONALITY

All the activities that were prioritized by the participants occurred either directly in front of them, such as picking up an apple or a drink or perhaps turning a page in a magazine. They occurred in the vicinity of the face, such as eating the apple, taking a sip through a straw or scratching an itchy nose. The focus on the area around the face as a work area for the arm meant that particular attention must be paid to making the participants feel secure while using the arm and making sure that the arm did not make sudden or unnecessarily fast movements around the face. Furthermore, since the work area was the immediate vicinity of the participant, less force would be needed to manipulate the surroundings. This is because picking up an object directly in front of the person needs less power than picking up an object that is farther away or at an odd angle to the wheelchair. This work area, combined with the fact that none of the participants stated a need or an activity that required lifting anything heavier than a carton of milk or a bottle of wine, meant that the engineers had ample opportunity to focus on the size and sound of the arm rather than its power.

Furthermore, knowing more about the routines of the participants had an effect on the requirements for the solution. First and foremost, it was clear that the morning and evening routines of the participants were already quite time consuming, so the solution to be developed had to be rather easy to mount and take off. Moreover, it was evident that the caregivers employed by the participants were not likely to have technical training and that they changed relatively frequently because they got other jobs or were not a good fit for the participant. This means that the exoskeleton solution to be designed must be rather easy to fit and take off, at least to the extent that it does not require much training to do so.

Many of the participants had a lowered immune system, which means that hygiene was very important to keep them as healthy and safe as possible. Therefore, it should be possible to clean the external parts of the exoskeleton solution without needing to disassemble it very much, and it should be something that caregivers can do. Lastly, while most of the technologies that the participants used in their everyday lives could be either replaced by the exoskeleton solution or would not interfere with its use, the participants' electrical wheelchairs would remain a big part of their everyday activities and lives. Most of the activities discussed during the interviews had an intersection between the envisioned use of the arm and the functionality of the exoskeleton arm. First and foremost, the wheelchair is needed to position the participants where they can reach drinks, snacks and so on. Second, the battery of the wheelchair is the only mobile power source available to power the exoskeleton, so being compatible with the battery must be considered when designing the exoskeleton arm. Lastly, there must be some consideration of the possible adverse effects of the arm on the participants' current arrangements. While discussing the use of wheelchairs in their everyday lives, it became obvious that the amount of available power in the batteries was very important to the participants. None of the participants stated that they had issues with battery levels on a normal day, as the wheelchair would be charged every night. However, in some circumstances, for example, when on a trip, a lack of electrical charge could be an issue. Therefore, the amount of power the arm takes away from the battery must be carefully considered and lessened as much as possible.

CHAPTER 8. THE PROTOTYPE

In this section, I sketch out the impact that the insights from the interviews had on the design and development of the prototype, which is shown in Figure (6). The three main areas that were affected by the participants' wishes are circled.

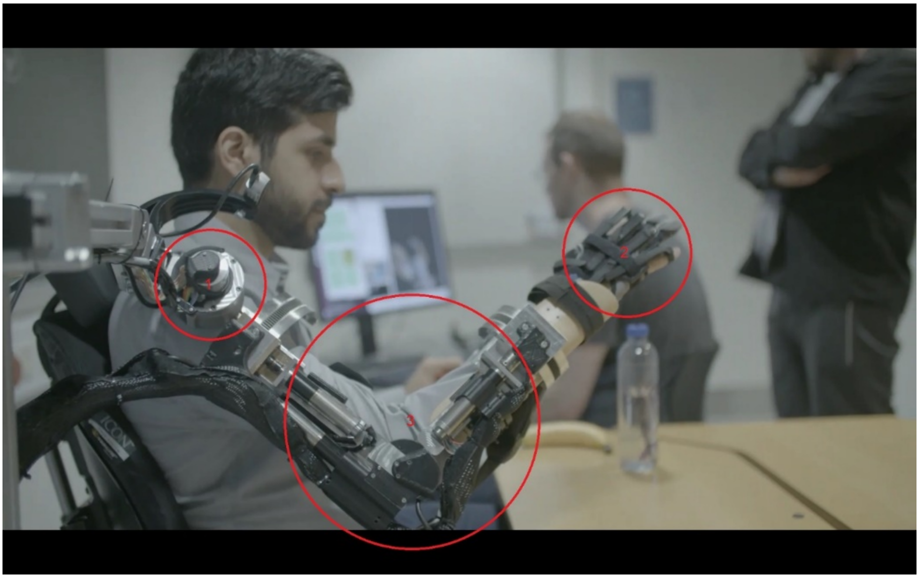

Figure 6 - The Prototype

The first aspect of the arm that was directly affected by the wishes of the participants was the actuators, especially the shoulder actuator in circle 1. Because the whole arm is attached to this joint, the actuator that moves the arm should also move the rest of the exo. This requires a strong motor. Therefore, because of the wish that the arm would not be too loud, a lot of attention was paid to making sure that the actuator provided the needed strength while still being relatively quiet. In the end, a harmonic drive was chosen to actuate the shoulder joint, which, in layman's terms, means that an expensive motor was chosen for this specific joint to comply with the users' wishes.

The second aspect influenced by the participants was the grip of the arm. The glove used for the exoskeleton arm was purchased; it was not designed in this project. However, the choice of glove, as well as some modifications, was based on the wishes

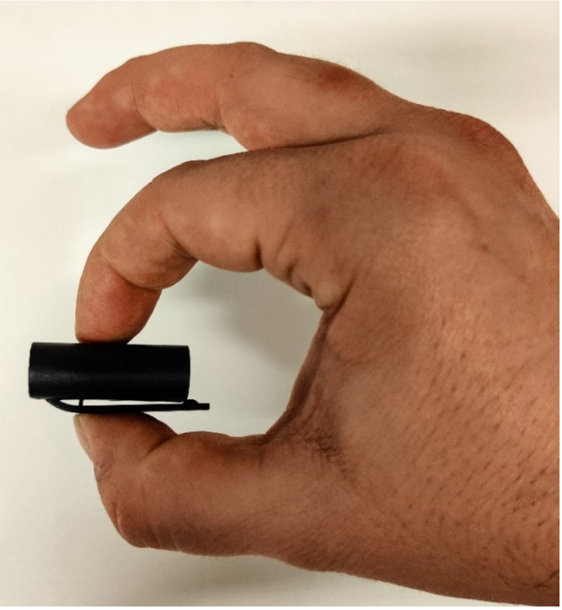

Figure 7 - Pincer Grasp

of the participants. To eat snacks, one must be able to pick up small items. To do this requires what is called a pincer grasp, as seen in Figure (7). To do a pincer grasp, the fingers must open and close individually. However, most gloves did not do this. The glove that was purchased could close fingers individually but not open them one at a time. Therefore, it was modified by placing elastic in its plastic rails. This pulled on the fingers so that they would close only when the glove was actively pulling the fingers together.

The third and fourth aspects that were influenced by the wishes of the participants were the size, adaptability and shape of the exoskeleton. During the planning for the exoskeleton, different designs were discussed in terms of their feasibility, the scope of the project and the participants' expressed wishes. The final design was sleek, and it did not protrude too far from the participant's arm. Further, the exoskeleton arm was designed to cover the least amount of the arm while supporting the participant's arm enough that it did not fall out or become unnecessarily stressed. The exoskeleton arm was designed in such a way that the participant's arm rests in a brace that can be custom-made to each participant. This, as well as the ability to adapt the length of the exoskeleton arm, ensures that the solution fits any future user who wants to use it. When the exoskeleton arm is to be mounted, the participant's arm is moved into the brace to rest comfortably. Then, two straps ensure that the arm does not move out of the brace. This simple solution for attaching the arm requires little to no technical knowledge. The only challenge in attaching the exoskeleton might be the glove, which can be difficult to mount. Therefore, this is a priority for the next stages of the project.

CHAPTER 9. DISCUSSION

This chapter reflects on the findings of the study. It is divided into four smaller discussions. The first evaluates the insights and implications for the prototype. The second concerns the design process. The third concerns how it was to work with the participants, and the fourth concerns the limitations of this study.

9.1. EVALUATION

In the last round of interviews, the participants were asked about different aspects of the arm and whether they felt that the prototype was in line with their expressed wishes. The following are based on the questions posed during the interviews and the utterings of the participants during the clinical trials.

A major focus of the participants was the sound of the exoskeleton arm. Therefore, the engineers included this in their criteria while shopping for actuators. After having tried the arm, there was a consensus that the level of noise from the arm was acceptable for the ways that the participants would use it. One participant stated that while the arm should be quiet, it should not be silent. This, he stated, is because many tetraplegics use sound as an indicator for when a lift is moving, whether the wheelchair is moving and how fast. This is especially relevant if the severity of tetraplegia does not allow future users to move their heads around on their own. While the participants found the level of sound acceptable, it must be noted that the clinical trials took place in a health clinic with at least three people in the room at any given time, often more. The environment of the participants' houses might have distinctly different levels of background noise. Furthermore, because of the clinical setting of the trials, the participants did not use the arm while watching television or having a relaxed conversation, perhaps even with music playing in the background. To ensure that the level of noise was acceptable in the actual context of use, further trials would have to be conducted in settings that approximate the everyday experience of the users.

During the clinical trials, the participants were asked to conduct a number of activities that were mentioned during the interviews. For instance, the participants would lift a bottle with a straw to a position where they could drink from it. They would lift a plastic strawberry from the table and move it to their mouth to simulate the eating of snacks. They would grab a scratching stick and use it to scratch the side of their head. Finally, they would toggle a light switch that was set in front of them. These activities, except for toggling the switch, were all activities for which the arm had been designed based on a previous understanding of ADLs. However, they were also based on the interviews. Therefore, in the evaluative interview, the participants were asked again about their activities, whether other important activities had been missed and whether the arm carried out the activity at an acceptable level of speed and control. Generally, the participants stated that they were happy with the activities that the arm was designed for and that they did not think that others had been overlooked.

As part of the trials, different modes of interaction with the technology were tested, including the following aspects:

- The participants had full control of the exoskeleton arm and could conduct each movement on their own.
- The exoskeleton arm was controlled semi-autonomously, such that the arm would evaluate an interactable object and support the participant by adjusting itself to ensure a good grip.
- The exoskeleton arm would function autonomously, meaning that the participant would indicate his or her intended action and then just hold down an automation button. The arm would then move to the correct position and grab the object.

During the evaluative interviews, the participants stated that the mode in which the arm was set affected not only how it felt to carry out the activities but also how secure the participant felt performing the activity and how ‘good’ that felt. In general, the participants favoured semi-autonomous control, as this allowed them to feel in control of the movements of the arm even as it dramatically increased the speed of performing the activity. All the participants who were interviewed during the clinical trials stated that they never felt insecure about the arm. This was partly because it would never move unless they directly interacted with it, but also because it did not move too quickly and it generally moved fluently. While these findings were interesting and provided some justification for the resources that had been allocated to making the participants feel secure and in control and to the general feel of the movements produced by the arm, it should be stated that none of the participants in the clinical trials had been part of the three rounds of interviews conducted earlier. Therefore, it was not possible to ask whether the solution actually lived up to the expectations that the participants had expressed in those interviews. Finally, as part of evaluating the solution during the clinical trials, the caregivers who assisted the participants were asked to help with mounting and dismounting the exoskeleton arm. Both the caregivers and participants stated that the mounting process was rather simple and could be done in an acceptable amount of time. This was the case even though they were required to wear multiple rubber sleeves and gloves because of concerns about COVID-19 and security.

9.2. THE DESIGN PROCESS

As stated previously, the study was divided into three phases that were linked to one or more levels of abstraction from the HAM. The first phase primarily concerned the motivational level of abstraction: *the why*. The second phase primarily concerned the instrumental aspect of abstraction: *the what.* Finally, the third and evaluative phase of the project primarily concerned the operational level of abstraction: *the how*. Using the activity hierarchy as a guide to understand and direct attention towards a specific level of granularity really helped not only in organizing the collection of data, but it also helped enormously in the dissection of the data afterwards. Since I had been trained in and used a thematic analysis model for coding data throughout the project, the levels of abstraction correlated quite neatly with the global, organizing and basic themes of the mode of analysis employed (Braun & Clarke, 2006). This made it very easy to organize the coded data intuitively during the different phases of the analysis. Similarly, basing the design games for the first and second phases of the study on the levels of abstraction really helped focus the games on what made sense to discuss in the individual phases. For example, during the first phase, which focused on the motivational level, the game was designed to create a common understanding of what constitutes an activity today and how it could be improved in the future. The focus on creating a vision for a better future was paramount to enabling the participants to consider activities that they found important. The focus on personal motivation rather than survivability, which is the case with ADLs, further allowed the users to contemplate possibilities on an emotional level. This supported the notion of focusing on activities that were truly important to them, rather than activities that they might have expected to be part of the design or activities that were the concern of previous researchers. One example of such an activity that came from the focus on motivation was shaving. That activity was not explicitly designed for (that was far too difficult because of security concerns). However, the focus on a future vision and motivation as distinctive parameters for choosing activities meant that even though the participants knew that something might not be feasible or that it was relevant to only about half the participants, it was still discussed. Furthermore, knowledge about the motivation for this activity was useful in the design in general.

During the second phase of the study, the focus on the operational level of the activities meant that the design games could get more in-depth information about what the activities actually were and how they were carried out. This revealed knowledge about the settings in which the participants wanted to snack and drink, and it thereby cemented the requirement about the sound of the system. Further, the focus on the timeline for activities yielded greater understanding of the participants’ morning routines and how the arm had to fit into them. It was partly because of this focus that an understanding was reached about the speed at which the exo should be mountable and the ease with which it could be mounted and dismounted.

An interesting side effect from the emphasis on the levels of abstraction, especially during the first phase of the study, in which motivation was the focus, was that it made it easier to create a third space to enable the participants to take part and discuss the different aspects of exoskeleton design indirectly. Focusing on and emphasising their areas of expertise – their lives, how the daily activities of a tetraplegic unfold, and their aspirations and motivations for a better life –really engaged the participants. They became active partners in the design of the exoskeleton. One can wonder whether basing the design games on scenarios alone would have created this effect. I would argue that the focus on motivation and directing the attention towards a future vision put the spotlight on activities that the participants found annoying, inspiring or interesting. This really engaged them in the design process and made the conversations that occurred while playing the games very natural and 'easy'.

Besides the hierarchical understanding of activities that the HAM involves, it also includes a high focus on the relationship between artefacts and humans. The notion of actively involving artefacts in how activities are carried out and allowing the participants to contemplate how they use technology in their daily lives really helped situate the proposed exoskeleton design into the artefact ecology that exists at the homes of the users. Whilst a main focus was not to elaborate on the role of users' current artefacts, other than for example the wheelchair that was naturally in focus through quite a bit of the study, the inclusion of any and all artefacts that were used or could be used to conduct daily activities really helped with identifying priorities. It also helped to avoid activities in which other artefacts might be of more use or where the arm might conflict with artefacts used by the participants. To elaborate on an example that shows this, during the first design game, quite a few participants created an activity card for turning on lights. They agreed that the activity was very important and being able to turn lights on and off would allow them to enter and exit rooms unassisted, easing the need for caregiving. However, when looking at the activity and the technologies already involved or could be involved to do this, it quickly became evident that spending a lot of resources getting the arm to push light switches would not be a desirable. Most of the participants already used some sort of voice-based assistant, such as Alexa and Siri, in their daily lives, and those who did not were in the process of researching the possibilities or had gotten one that had not been set up. With modern light bulbs and voice assistants, there is no longer a need to interface physically with something like a switch. Therefore, that activity was not prioritised by any participant. This further exemplifies the statements of Graham Pullin (2009) that changes in environments and society make disabilities contextual. If this study had been carried out just five years earlier, pressing buttons might have been the most highly prioritized activity

9.3. THE PARTICIPANTS

Working with participants who live with tetraplegia has offered both opportunities and limitations that should be considered when designing a study involving participants with highly unusual characteristics. First, when working with participants who have any physical or cognitive disability, it is very important to be aware that a person is not their diagnosis. Instead, they are people who live and deal with their diagnoses in their own unique way. This notion of focusing on the person rather than the disability is described earlier in the thesis, and it was very important to me from the beginning of the study. Throughout the phases, this notion has proven very useful for attaining insights that are firmly situated in the context of use. Furthermore, focusing on how the challenges that users face are dealt with and overcome, rather than focusing on the challenges themselves, has implications for designing products that actually address the lives of users, be that good or bad. Furthermore, throughout this study, it has become quite evident that to understand the lives of the participants, it is paramount to situate oneself in their context and surroundings. In this study, an exoskeleton arm was built that participants could use every day. Therefore, a choice was made to go to the homes of the users, both to observe the space and technologies where the solution must work, but also to help the participants situate the conversation about the design in their own contexts and everyday routines. The choice to conduct the first two phases of enquiry at the users' homes had another very important effect. As stated in the results, the participants often had a limited amount of energy to work with each day. A comment that I often got at the end of my interviews was that the participants had become tired and that it was tough spending so much energy thinking, moving and talking for an extended period of time. This became even clearer during the clinical trials, in which two participants needed a respiratory system to help them breathe. The interviews conducted in relation to the trials were held at the end of the third and last day. This meant that the participants were completely spent and did not have sufficient energy to conduct long, in-depth interviews. Therefore, most of the interviews lasted 15 minutes or less. During the first two phases of interviews, taking fatigue into account had been firmly established, so the evaluative interviews were designed to be very focused and short, a clear suggestion for future studies involving participants living with tetraplegia.

In the works related to this thesis, a number of calls were made about what should be considered and what more must be learned to design acceptable exoskeleton solutions. Two of the calls were based on the need to understand not only how a solution alters a person's activities, but also how the users of the solution view themselves, their lives and their contexts (Louise-Bender et al., 2002). It also involves acknowledging that the solution could induce stigma (Brown-Triolo et al., 2002). Throughout the study, this focus was taken quite seriously, as we had a preconception that an exoskeleton arm might induce a feeling of stigma when worn. In the study, the participants stated that they did not envision that the arm could induce such stigma, yet they insisted that the arm should be made as unnoticeable as possible by reducing its size and sound and whether its movement seems robotic. In addition, it should be stated that all the participants we recruited for this study were very active and generally felt very comfortable with themselves and their lives. While this might be the case for some people living with tetraplegia, the stories of those others who were not so comfortably settled in their situation were manyfold. The fact that we could recruit such participants means that even in a Danish context, that insight might be described as somewhat contextual.

Lastly, during the interviews, seeing how the participants viewed their own lives and how they dealt with situations and challenges with the help of caregivers and technologies revealed something important. It is not enough to understand only the participants. Caregivers, too, must be considered. They are the ones who perform many daily tasks and are therefore the main competency in solving many issues. This leads to the limitations of the study.

9.4. LIMITATIONS

During the study, a couple of limitations came up, and they are treated in the following sections. It is important to note that they were both identified early in the process. For the first one, a choice was made, and the second limitation occurred naturally.

The first limitation that is important to state for this study is the limited scope of including only future users as participants. The hard work to recruit and engage the primary user was a priority, and it yielded deep insights into the primary target group. However, insight into secondary users who form an important role in the use context was limited. This narrowed scope means that little attention has been paid to health professionals, as it was deemed that they were already represented in the use of ADLs as a point of departure. It is also the case that health professionals have generally been overrepresented in previous studies, leading to the wish that this thesis could focus on giving voice to the actual users. Another stakeholder that was purposefully kept out of the study was the municipalities. If stakeholders were to be rated based on their importance for a commercial product, in Denmark the municipalities would go right near the top, as it is the municipalities that provide the assistive technologies that the participants employ. Therefore, they have become gatekeepers for any successful solution. However, as this project deals in an exploratory and early stage of exoskeleton development, it was decided that it would be most prudent to focus on the wishes of the users before considering what the municipalities would pay for. Throughout the study, this choice has been challenged as insights into a troubled relationship between the users and the municipalities have emerged. To further understand this relationship and how it would affect a possible commercial product, the municipalities would naturally have to be included as stakeholders. Finally, the participants' caregivers were not included directly in the design of this study. This was done to allow the participants to talk more freely if the caregivers were not directly included in the design games and interviews. During the interviews, however, the caregivers were often present to assist the participants, and the participants often included the caregivers in playing the games.

The second limitation of the study concerns the evaluation of the solution that was developed. When interviewing the participants for the study, future scenarios and technologies were imagined, and throughout the games, the participants were asked not to focus on technological limitations, but rather on their dreams and aspirations for the solution. This naturally means that not everything that came up during the interviews could be manifested in the prototype – it is a prototype after all. In previous sections of the thesis, I have presented how a focus was placed on the sound of the exoskeleton arm, its movement and the workspace within which the arm functions.

Other aspects, such as the look of the arm, were simply out of scope because of the time available, the cost of developing the prototype and the human resources available for the project. Therefore, the evaluation of the project focused on a very small number of aspects of the arm. However, the participants still commented on the appearance of the arm, though under the guise that it would look different after further development. Although this was a limitation of how many of the insights produced could be traced to the final design of the prototype, it was a necessary limitation. Its nature was often negotiated, and its elements were carefully chosen based on the available resources.

CHAPTER 10. CONCLUSION

In this chapter, the findings made throughout the thesis are discussed. The chapter is divided into three sections, each representing one of the research questions stated at the beginning of the thesis. They focused on how participants could be included in a way that allowed for informed contributions to the exoskeleton design, how understandings of use can have a meaningful impact on the design of an exoskeleton solution and what lessons were learned about involving participants with tetraplegia in a participatory design process.

The first section concludes by attending to the ambition of creating a third space. The second section concludes with the contributions of the theoretical frameworks to methods that use the levels of abstraction and how this helped make the findings actionable. The third section concludes with experiences and recommendations for future studies aimed at facilitating participation in technology design by people with severe paralysis.

10.1. CREATING A THIRD SPACE

In the beginning stages of the research for this thesis, a scoping review was conducted on literature relating to the user-centred and participatory design of assistive exoskeleton solutions. While some studies involved users in some capacity, most of the projects relied on health professionals and physiotherapists to figure out how to design solutions to accommodate the users of their exoskeletons. I make no claims that including health professionals does not give useful insights for exoskeleton designs. However, I do claim that it inevitably puts a focus on designing for a diagnosis rather than on the actual people who live with the diagnosis and who will use the exoskeleton. In this thesis, the focus was on understanding the future users of the solution that was to be designed as well as understanding their lives and the activities that they carry out during a normal day. The aim was to give users the opportunity to be partners in the process and feel the success of their input. However, several obstacles had to be overcome. The largest obstacle was the complexity of designing robotics. While the participants are certainly experts when it comes to their own lives and contexts, one cannot assume that they have the necessary know-how to engage in discussions about power moments, torque calculations for actuation, and so on. To bridge the gap between the knowledge domains of the users and the technical experts, a choice was made to create a third space between those domains. There, the knowledge of the users could be leveraged for actual design inputs for the engineers. To give the participants agency to be involved in the design, it was decided that scenario-based design games would be created in an attempt to ground the design inputs of the participants in their own lives. Then, through discussion and exploration, the very activities that they found important were identified.

Using the design games proved useful as they eased the engagement of the users and ensured that their insights were focused. Dividing the first design game into two rounds and exploring the activities both as they are currently conducted and as future visions ensured an understanding of the current challenges that the participants face, as well as how they envision how the arm could address their challenges and contribute to the artefact ecologies of the users. Finally, exploring the activities through the lens of the participants' own lives allowed for an understanding and elaboration of the motivation behind the different activities and why the participants engaged in said activities. However, it also revealed the reasoning behind using current technologies and why one activity might be prioritised over another.

10.2. UNDERSTANDING THE CONTEXT

One of the main findings from the work for this thesis was that participants prioritised six activities in which they hoped the exoskeleton arm could have a positive impact: eating, drinking, scratching an itch, reading, shaving and brushing teeth. While the activities in themselves are interesting as a departure point for exoskeleton design, it is the deeper understanding of the activities themselves, the motivation behind the prioritization and the contexts that really contribute to an increased understanding of what should be designed for.

The findings presented in this thesis show that the common understanding of eating – eating lunch or dinner – does not comport with the wishes of the users. Rather, when they spoke of eating, activities such as snacking were prioritized very highly. In general, the participants emphasised activities that occurred over an extended period of time or in which the participant had to continuously ask the caregiver for something. In terms of snacking, in one example, the participant wanted to eat liquorice in front of the television at night. In that scenario, the participant would have to ask repeatedly for more pieces, interrupting the movie and requiring the caregiver to be present all the time. The participant emphasised that adding an exoskeleton arm to this scenario would allow him to eat independently, giving him the option to watch the television alone. Another example of the importance of context for understanding an activity involved drinking. While the participants wanted to be able to drink water on their own, they focused more on drinking liquids such as coffee and wine. In both cases, they wanted to be sure that nothing was spilt, especially with a person who could not feel burned by the coffee. That could be quite dangerous. Besides making it safe to drink liquids, both coffee and wine were examples of drinks that were had in social settings, and this imposes other concerns that must be addressed. With drinking and eating snacks in front of the television, the amount of noise from the arm was very important in making it useful for the participants. If it is too noisy, they might not hear the television or the person with whom they are speaking.

The understanding of context in the study was supported by the use of the HAM, both in terms of understanding the activities that were explored on different levels of granularity, but also because of the emphasis that the model places on understanding artefact ecologies. The findings about specific eating-related activities and how the context of an activity in terms of time and place are as important as the activity itself came directly from working with the activities at different levels. During the first round of design games, in which the motivational aspects were the primary focus, it was uncovered that the motivation for prioritizing eating was that of eating snacks, leading to the requirement of a pincer grasp. During the second iteration of the design games, activities were further explored in terms of their operational aspects. It was found that the instances in which the participants envisioned snacking included being in front of the television or in the company of other people. This led to the requirement that special attention should be paid to the noise that the arm produces. Finally, during the last iteration of user studies, in which the arm was evaluated and the participants were observed using the prototype, the requirement concerning sound was further nuanced when participants noted that the sound of the arm moving helped them interface with it. Because of the sound, they could tell how the arm was moving.

Understanding the artefact ecologies of the users and how a proposed future design could fit into said ecology were shown to be quite important in the thesis. First and foremost, understanding what artefacts play a role in the different activities and how the introduction changes those dynamics allowed activities to be prioritized not only in terms of which ones would be nice to change but also which activities could actually be changed for the better. One activity that was given lower priority as a result of understanding the artefact ecology was turning lights on and off. After discussions about the other technologies that the participants used or could use, this activity was seen as less important. Other ways to surmount this challenge were available in terms of virtual assistants like Siri and Alexa. Further, understanding the artefact ecologies of the participants helped to understand what other artefacts the arm could be compatible with. This understanding helped solve a problem that persisted in the early stages of the project, namely, how to power the exoskeleton. With a deeper understanding of the participants' electric wheelchairs, it was deemed that the wheelchair battery could be a viable option for powering the arm, making it weigh less and increasing its mobility.

10.3. LIVING WITH A DIAGNOSIS

Working closely with the participants and learning about their lives, their motivations and how they overcome their daily challenges yielded a lot of findings that contradicted my initial assumptions. Before ever going to a house and meeting a participant, I conducted research on tetraplegia and I had conversations with the professionals of the clinic who were partners of the project. Throughout this process, an understanding of what tetraplegia is and what challenges it creates for people who have it was uncovered, as were the causes and adverse effects that it might have.

However, the first time I stepped into a participant's house and heard his story, most of my assumptions about how one deals with tetraplegia changed. When researching tetraplegia, all one hears about are the challenges it creates, the costs it can have and how symptoms are clinically treated. You hear and read all the things that clinicians, doctors and physicians work with in their professional capacities. In other words, you hear nothing about the actual people, what they feel and what they dream about. What was immediately evident at that first visit was that the participants with whom I was about to collaborate found their own ways of overcoming their challenges. Furthermore, and contrary to my assumptions, mostly did not consider them challenges. They were just the facts of life. I had assumed, based on my research, that almost all their time and energy were spent overcoming the effects of tetraplegia, but that was far from the truth. The participants had very fulfilling lives in which they spent time with their families, volunteered in different communities relevant to their interests and generally focused on spending their time on things that really added quality to their lives. This is not to say that being tetraplegic does not pose challenges to one's daily life. The participants spent much more time than an average person on things such as getting out of bed, taking showers, eating and so on, but this just means that what they do with the rest of their time is prioritized differently. Before it spoke with the participants, I assumed that they would like to have an exoskeleton arm to help make mundane tasks easier and ensure that things like eating and drinking would become less taxing. However, I found that they were fine with these activities. Even though they took time, the participants were accustomed to that. Sometimes, they even appreciated the routines. What they really wanted to do were things that were impossible for them now. They wanted to be able to sit alone at night in their own company while snacking and not caring whether the caregiver thought they were being greedy. They wanted to be able to have a conversation without interrupting it if they got thirsty, and they wanted to be able to scratch their noses if they started to itch without having to ask for help. In other words, where I was initially focused on efficiency, they were focused on quality of life. This might not sound like much of a finding. Quality of life is not a new thing in research by any means. However, this finding lies at the very base of all the other findings that were made during this study, and it shows that while quality of life was also the main priority for me, my assumptions did not allow me to understand exactly what that meant. As soon as I heard that the participants wanted to eat, I immediately thought of knives and forks. However, when I understood their motivations for eating and the context of the activity, it was clear that something entirely different was needed. These are the contributions that I offer and the recommendations that I pass on to any researcher who wants to work with people whose lives are radically different from their own. Be that because of different cultural, physical or perhaps mental conditions, they should set themselves and their assumptions aside and allow for an entirely different set of values, dreams and ideas to guide their research.

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