Human-Centered Design for Hemiparesis

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Abstract: Disability was a difficult topic decades ago but in modern society where people want to make everybody feel included in all life aspects and provide all opportunities for each other. Our research group is people with paralysis. Their participation and empowerment in society are described. Social challenges for disabled people and caregivers are discussed.
Our case owner is partially paralysed in his left arm and leg. He has a type of paralysis which is called hemiparesis. It is recommended to implement Assistive technology in their daily life. AT is any object, system or software that is used to increase, maintain, or improve the functional capabilities of persons with disabilities. In this context, technology abandonment and appropriation were explored to better understand how a product can be accepted, used and not rejected by users. In this project we use Human centred design as a design strategy, to find a product that can help our case owner. The goal is to work closely with the case owner to make a product that fills his needs. Exploring already existing products and solutions and doing market research it was found out there are many variations of solutions for the problem. Co-design is combining lived experience and professional expertise in the design process of a product or service. It requires working closely with users, and better understanding their needs, wants and insights. The design challenge stated as follows: "How might we help our co-designer with more mobility in his arm/hand?"

Keywords: Assistive technology, Hemiplegia paralysis, Human-centered design, Co-design, ischemic stroke, Disabilities, Physical impairments

1. Introduction

This context mapping study has been done to better understand and form a guideline for the design process with a co-designer. This way the best possible end result can be achieved for the co-designer. More knowledge is gained during interviews with the co-designer about his personal situation and other research is based on existing knowledge.

2. Literature Study

Social trends and the changing perspectives on disability

For humans, it was always typical to form groups and have collective behaviour among individuals who are "like them" (Liu et al., 2018). For this reason, there could be challenges in interaction and perception between disabled and abled people. When social life is discussed, the limitation of everyday activities brought on by functional limitations has a detrimental impact on community participation. (Akyurek & Bumin, 2017). Nevertheless, with technological and educational development, stereotypes in society are decreasing, and disability is perceived differently compared with decades ago. However, modern society tends to be inclusive i.e., everybody can have equal access to the resources and opportunities in the community despite their disabilities. For example, cities are upgrading their city facilities to ease movement for people with impairments, or

technologies are improving with the help of co-designers, so there are fewer challenges on a daily basis for people.
The reduction of muscular function in a segment of the body is known as paralysis. People with this diagnosis are our study group. It occurs when there is a problem in the transmission of signals between the brain and muscles. There are several levels of paralysis: complete and incomplete. That could happen on one or both of the body's sides. It may either be localised or broad, depending on the situation. Paraplegia is the medical term for paralysis of the lower body, which includes both legs. Quadriplegia is when the arms and legs are paralyzed. Hemiplegia is when only one side of the body is affected. The majority of paralysis cases result from strokes or accidents such as broken necks or spinal cord injury. (U.S. National Library of Medicine, 2016).
People with this diagnosis have struggled with taking care of themself depending on how strongly the body is affected, so a part of disabled people have a caretaker. Most households with a person with paralysis have a low income because statistically 41.8 % of people with paralysis are indicated as unable to work, and just 15.5% of people with the diagnosis are employed. (Cristopher & Dana Reeve Foundation, n.d), so in most cases, the caregivers are family members.
The biggest social challenge when it comes to caregivers is that they suffer more frequently from depression, stress and anxiety than the general population. Most of their free time is spent giving care to another person, so it can be a reason why such people feel excluded from society. According to statistical reports, 70% of caregivers struggle with depression and 51% with sleeplessness. (Cristopher & Dana Reeve Foundation, n.d). For this reason, appropriate and effective use of social skills is essential for people with disabilities in order to solve their problems and strengthen social support and connection with the caregiver. (Müller et al., 2013).

Introduction to Assistive Technologies

Assistive technology (AT) is described by AITA (Assistive Technology Industry Association) as "any item, piece of equipment, software program, or product system that is used to increase, maintain, or improve the functional capabilities of persons with disabilities." Assistive technology enables people to live a healthy, productive, independent and dignified life in all aspects from education and work to societal inclusion.
AT can come in various forms, from low to high tech, hardware, software, general and or specialised. These technologies help people with not only physical but also cognitive and mental disabilities. Each of these varied in their type, severity and context require different assistive technologies. Some examples of assistive technology include hearing aids, spectacles, wheelchairs, prostheses, memory aids and much more.
According to the world health organisation (WHO) more than a billion people globally, need at least one assistive product and this number is expected to rise to two billion by the year 2030 due to an ageing global population. However, currently only one in ten people in need of AT have access to it. This low level of access is due to high costs, lack of awareness, availability, trained personnel, policy, and financing.
To better ensure a successful product that will be used, it is important to understand technology abandonment and technology appropriation. This can then be used in the design process to approximately predict if the AT will be used and what changes could be made to better improve it.
Technology abandonment for assistive technologies is a concern, for example, studies have shown that hearing aids have an abandonment rate of up to 78%. The causes of abandonment have multiple variables to take into account. The first cause being an improper fit to the user, if the physical dimension does not match to the specific user it makes it uncomfortable for long-term use. This greatly increases chances of abandonment even if the AT performs the required task. The next cause is if the AT is an improper fit to

the needs of the user, such as not enabling the performance of desired tasks easily.
Some research suggests that the greatest predictor of technology abandonment being changes in the needs of the user. These changes can be "permanent (e.g., a progressively worsening sight condition, such as macular degeneration), temporary (e.g., an increased tremor in Parkinson's disease which can be addressed with altered medication) or fluctuating (e.g., increased problems with spelling by people with dyslexia when tired or stressed)." To address this, ATs can be designed with adjustments so as to allow changes to the user's specific needs and context. However, with improper design can lead to difficulty in making these adjustments and ultimately lead to technology abandonment. Another type of abandonment can be positive, in that the user is no longer in need of the product or switching to another more innovative solution.
Technology appropriation is when users adapt and adopt technology in ways not initially thought of by the designers, be it unintentional to deliberately deviating from the designer's intentions. This can be viewed as an important sign of technological acceptance. Appropriation can happen if there is no existing/available tool for the user's task. This can have benefits to the use of the product and avoid its abandonment. These come in diversifying context and environment of use, the users themselves and gives them a greater sense of ownership. According to Alan Dix, "You may not be able to design for the unexpected, but you can design to allow the unexpected." This creates a greater chance of appropriation and less risk of abandonment. Designing for appropriation can be assisted by using the following principles:

Allow interpretation: Allowing some aspects of the design/system to be interpreted differently by users. Not everything has to have a fixed meaning.
Provide visibility: Make the function of the product/system obvious so users will likely know outcomes of actions and do what they like.
Expose intentions: Exposing the intention of the design can have people willingly comply but can also elicit people to deliberately go against it and appropriate it for another purpose.
Support not control: Do not fixate the product/system to achieve a single task but rather assist the user in completing it. Provide functions to complete the task but do not guide the user through all the steps.
Pluggability and configuration: Allow users to change the structure of the product/system in different ways.
Encourage sharing: Allow users to communicate with other ways in which they have appropriated the product/system.
Learn from appropriation: Observing the appropriation can give insights into possible redesigns to better support newly discovered uses.

Human Centered Design

Human-Centered Design (HCD) is important because you design products that people can understand and want to use. Rather than a product that just looks nice and is overly complex and therefore nobody will use it. According to Don Norman, Human-centered design has 4 fundamentals:

1. Designers should solve the core issue, not just the problem the client gave them.
2. Designers should focus on the people they design for (and the people that are involved in the target group's lives)
3. Designers should focus on the system the problem is in, not just the one component with the problem.
4. Designers should test their product multiple times during the process, so the client's needs get fulfilled to the fullest. (Norman, 2019)

This process is a lot of trial and error, a lot of ideas and prototypes are made to get the perfect design. The ideas and prototypes come forward by observing the target group and asking them what they do like and do not like about the prototype you just made. (Design kit). Keeping these ideas in mind, we will use them for our own project. We first have some interviews with the case owner to see what his needs are. The interviews consist of some general questions, like "how are you and what do you do in life" and some more in dept questions, like "how did he get the insures and what does he want to see we try to solve". When we know the case owner, now the co-designer, a little bit better we plan to have a brainstorm with him so that we know what kind of ideas he likes and dislikes. This makes sure we design something that fits his needs. After that, we start ideating and prototyping by ourselves but keeping the co-designer up-to-date. We plan to have a bi-weekly meeting with him so we can see if the prototypes work and what we should change.

Theoretical introduction to the disability/condition of your 'specific user'

The case person has paralysis of the left side of the body. "Loss of strength in the arm, leg, and sometimes face on one side of the body. Hemiplegia refers to a severe or complete loss of strength, whereas hemiparesis refers to a relatively mild loss of strength." (U.S. National Library of Medicine, n.d). According to the definition and our observations during the interview, it was concluded that the diagnosis is hemiparesis.
During conversation, it was observed:

1. The whole left side is paralysed including facial nerves (not visible).
2. No ability to actively move the left hand while walking.
3. No ability to actively use the left leg while walking, it follows the leading right leg.
4. Weak movements of the left arm and the left leg: the lower arm is paralysed.
5. Ability to grab objects tense enough to hold them, but there are difficulties in the extension of the hand.
6. Ability to raise the left arm to 60 degrees but experience strong fatigue after.
7. The left leg is partially functional: knee muscles are slightly active, hip muscles are slightly active, and feet muscles are slightly active.
8. Ability to sense object (a light feeling)

Usually, it can be caused by stroke, multiple sclerosis, spinal cord injury, cerebral palsy etc. In the case of our co-designer, ischemic stroke was the cause: stroke appeared due to a decrease in blood flow to a certain area of the brain. (American Stroke Association, 2023). Additionally, the co-designer was in a car accident, causing a decrease in mobility of his right shoulder due to a ruptured tendon. It makes him feel pain while moving his right arm, but he is still able to adduct his right arm up to 90 degrees. The person takes all required medicines, including permanent painkillers to reduce pain. Implications to keep in mind during the design process could be the pain and stress on his right shoulder, reduced balance, low shoulder, leg, and finger mobility.
The people with this diagnosis struggle with daily living activities. Most activities become more complicated to perform when one side of the body is paralyzed. On a daily basis, people can have difficulties in such activities:

1. Activities with the use of both hands: cutting food, grooming, toileting, bathing, dressing, and keyboarding.
2. Activities with the use of the dominant hand and arm if that body side is involved: eating, brushing teeth, combing hair.
3. Activities with the use of both hands and arms: meal preparation, laundry, cleaning, opening mail, driving, pushing a shopping cart, and paying with cash or credit/debit card.
4. Activities with the use of the dominant hand if that hand is involved: writing, using a key to open a door, and pushing buttons on a remote.

Additionally, people can find it challenging to engage in things they used to like due to changes in their sensorimotor, cognitive, or psychosocial abilities. From the sensorimotor aspect, People can experience that one side of the body, or one upper extremity could be lost or become less functional. Due to subluxation, abnormal muscle tone, restrictions in shoulder range of motion, capsular contractures, adhesive capsulitis, rotator cuff ear, brachial plexus injury, shoulder-hand syndrome, or pre-existing conditions, a person can suffer from shoulder pain during shoulder movement in flexion and abduction. The scapula of the person can retract and rotate downward, internal rotate and provide arm adduction, elbow flexion, and the minimal movement of the wrist and fingers or absence of it. When speaking about cognitive functions, people can lose or feel a cognitive decline in attention, learning, memory, and executive functioning. Different problems in life supported by daily difficulties can lead to depression and anxiety. (Reed, 2014)

Market research on existing products

Hand devices: There is a big variety of products on the market that help people who suffered a stroke. Some examples are robotic gloves that help train the muscles and assist a person with basic hand movements. Some of these gloves are very well designed and even include an application in which progress can be tracked (NEOFECT's RAPAEL Smart Glove).

Figure 1: NEOFECT's RAPAEL Smart Glove

Figure 2: Leg Patches

Figure 3: Exoskeleton

Other devices that are merely used for everyday life are still in development. However, there is a company called Emovocare who have a simpler and everyday use design of this idea. This device can successfully open and close the hand of a user and is designed to fit an individual. Fine motor skills, muscle strength, range of motion, coordination, and spasticity are some aspects that we can focus on.

Physical therapy: Another option to help recover from the paralysis is to use electrical stimulation. This is done by placing electrodes over the muscles that need to be stimulated. Ultimately this process imitates the process of nerve input and will help to move the muscles. A device used for this therapy is a handheld device with patches which can be placed on the patient. (Figure 2).

These forms of electrodes can put an input to contract muscles; however, our co-designer has trouble relaxing and extending his muscles in his hand. Therefore, electrical stimulation is not a good solution to help the co-designer.

Robotic arms: In our day and age, robotic arms are getting more and more advanced. As of May 28th an article was released by Wired about a robotic arm which is controlled by the brain (This Brain-Controlled Robotic Arm Can Twist, Grasp—and Feel, Max G. Levy). In this article a study by the University of Pittsburgh is shared. A participant who lost almost his full mobility of his body joined the study and the researchers implemented a chip into his brain in which his brain became a 'brain-computer interface'. With this interface he was able to control a robotic hand after a lot of practice and after years of practice he was able to move a whole arm as well. This research is very complex and took place over several years. Whereas this might be a solution to help the co-designer, it is a very hard process which will take up to more than one year and a lot of practice.

Exoskeleton: A satisfying and technological solution to help mobility for paralyzed people is an exoskeleton. This product can help with structure, mobility and can even protect a user. Some exoskeletons are just legs (lower body), some are to support arms (upper body) and there are even ones that are full body. (Figure 3)

Co-design/ Participatory Design

Co-design is a creative design approach that stems its roots from (Scandinavian) participatory design and user-centered design. It describes a range of methodologies and ideologies used in the design of products/services. It changes the old designer to client approach and takes an active role in the involvement of users and other critical stakeholders. Co-design's main ideology is to combine lived experiences and professional expertise in the identification of a problem, ideation, development and generation of solutions in the form of a product/service. Engagement of participants from experts to end users is viewed from a socially democratic perspective. This ideology can also be seen in Kleinsmann and Valkenburg's definition of co-design as, "the process in which actors from different disciplines share their knowledge about both the design process and the design content… in order to create shared understanding on both aspects… and to achieve the larger common objective: the new product to be designed." Co-design is also known as generative design, co-creation or co-operative design, stemming its roots from (Scandinavian) participatory design and user-centred design. Participatory design as described by Schuler and Namioka is necessary because "technology is not developed in isolation, participation in decisions about technology also involves decisions about work content and job design," and that "system developers need to…. rely on the expertise of workers." This need to better understand and actively collaborate with users is the core of participatory and co-design. From the found literature, there seems to be little to no difference between the two. It utilises a wide range of tools and techniques and can help participants create personas, storyboards and user journeys. Co-design values the use of prototyping and scenario generation to make further improvements and finalise a product or service. Co-design also is seen as having a wide range of short-term and long-term benefits:

Short-term benefits

- Improved generation of ideas with more originality and user value (greater creativity)
- Greater understanding of customer or user needs
- Immediate validation of ideas or concepts
- Higher quality and better product/service differentiation
- Improved decision making
- Reduced development time
- Lower development costs
- Greater interdisciplinarity across people and organisations

Long-term benefits

- Greater relationship between product/service and customers/users
- Higher levels of satisfaction and loyalty from customers/users
- Higher level of support and enthusiasm for the product/service (seen as innovative)

When and how to use Co-design

Co-design can be used in various stages of a product or service's phase of development, from generation, re-development and evaluation. Co-design should be understood as a

non-linear process that is as generative as it is reflective. It is cyclical and requires multiple stages of reassessment and re-design before coming to a final product or service. The exact process depends on the problem being addressed, the people involved and their needs.
A basis starts with the aspirations and identification of shared values of the stakeholders. It includes three main phases:

- Clear understanding and definition of the problem
- Developing potential solutions
- Prototyping and testing possible solutions

Involved stakeholders can navigate between phases or work in them simultaneously while participating in various discussions and activities. Changing the perception and behavior of stakeholders, encouraging greater support through innovative processes and solutions as they identify the most optimal direction. The process brings a new perspective into understanding the problem, and then together develop, test and understand what could work as a solution.

Co-design Principles

To ensure a conducive and productive environment some general principles can be used. These include inclusivity, respect, participation, iteration and to be outcome focused. The process includes critical stakeholders in all aspects of the design process who are seen as experts and their input equally valued. Strategies should be used to remove any disparities, and everyone is responsible for managing their own and others' interests and feelings. The process should be open, empathetic, and responsive. Ideas and potential solutions are continually researched and reflected upon. Re-design, adaptations, failure and risks are part of the process as they can then be fine-tuned and be evaluated for effectiveness. It is designed to achieve a certain outcome or series of outcomes which can be rapidly tested, evaluated and potentially further developed with stakeholders.

3. Case-Owner

After the interview, we got the inside we needed to form a persona and storyboard. These two items will help us design a product that fits the case owner's needs.

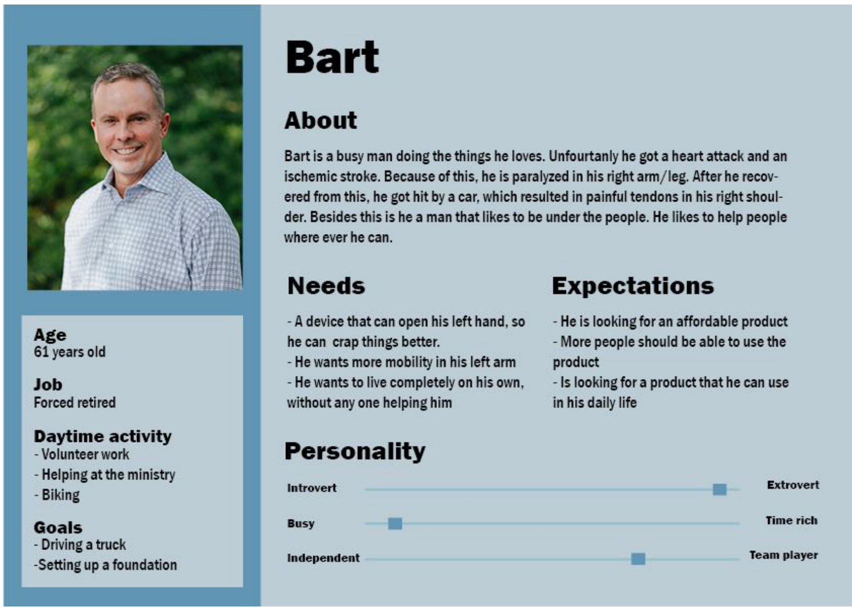

Figure 4: Persona of case-owner

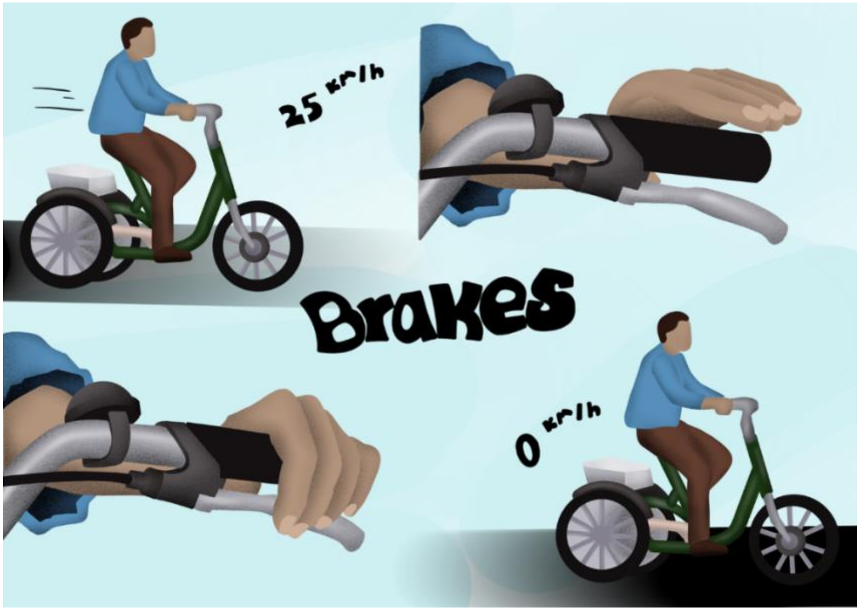

Figure 5: Storyboard

4. Conclusions

We must design a product that helps our case-owner move his arm/hand better. He likes to have something that he can use in his daily life, with wishes of it being low-tech to increase the likelihood of everyday use and to increase accessibility for other people with similar impairments. Our design challenge is stated as follows: “How might we help our co-designer with more mobility in his arm/hand?”
We make sure this design challenge is completed by using the Human-centered design and co-design techniques. We will have close contact between our process and the co-designer to better produce an effective and satisfactory product.

Author Contributions: Abstract: Anouk Müller, Michael Mukaratirwa, and Anastasia Nikishova; Introduction: Mathijs van der Burgh; Social trends and the changing perspectives on disability: Anastasia Nikishova; Introduction to Assistive Technologies: Michael Mukaratirwa; Human Centered Design: Anouk Müller; Theoretical introduction to the disability/condition of your ‘specific user’: Anastasia Nikishova, Michael Mukaratirwa; Market research on existing products: Mathijs van der Burgh; Co-design/Participatory Design: Michael Mukaratirwa; Conclusion: Anouk Müller, Michael Mukaratirwa; Persona: Anouk Müller; Storyboard: Mathijs van der Burgh; Assembling the report: Anouk Müller, Anastasia Nikishova, Mathijs van der Burgh and Michael Mukaratirwa.

Informed Consent Statement: Informed consent was obtained from all subjects involved in the study.

Acknowledgments: The case owner is a big part of our research; he also gave a lot of insight into his disability.

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