Co-design and Human Centered Design and how to apply these while designing for people with Achondroplasia.

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Citation: Rijckevorsel, C. van.; Novikova, E.; Aizpurua, I. P.; Schoonhoven, J. van; Garcia, J. P.; Chapochnikov, M.; Duckers, Z.. Title. *Co-design and Human Centered Design and how to apply these while designing for people with Achondroplasia.* **2021**, *5,* Enschede.

Academic Editor: Nathalie Overdevest and Femke Wonink

Publisher's Note: University of Twente stays neutral with regard to jurisdictional claims in published maps and institutional affiliations.

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Abstract: Before 1960 a disability was seen as punishment by god. Since 1960 we have started to empower disabled people and want them to excel in everyday life. There are two forms of empowerment and participation: Individual, focussed on a single patient, and Collective, focussed on a group of patients with similar disabilities. Assistive technologies are meant to help people with a disability but most of them are designed by people who aren't disabled. This could cause abandonment, that means that the assistive technology is disused. To prevent abandonment from happening Human Centered Design and Co-design are important methods of design. For Human Centered Design to work we need to understand our Co-designer and get to know his disability in and out. In Co-design you work with your target group, and see them as experts in their field. Combining Human Centered Design and Co-design should be a perfect mix where the designers understand the disability, and the participant is the expert in their disability.

Keywords: Disability, Achondroplasia, Empowerment, Co-design, Human Centered Design, Assistive technology, Abandonment, Appropriation, Impairment, Quality of life.

1. Introduction

During this module we are tasked with coodesigning with Stef, a 19-year old boy with Achondroplasia. Therefore, in this study we want to familiarise ourselves with the disability, its impacts and its past and how co-designing and human-centered-design could be applied, by researching these aspects. We aim to get an insight into Stef's disability and how we should work with it and use this knowledge as a starting point of our project.

2. Social trends, and changing perspectives on disability

2.1. View on disability

In ancient times disability was seen as punishment by the gods for sins [1]. However, gradually medical reasons for disabilities were discovered and this view changed. Since 1960 the focus on incapacity of disabled shifted towards wanting to empower them by breaking barriers in everyday life [3]. Now, for example, train stations have guides on the floor for blind people.

Another viewpoint that existed throughout history, is seeing disabled as entertainment. Especially in the 18th and 19th century people with bodily disabilities such as achondroplasia, hunchback and gigantism were entertainers on so called "freak shows" [2]

2.2. Participation and empowerment

In healthcare there are two main forms of care, participation and empowerments. Participation means that the patient takes a more active role in their own care, along with that the patient also helps organise their own care, there are two forms.

- Individual participation: improve care for the patient by getting them to contribute to the decisions about his care. [4]
- collective participation: get a patient to work or talk with organizations to better policies and treatments that are in place for their condition. [4]

Empowerment gives the patient an active role in the decision making. It too consists of two forms.

- Individual patient empowerment is a process that enables patients to exert influence over their individual health by increasing their capacities to gain more control over issues they themselves find important. [4]
- Collective patient empowerment is a process that gives groups the power to express their needs and take action to meet those needs and improve their quality of life. [4]

In this project we will be working on both forms, at the start we focus on our co designer thus empowering the individual, later on we need to broaden our solution for a bigger group of people thus empowering the collective.

3. Introduction to Assistive technologies

3.1. Assistive Technology and Abandonment

Assistive technology refers to products and services which enhance functioning, participation and allow independence for people who have disabilities.

Although AT is designed for people with disabilities, they are most often designed by people without disabilities. This causes wrong or misguided assumptions about disabilities that may end up with AT abandonment. [6]

Abandonment refers to the disuse of the AT. It isn't necessary for the person to have previously used it, the abandonment could happen in the first interaction with the product. There are many reasons for it:

- The AT needs to be worn or held but doesn't physically fit the user's body, causes discomfort, or pain over long term use
- The AT doesn't perform adequately to the tasks that the user relies on the AT
- Additionally it is possible that the AT fit the users needs well and with comfort, but over time the user's needs changed but the AT was not adaptable enough to keep up. [5]

3.2. Appropriation

Appropriation is the idea of how the user adapts a product for a use it wasn't necessarily designed for. Adaptation or appropriation is in some sense the customizability and adjustment a product has, although its unintended by the creator. It only makes sense that the more flexible an AT is, the more room there is for appropriation. [12]

If applying this to our case, the person in question has difficulties with driving a car. The designed AT in this case should be simple yet efficient, applicable to all cars, and with adjustable dimensions, while remaining reasonable in price.

4. Human centered design (HCD)

4.1. What is HCD

Making use of Human Centred design results in designing products, systems and experiences by taking into account the needs of the user [15]. The characteristics that differentiate HCD from conventional design is the design team's intent to understand the user. By understanding the user and approaching their perspective the design team can create a better solution tailored to the users needs. This understanding can be obtained through various methods such as: Interviewing the user, observing their environment, asking experts and reviewing literature. Human centered design is about understanding the people for which the team is designing rather than assuming their needs based on presuppositions.

4.2. Why HCD and implications for the project

HCD is critical for this project as we are tasked to design for people with disabilities. Most of us don't know what problems these people go through, therefore designing a solution for said problems would prove difficult as we dont have the adequate knowledge. By implementing HCD we can learn more about the different conditions and the struggles these people go through [15]. Thanks to this we will get closer to having a glimpse at the perspective of people with disabilities and be able to design better solutions to their problems.

4.3 Design Ethics form HCD perspective

The most important implications of working with a co-participant would be as follows. First off, in order to design a suitable solution to their problems we will need access to sensitive information about the participant, therefore it is our duty to guarantee the safety of said information. Secondly, we wish to not only use the participant as a mere source of information. We would like to properly integrate him in the design process to guarantee that we can find the best solution for his problems.

5. Theoretical introduction to the 'impairment'

5.1. Achondroplasia

The special need of our user group is Achondroplasia, which is the most common type of short-limbed dwarfism. It is a disorder that affects bone growth by preventing converting cartilage to bone. It is caused by a gene alteration (mutation) in the FGFR3 gene [16]. The FGFR3 gene makes a protein called fibroblast growth factor receptor e3 that is involved in converting cartilage to bone. Achondroplasia occurs in approximately 1 in 20,000-30,000 new-borns [17]. There is no treatment present for this condition. Its main features are a short stature, an unusually large head with a prominent forehead, a long, narrow trunk and short limbs.

5.2. Psychological and social aspects of achondroplasia

Determining how achondroplasia affects the mindset and searching for possible trends among the concerned people regarding their mental health is done with the help of two studies.

These studies focus on the effect the condition has on young people. The first research document [18] made by a group of German investigators analyses how the effects of the condition affects the perceived quality of life of these people. The second research conducted by Japanese investigators analyses the psychological profile of young people suffering from achondroplasia.

The conclusion the first document drawed was that young people did not perceive their quality of life (QoL) differently from healthy controls. However, what had the

most effect on their perceived QoL wasn't their height, but the problems and limitations linked to it.
The second study [19] concludes that children with achondroplasia experience more stress related to their height, but that despite this they did not show evidence of maladaptation. However, among other aspects concluded by the research that could be considered relevant for this research, was that self-efficiency is an important coping mechanism to promote psychological adjustment for children suffering the condition.

5.3. Implications for design

Short stature, smaller reach/range of motion, mobility and accessibility are relevant elements that have an impact while designing.

6.Co-design and Participatory Design

6.1 What is co-design?

Co-design is the act of creating *with* stakeholders, specifically within the design development process to ensure the results meet their needs and are usable. [20] Co-design can take place at any point across the design development process. However, involving people with different perspectives early can help determine the real problem space early on.

6.2. Roles in co-design

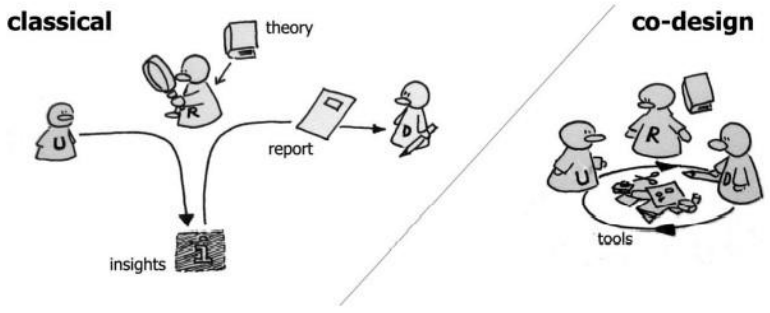


Figure 1: *Classical roles of users, researchers, and designers in the design process (on the left) and how they are merging in the co-designing process (on the right).*

In co-design, the roles get mixed up. The user is given the position of 'expert of his/her experience', and plays a large role in knowledge development, idea generation and concept development. This can be very powerful and can lead to more culturally relevant results than individual working does. [21]

6.3. Empathy in design

It is important for designers to gain empathy with the users for whom they are designing. Empathy is a necessary quality for developing products that meet customer needs. The designer steps into the life of the user, wanders around for a while and then steps out of the life of the user with a deeper understanding of this user. [22]

6.4. Engaging with the practice

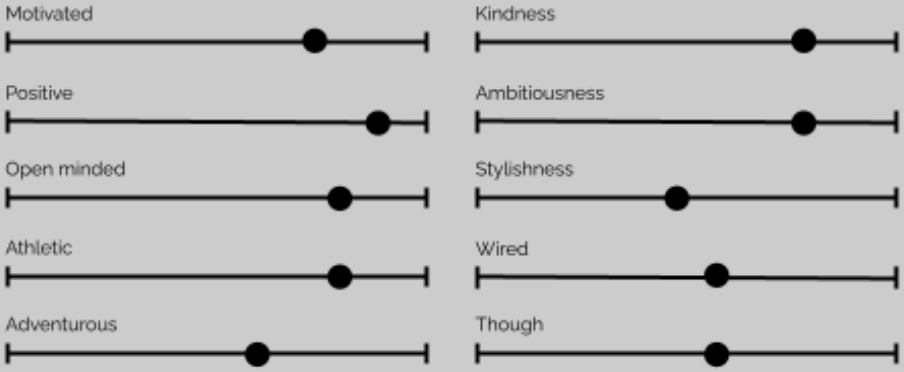
Numerous creative techniques exist for making users' experiences available for discussion. These include the use of visual materials, story-telling, fun and playful activities, and the physical creation of products. Materials that can support such processes with participants of all ages include whiteboards, collages, storyboards, inspiration cards, modelling tools, and games. We have chosen to engage with Stef via video calls and discussed with him the problems/ challenges he faces on a frequent basis. We had Stan take pictures of his everyday life to visualise his day and his struggles. We also brainstormed together creating several mind maps of ideas and problems. Additionally we asked him to draw and describe how he wants the product to function, of course this comes with the limitation that as he isn't use to illustrating his ideas the drawings are a vague and hard to comprehend, which is why we discussed with him his drawings and gave the opportunity to not only illustrate his idea but to also describe it verbally. We made sure to update and discuss with him each of our decisions/ ideas to ensure they correspond to his needs and wants.

7. Persona

This persona is created to get to know the participant while also allowing them to keep their privacy.

Stef

Age: 19 years
Gender: Male
Quote: "You can give my disability any name, it doesn't change what it is!"
Condition: Achondroplasia.



Psychographics

- A very positive person. He is very active and likes to undertake challenges. He does not let his condition stop him.
- His dream to become part of the army, shows his willpower and mental fortitude. He is very committed to the things he does and puts its 100%

Technologies

Stef isn't a huge fan of technology, he uses his phone and laptop a lot but that is about it. When he has some free time he watches some documentaries on youtube or netflix. But since he lives a busy lifestyle he can not do that often.

Stef's situation

Personal background

- Was studying Medical technology, but due to having too much fun he had to drop out, still wants to study something in the near future.
- Household: Has 4 siblings, he is the youngest. His parents are still together. He lives in Den Haag
- Education: Finished high school with HAVO diploma

Activities

- In the morning he does stretching exercises to stay in shape
- At 12:00 He goes to work at a sales department for a company.
- At 19:00 he goes back home
- In the evenings he likes to hangout with friends and go to parties/clubs

End goals

- At the moment still lives with his parents, but in the end he wants to be self-sustainable and live on his own. He doesn't want to be cared for. So an actual standalone house or an apartment would be the dream for him. Wants work in the army but due to his condition he can't, he hopes that somehow in the future he could work there. As for now he stays healthy and goes to the gym almost every day.
- A more current goal is being able to drive a car. He does not want/ does not have the money to rebuild a car to fit his condition. Also, most driving schools will only allow him to drive an automatic. However, he would like to be treated "normally" and wants to drive stick shift.

Influences on Stef

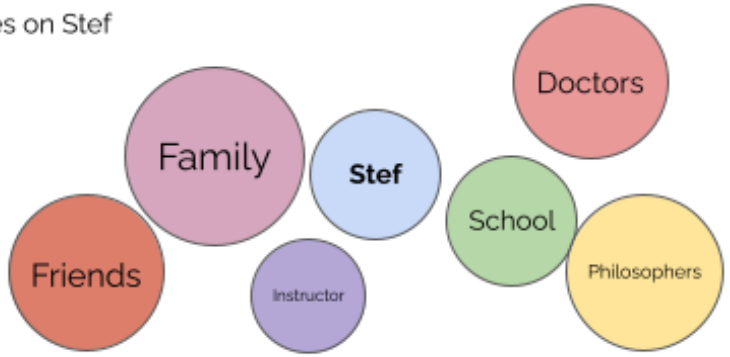


Figure 2: Persona with our participant as inspiration

8. Storyboard

This storyboard is created to present and visualise two scenarios which our participant faces.

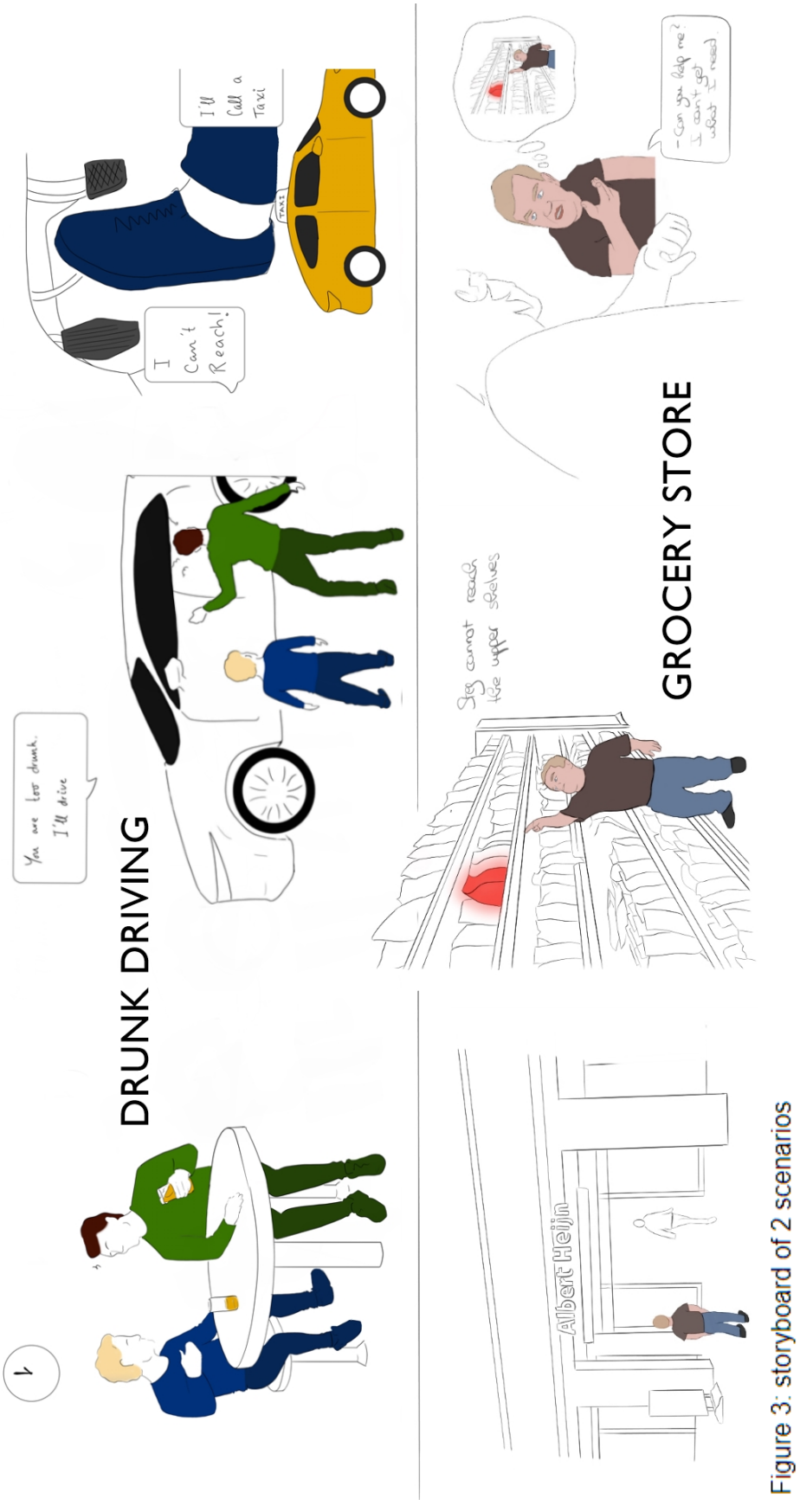


Figure 3: storyboard of 2 scenarios

9. Discussion and conclusions

In this study you read about Achondroplasia, co-designing and Human Centered Design and how to apply these while designing for our participant Stef.These design methods are important tools, which can improve lives and empower specific target groups oneself might not belong to.

After interviewing Stef we decided with him that we want to make him feel empowered by enabling him to navigate throughout his daily life like an average person.

Author Contributions: Abstract, Zen Duckers; Introduction, Zen Duckers and Caroline van Rijckevorsel; Social trends and changing perspectives, Joel van Schoonhoven and Zen Duckers; Introduction to assistive technologies, Evgenia Novikova; Human centered design, Jorge Perez Garcia and Miron Chapochnikov; Theoretical introduction to the impairment, Caroline van Rijckevorsel; Co-design and participatory design, Itxaso Pamies Aizpurua; Persona, Joel van Schoonhoven and Zen Duckers; Storyboard, Evgenia Novikova; Discussion/Conclusion, Caroline van Rijckevorsel; Editing, Caroline van Rijckevorsel, Evgenia Novikova and Zen Duckers.

Informed Consent Statement: Informed consent was obtained from all subjects involved in the study. Written informed consent has been obtained from the patient(s) to publish this paper.

Acknowledgments: Our participant, Stef; Tutor, Edsko Hekman

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