



Proceedings of the 6th International Conference on Design4Health
Amsterdam 2020

Editors: Kirsty Christer, Claire Craig & Paul Chamberlain

Volume 4



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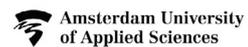
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Volume 4

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Foreword

When the Design4Health Conference organising committee collectively chose 'The Future is Now!' as the theme for the 2020 conference we had not anticipated a future shaped by the emergence and ensuing devastation of COVID-19.

This would have been the sixth Design4Health Conference. In January, plans were well underway with Sabine Wildevuur and colleagues in Amsterdam, hosts of the event. With over 300 submissions from 30 countries, this would have been our largest conference yet. However, a few weeks after a successful review day we began to hear from friends and colleagues affected by the COVID virus. Our priority has always been the health and wellbeing of the wider Design4health community and we made the difficult decision to cancel.

In recognition of the time and effort that had been put into crafting submissions, we invited those with accepted abstracts to submit full papers, which would be published in online proceedings. The result is found here - 95 papers across 4 volumes.

The papers are an exceptional testament to the Design4Health community. Whilst many do not reference COVID-19 directly, the research themes they interrogate and their exploration of the role of design in creating solutions to societal health challenges are exceptionally relevant.

As we move forwards, we recognise the importance of continuing to create opportunities where researchers are able to transcend their own disciplines, to share research and create new intellectual spaces and paradigms. We feel confident, that in these extraordinary and unprecedented times the Design4Health community is well placed to make a difference.

On behalf of Lab4Living and the Conference organising Committee, welcome to these proceedings.

Claire Craig, Kirsty Christer & Paul Chamberlain (Lab4Living)

Reflections from Sabine Wildevuur – host of Design4Health 2020

In September 2018 the decision was taken that the sixth Design4Health Conference 2020 was going to be hosted in Amsterdam, the Netherlands. How happy we were as organizing committee, and started immediately to develop the conference planning in close collaboration with the initiators of D4H - Paul Chamberlain, Claire Craig, and Kirsty Christer - from Lab4Living, Sheffield Hallam University. A team of knowledgeable and enthusiastic people with very different academic backgrounds but all devoted to design for health, was assembled for the Academic Programme Committee and Review Committee.

The first milestone for the organisers was the deadline for submissions; the amount of submissions exceeded our wildest expectations. The UK-NL review committee joined forces in the review process. And on a special review day on 23rd of January 2020, in the historic anatomic theatre of Waag in Amsterdam, 20 members of the review committee divided into the teams red, white, blue (indeed, the Dutch flag!), and orange took the decisions on the 347 submissions. There was something in the air that day; a great vibe, a strong bonding feeling, and everyone was looking forward to the first of July 2020, when the official opening of D4H2020 would have taken place, and the D4H community would be (re)united in Amsterdam.

The rest is history. We would have loved to welcome you in beautiful Amsterdam. But in April 2020 we had to take the tough decision not to proceed with the conference this year. Keep on the good work on design for health, and remember: The future is now!

Special thanks to the members of the organising committee:

DesignLab University Twente (Anke de Koning), *Amsterdam University of Applied Sciences* (Somaya Ben Allouch and Nathalie Brommersma), *Lab4Living, Sheffield Hallam University* (Paul Chamberlain, Claire Craig, and Kirsty Christer), and *Waag|society&technology* (Paulien Melis). This committee collaborated with 4TU (*University Twente (UT), Delft University of Technology (TU Delft), Technical University Eindhoven (TU/e), Wageningen University & Research (WUR)*).

Academic Programme and Review Committee

- Armagan Albayrak (TU Delft)
- Somaya Ben Allouch (HvA)
- Remi Bec (Lab4Living)
- Marina Bos-deVos (TU Delft)
- Daniel Bossen (HvA)
- Paul Chamberlain (Lab4Living)
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- Peter Weijs (HvA, VUMC-AMC)
- Gemma Wheeler (Lab4Living)
- Sabine Wildevuur (UT)
- Ursula Ankeny (Lab4Living)
- Paul Atkinson (SHU)
- Helen Fisher (Lab4Living)
- Naomi Raszyk (Lab4Living)
- Heath Reed (Lab4Living)
- Noemie Soula (Lab4Living)

All abstracts included in these proceedings were double blind refereed by the review panel, and expanded to full papers taking into account the referees' recommendations. The review panel further refereed full papers.

Particular thanks to Dr. Alison Mayne, Rebekah Di Maulo, and Nicola Alexander (Design Futures) for their support in the final formatting of the work. Thanks to Graham Nesbitt for the D4H visual ident and cover design.

Themes of the conference

The overall theme of Design4Health 2020 was designing in the context of future health and healthcare with an aptly named title: The future is now!

The conference sought papers which considered:

- What will health look like in the future?
- Where will health and healthcare be enacted?
- How might our lives be configured?
- What will the future designer look like?
- What skills will they need?
- How might current research trends (e.g. personalisation, interdisciplinarity, circular design) translate into this future for design and health?

The papers contained in these proceedings were submitted in response to the call and they interrogate a number of areas. In addition to exploring methods, ethics and broader questions about ways we evaluate the impact of design you will see research that relates to:

- Designing citizen science and community-driven care
- Designing for urban vitality
- Care model design
- Designing personalised eHealth technology
- Care model design
- Health data design/digital self
- Sustainable health and wellbeing
- Wildcard Chindōgu. Designing dystopian futures
- Meta themes (methods, ethics, evaluation that cross linked across other themes)

Thank you to everyone who submitted papers and to your contribution to the broader discourse that is Design4Health. This is an exceptionally rich and comprehensive body of work and we very much hope that you enjoy reading the papers as much as we have enjoyed reviewing them.

Citations

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Lab4Living | Art & Design Research Centre | Sheffield Hallam University | Sheffield | S1|1WB |
tel: +44 (0) 114 225 6918 | www.lab4living.org.uk | www.design4health.org.uk |
@Lab4Living | @Design4Health

CRAFTING NARRATIVE: POETIC THINKING FOR HEALING: ALTERNATIVE HEALING METHOD INHERITED FROM BLACK MOUNTAIN COLLEGE

Eriko Takeno

Royal College of Art, UK

Abstract

This research discovers ways how fundamentally one's introspective experiences can help others in their healing processes and proposes an alternative healing method for anxiety. With applying the theory of the philosopher Federico Campagna who proposes vulnerability as an endless possibility for resolution, this project departed from an examination of the arts-centred education provided by Black Mountain College in North Carolina that created a nexus for experimental artistic practice in the USA. Based on the examination, the author explored her introspective experiences with her anxiety through her art practice. Inspired by Italian theorist Franco 'Bifo' Berardi who claims "the poetical act is a revelation of a possible sphere of experience not yet experienced, that is to say, the experienceable" (2019, 21), she utilised poetry as a mode of thinking and reflected on her psychological experiences. To share her discovery of introspective exploration with poetry as a therapy for anxiety, she developed The Sensory Multimodal Workshop; Space as a medium, Poetic thinking as a tool. The workshop invites participants to develop a mindful approach to their perceptions of the physical environment and to communicate their experiences with the rest of the group. Working in collaboration with psychologists, she developed a method of somatic thinking through poetry that

activates a mutual connection between the internal and external spaces of one's own body. The somatic thinking of the workshop enables a participant to deconstruct traumatic narratives of anxiety and to shape them into new narratives. The resulting Crafting Narrative installation work invites the audience to experience the healing power of poetic thinking as an alternative healing method by following the author's journey of poetic discovery and emotional recovery from anxiety.

Keywords: art-centred education, poetic thinking, metaphysics, self-healing, diffractive methodology, anxiety

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ADDRESSING THE ISSUE OF COMFORT IN INTENSIVE CARE UNIT ENVIRONMENTS THROUGH INTERDISCIPLINARY DESIGN WORKSHOPS

Anne Britt Torkildsby¹, Lars Hallnäs² and Sepideh Olausson³

¹Norwegian University of Science and Technology, NO

²University of Borås, SE

³University of Gothenburg, SE

Abstract

Research shows that comfort in an ICU can promote healing, recovery, and wellbeing in patients; discomfort can result in complications that can, in a worst-case scenario, be life-threatening. ICU patients are continuously exposed to many sources of discomfort. Although the majority of these are related to the patient's health, ICU design can also be a contributing factor. As a result, the meaning of comfort and how comfort might manifest itself in everyday objects and materials was explored through three one-day workshops, which were planned using a mixed-methods approach drawing on both the design and healthcare fields.

In total, 53 participants from various disciplines – facility planners, designers, architects, and healthcare professionals – participated. Our

results confirm previous findings: that comfort stems from much more than the functional aspects of an object or a material, and that the importance of being comfortable extends beyond mere practicalities. Moreover, they suggest that alternative methods may be used alongside traditional ones in the initial stages of a design process to stimulate discussion and reflection regarding the design of future ICUs. Finally, this paper presents novel ways of working that can assist designers, architects, etc. in generating and sharing knowledge – thus becoming more informed about and skilled at designing for patient comfort from an interdisciplinary perspective

Keywords: ICU design, patient comfort, wellbeing, interdisciplinary workshops, knowledge-sharing, design methodology



ICU Design

'People say the effect is only on the mind. It is no such thing. The effect is on the body, too. Little as we know about the way in which we are affected by form, by colour, and light, we do know this, that they have an actual physical effect. Variety of form and brilliancy of colour in the objects presented to patients are actual means of recovery' (Nightingale 1860, 59)

The reputedly hardy Florence Nightingale stressed patient comfort as early as the mid-1850s (Nightingale 1860), and it truly became a point of focus in the design of hospitals thanks in large part to Ulrich's work in the early 1980s (Ulrich 1984). Comfort in an ICU patient room is generally associated strongly with functional and measurable design elements, such as therapeutic effects (e.g. carefully selected colour palettes, furniture, (cycled) lighting, art, exposure to nature, fabrics to absorb noise) and materials that are easy to maintain and clean in order to improve infection control (Thompson et al. 2012; Engwall et al. 2015).



Figure 1: Examples of design features in an ICU patient room, from left to right: A view of nature through a window; a personal gift in the form of a teddy bear; a flip chart that can be used to give caregivers additional information and help the ICU patient to feel more comfortable and 'at home'

The Workshops

Based on the belief that physical objects and materials embody different things to different people in different periods of their lives, we set out to explore what comfort means in the context of ICU patient rooms from an interdisciplinary perspective.

Preparation and Participants

Workshops were chosen as the medium for accomplishing this due to a desire to link theory and practice and so give the participants the opportunity to express themselves and share their insights through not only words but physical objects and materials. The approach used for the workshops was exploratory in nature, making use of mixed methods and drawing from the fields of design, architecture, and nursing.

The workshops were hosted in cooperation with the Centre for Healthcare Architecture (CVA) and Chalmers University of Technology (CUT); the recruitment process involved advertising on both CVA's and our respective universities' websites, as well as personally inviting nurses and physicians from three ICUs in Sweden. The participants were asked to photograph or bring with them two or three personal items from their homes or other private spaces that they associated with comfort. In addition, they were asked to reflect upon why these items are essential to them in relation to comfort: what meaning do they have, and why?

With a total of 53 participants – 22 men and 31 women aged between 31 and 69 from various European and East Asian countries – from the disciplines of design, architecture, and nursing science, it was

necessary to first map the scope of the term 'comfort' in terms of its lexical meaning and so come to a common understanding. Accordingly, a conceptual analysis – both in Swedish and English – was performed based on Koort's process of hermeneutic semantic analysis (Sivonen, Kasén, & Eriksson 2010), which resulted in the identification of numerous synonyms later used as keywords in the workshops.

Workshops 2 and 3 took place as part of the annual study programme at the School of Architecture at CUT, and thus was only open to participants with an architectural background. This gave a new direction to the research project in that – besides exploring the meaning of 'comfort' in ICU patient rooms from an interdisciplinary perspective – it involved 'educating'

architecture students. However, the narrow focus on care spaces from an architectural point of view – rather than seeking a wider understanding of comfort – was a limitation and will be reconsidered in future workshops.

Design

Although the timing of the workshops varied, their overall structures, in terms of the time spent on and order of each activity, were essentially identical. Consent forms were signed and collected before the end of each day, giving the participants the possibility to withdraw at any time and allowing the materials (pictures, quotations, etc.) to be used within the frame of the project.

Table 1. The timetable for an average workshop

Time	Activity	Stage no.
10.00-11.00	Welcome and introduction, plus individual work	1
11.00-12.00	Group work session one	2
12.00-13.00	Lunch	
13.00-14.00	Group work session two	3
14.00-15.00	Discussion and summing-up	4

The Stages

1) After we had introduced ourselves, our backgrounds, and the purpose of the workshop, we asked the participants to introduce themselves and their reason for participating. We also asked them to describe the items, or the pictures of the items, that they had brought to illustrate what they considered 'comfort' to be in their respective homes (keywords were noted down and the pictures were collected after the session had finished). A fictional patient story was introduced, along with photographs of ICU patient rooms to stimulate reflection and contemplation on the theme of comfort. Some 'hard facts' regarding the functional and aesthetic characteristics of the environment were

provided, along with a description of what it could mean to be cared for in such a space. The idea with this activity was to set the mood for the workshop.

2) The first group work session involved the participants being exposed to 50 different materials, including cardboard, plastic, wood, textile and metal, as a way of exploring and discussing their experiences relating to comfort. The participants were asked to sort the samples into five groups and document this: 1 – not comfortable at all; 2 – not very comfortable; 3 – average; 4 – comfortable; 5 – very comfortable. This activity was undertaken in order to explore whether certain types of materials scored higher than others.

3) After the break, we introduced the findings of the semantic analysis conducted earlier in the project (Olausson, Fridh, Lindahl, & Torkildsby 2019) in the form of various synonyms for 'comfort' printed on small cards. The participants were invited to group the 50 material samples with the words on the cards, challenging them to exemplify the synonyms using the materials. The aim of the activity was simply to encourage the participants to express their ideas relating to comfort through both language and materials, creating awareness among the participants and providing us with insight into the conceptual landscape(s) ahead.

4) The workshop was concluded by summing up the day; what the outcomes were and what they would be used for, as well as what the participants had learned and why this was important as regards the design of ICU. Before the participants left, they were given postcards and were asked to digest their experiences and write down general and workshop-specific reflections and return them within a week or so. These were intended to provide feedback regarding what could be done differently with the workshop, allowing improvements to be made to its structure and methods, as well as to ascertain whether and in what ways comfort is an important consideration in design processes.

Workshop – Stage 1

Materials and Methods

During the first stage of each workshop, the participants were invited to each describe what they considered to be comfort in their home; this varied from tangible examples to printed pictures and oral presentations. This was generally followed by discussion of the particularly interesting personal possessions.

Preliminary Trends

The data collected suggests several trends. In the 'tangible' category, 'the sofa at home' scored highest, along with 'soft, dim light'. In the 'intangible' category, however, 'safety', 'family', and 'home' in some form were mentioned most frequently. The participants listed 'safety', 'being cared for, resulting in feeling safe, relaxed, and at ease', and 'freedom of choice, enabling the ability to move and be in control of one's own health, time, and possessions', for example, as essential.

Other intangible concepts that frequently arose were 'family', relating to e.g. 'visiting relatives and family members', 'pictures of one's children and/or other family members', and 'the thought of one's children or spouse'. Similarly, various versions of 'home', e.g. 'memories of home mounted on the wall', 'a cup of home-made coffee', 'a certain type of mattress and bedding, identical to those that the person had at home', 'feeling at home', 'thoughts and dreams of a childhood home', and 'being at home in the apartment'.



Figure 2: Examples of items that the participants associated with comfort, from left to right: A pillowcase, which the participant – an ICU nurse – had witnessed parents bring in for their child undergoing care; a teddy bear; headphones and reading/entertainment materials

Workshop – Stage 2

Materials and Methods

In this stage, the participants were divided into groups of 4–5 and asked to sort the 50 materials into five categories of comfort. The results were documented on handouts, which were collected for later analysis.

Preliminary Trends

Relatively early during this stage of each workshop, it was observed that material samples with a strong or direct connection to nature were received in a generally positive manner by the participants: e.g. ‘The materials I liked the most are the natural materials; being able to feel the nature inside’; ‘Nature is a winning concept’; ‘Most of my favourites are natural materials’.

Similarly, it was found that rough materials – those used primarily for construction, such as glass, plastics, and metals – were less frequently described as comfortable, although building materials that are used for interiors, such as painted wood panels and different types of flooring, were felt to be more comfortable.

There were also indications that any material that was somehow ‘familiar’ or ‘intimate’ to a participant, such as wallpaper, carpet, or furniture fabric, evoked positive responses that frequently related to nostalgia: e.g. ‘It makes me think of my grandmother; she had a couch like this’. These materials were felt to possess a greater sense of comfort than those which were not part of that participant’s home, e.g. metals such as aluminium.



Figure 3: The workshop participants in action, touching, discussing, and sorting the 50 material samples

Workshop – Stage 3

Materials and Methods

The participants stayed in the groups formed before the lunch break and were asked to lay out the synonyms of ‘comfort’ printed on small cards and, through discussion amongst themselves, decide which synonym best fitted each of the 50 material samples. The participants were encouraged to think carefully about their choices, particularly where there were differences of opinion within the group. It was acceptable to place samples between multiple cards if the participants felt that this was necessary in order to accurately describe the samples, and photographs were taken of each table.

Preliminary Trends

Even at the beginning of Stage 3, it was observed that some samples – particularly the soft ones, such as fur, silk, and wool – seemed to be easier to connect to a synonym than others. These were connected to words with clearly positive connotations, such as ‘pleasure’, ‘relaxation’, and ‘cosy/cosiness’.

The samples that generated more ambivalence – metals, plastics, various types of synthetic fibres and materials used primarily in construction and building exteriors – were referred to in discussions as being comfortable in a purely practical way or, as one participant described them, ‘durable and safe to use in

Conclusion and Considerations

This paper somewhat complements Torkildsby and Olausson's previous publication (Olausson, Fridh, Lindahl, & Torkildsby 2019), which describes the findings of the workshops, and deals with the method(s) behind the findings. Moreover, it suggests that alternative ways of thinking and doing design, such as the workshop design described here, may help designers, architects, and engineers – indeed, anyone who is involved in the planning, design, and maintenance of ICUs – in exploring, understanding, and communicating the impact that physical objects and materials can have on patients in regard to comfort.

Furthermore, bringing novel ways of thinking about design into the early phases of a design process – not as a substitute for traditional design methods, but as an addition – can open up the design brief, and so provide insights that designers and architects might otherwise miss. This, in turn, prompts the various professionals involved in the development of a project to see things 'with a fresh set of eyes' and from a new angle, and this is particularly important for the students who participated in the workshops, who are about to step into the real world and may have to deal with the concept at some point in their careers.

The discussions we had with the participants during the workshops support this, suggesting that the importance of patient comfort and wellbeing in relation to objects and materials will not go unacknowledged in their professional lives from now on. Reading the returned postcards, it is tempting to state that the workshops that were held seemed to be spot-on as regards subject matter and raising an issue for discussion that, in our opinion, is frequently neglected. In other words, the aim of starting a discussion between various professionals related to ICUs so as to come to a deeper

understanding of the topic was achieved, but the participants' engagement in the workshops is probably more valuable as regards the 'big picture' than either the methods acquired or the data gathered and analysed over the course of the three workshops.

The postcards that were returned support this conclusion: 'Very rewarding to meet people from various disciplines. Many great ideas. This subject can really have a positive impact on patients' stays in ICUs (often with limited resources)'; 'The workshop demonstrates a different approach to high-tech care. Artistically, sensually, holistically. Very inspiring. Look forward to the result'. Whether the participants bring this way of thinking into their daily lives as professionals, however, is a different story: We can only hope that a seed has been planted!

Acknowledgements

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All of the photographs presented in this article were taken by the authors.



COMPASSIONATE DESIGN: A METHODOLOGY FOR ADVANCED DEMENTIA

Cathy Treadaway, Jac Fennell and Aidan Taylor

Cardiff Metropolitan University, UK

Abstract

Predicted increases in the numbers of people living into the advanced stages of dementia pose a significant problem for health and care providers around the world. Finding ways to ameliorate the distressing dementia symptoms of anxiety and depression and assist people to live well into the advanced stages of the disease, is vitally important. There are currently few products available for people living in the later stages and understanding the complex needs of individuals on a unique dementia journey is vitally important for designers of products and services. This paper will propose that Compassionate Design provides an effective and tested methodology to help ensure that designs are appropriate and meaningful to users living with advanced dementia, or other forms of cognitive impairment as a result of accident or disease. The approach places loving kindness for the individual at the heart of the design process and focuses on three vital aspects of design: sensory stimulation, personalisation and connections with others and the environment.

This paper provides a case study from LAUGH EMPOWERED, a collaboration with UK NHS and an international residential care home company. It evidences how Compassionate Design methodology has informed the development and evaluation of HUG by LAUGH®, a new product designed to bring comfort and reduce anxiety for people living with advanced dementia. HUG® is a soft soothing object that contains embedded technology that provides personalised music and a beating heart. The study is evaluating design, safety and effectiveness of HUG® to support the wellbeing of people living with advanced dementia. Data is collected via the Pool Activity Level (PAL) tool and Bradford Dementia Wellbeing Scale, as well as interviews with caregivers, health professionals and family members. Early findings from the study indicate that HUG® helps to reduce patient anxiety and enhances communication with caregivers.

Keywords: dementia, design, wellbeing



Introduction and Context

This paper presents a design approach: 'Compassionate Design', which has been developed over the last 10 years from academic design research for people living with advanced dementia. It has been refined and evaluated in design practice through two funded research projects: LAUGH and LAUGH EMPOWERED. The methodology has been found to be useful in guiding design priorities and evaluating the use of outputs designed to support the wellbeing of those living with cognitive impairment as a result of dementia, disability or disease.

There are currently very few products designed specifically for people living with advanced dementia, despite a huge predicted increase in the numbers of people likely to be living with the disease over the next 30 years. The World Health Organisation estimate that there will be over 152 million people living with dementia globally by 2050ⁱ. Increasing life expectancy means that more people than ever are likely to live into the advanced stages of the degenerative disease in which activities of daily living become impossible without assistance and verbal communication is eventually lost. Finding ways to design appropriate products, services and activities for people to enable them to 'live well' through the final stages of life is vitally important.

Design Approaches

Wellbeing is defined by the Oxford English Dictionary as 'the state of being comfortable, healthy, or happy'ⁱⁱ. However, wellbeing is generally considered a much broader concept than moment-to-moment happiness and includes an estimation of how satisfied people consider their life as a whole, as well as their sense of purpose and autonomy. A report by the New Economics Foundation for the UK Government, published in 2008, proposed the following 5 themes as being essential for wellbeing: Connect, Give, Take Notice, Keep Learning

and Be Active (Aked et al. 2008). These five themes have influenced government policy in the UK and are routinely used as foundations for wellbeing programmes in the UK National Health Service (NHS) healthcare system. Research into wellbeing by positive psychologists have revealed the link between the experience of positive emotion and its impact on physical and mental health (Seligman 2011, Fredrickson 2004). Laughter has been shown to have proven therapeutic benefit to physical health; pleasure, gratitude and hope all help to contribute to greater engagement with life and deepen social connections (Fredrickson 2004). Human beings are social beings and lack of physical contact with others is detrimental to our physical and mental health. Research has shown that physical intimacy, social touch and comforting experiences are vitally important to wellbeing (Tanner 2017).

It is crucial for designers to understand the influence of design on user experience, especially if their aim is to enhance wellbeing. There are a number of design approaches that are routinely used by design practitioners to inform the creation of successful and appropriate designs that help improve a person's quality of life. Experience Design developed out of the work of Donald Norman in the 1980s (Norman 1988). He emphasised the need for designers to focus on 'user experience' leading to user centred design, interaction design and UX design. These design approaches are concerned with emotional, aesthetic and functional attributes of a design as perceived by the user. Positive Design (Desmet and Pohlmeier 2013) developed from Positive Psychology and advocates that designers should focus on three key themes of pleasure, personalisation and virtue in order to successfully design to support a person's wellbeing. While these approaches enable designers to focus on ways of designing for positive experiences and quality of life, they are not tailored to the specific needs

of those who lack cognitive skills or for whom life is severely limited by disability and disease. These people may not be able to experience pleasure in the same way as others, comprehend virtuous acts or be able to define personal preferences themselves. Compassionate Design (Treadaway et al. 2018) is an alternative approach that fills this knowledge gap (Fig1).

Compassionate design

Compassionate Design places loving-kindness for the person at the heart of the design process. It aims specifically to prioritise three key elements in the design process: Personalised – design to retain a person’s sense of self and maintain their dignity; Sensory – design to keep in the present moment and not rely on past or future; Connecting – design to encourage moments of high quality connection with others.

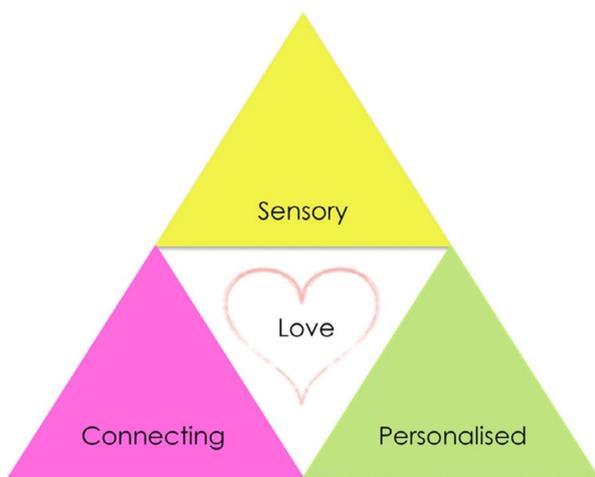


Figure 1: Compassionate Design © C. Treadaway 2016

Personalised

One of the three key themes of Compassionate Design is personalisation. By placing the needs and preferences of the individual at the heart of the design process it is possible to develop bespoke design solutions that can make a real difference to someone’s life. A person-centred approach to design takes account of the difficulties they may encounter day by day as a result

of living with a disease or disability. It includes their personal preferences as well as information about their life history, including significant relationships and cultural background. A designer can obtain this through empathic observation; by engaging them in conversation (if they have capacity) and via life story information supplied by carers and loved ones. Past experiences that someone may no longer recall, nevertheless contributes to the person they are now. By focusing on the individual in the context of their lived experience it is possible to design to help maintain their sense of identity and retain their dignity.

The inclusion of autobiographical themes within designs, such as references to a person’s job or career, their culture or family, can help to stimulate emotional memories. They may not be able to remember explicitly what is being referenced but the sense of familiarity and associated feelings can be stimulating and pleasurable. Equally, it is important to know whether there are subjects to be avoided, or themes that a person will find emotionally uncomfortable.

Music has been found to be particularly stimulating for people with cognitive impairment and those living with advanced dementia. Personalised playlists can quickly transport an individual back in time and provide an emotional release or lift a low mood. Finding the right musical choices is imperative, but when identified and integrated into designs, can bring extraordinary moments of reawakening.

Sensory

Our moment by moment experience of life is perceived via our senses which can also help trigger emotional memories of past experience. Even when memory is severely compromised, sounds and smells can evoke a sense of place and time instantaneously, and music can transport a person back to how they felt at a particular moment in their

life. Sensory re-awakening can stimulate moments of lucid remembering and trigger verbal accounts of memory from those who were considered no longer able to remember or communicate verbally. It can also enhance positive emotion, provide comfort and relieve stress.

The sense of touch is particularly important for those who have restricted mobility and are confined to a chair or bed. Exploring through touch, fiddling and fidgeting can be a way of relieving boredom, agitation and frustration for people living with cognitive impairment. By incorporating tactile surfaces, interesting textures and materials it is possible to specifically design positive opportunities for sensory touch, to relieve stress and enhance pleasure.

Many older people living with dementia also have age related sensory impairments such as hearing loss or poor vision. Dementia can also impact on the interpretation of sound and visual perception resulting in hearing problems and disturbing visual effects. For some people, an overload of sensory stimulation can result in distress, while others need stimulation and benefit from it. When designing for people living with advanced dementia and cognitive impairment, appreciating a person's sensory strengths and limitations is vital. Music can have a particularly profound impact on people living with advanced dementia. Rhythmic sound can help stimulate movement and exercise. It can influence and enhance mood, lift spirits and sometimes enable a person living with advanced dementia to remember words when singing, even when speech is lost. Designs that incorporate playlists of favourite music or provide rhythmic vibration or sound can provide deep emotional comfort and soothe people who are agitated, in pain or distressed.

Connecting

Connections with other people are fundamental to happiness. Research has shown that we are interdependent beings and need high quality relationships with others to flourish and live well (Fredrickson 2014). Loneliness and isolation have huge negative impacts on health and can lead to depression and other medical conditions. One of the distressing impacts of advanced dementia is that people become increasingly disconnected from others and the world around them as the disease progresses. Maintaining relationships is difficult since they may no longer recognise loved ones, the people who care for them or even remember their own identity. This can be very confusing and frightening. Finding ways to stimulate positive emotion and re-establish a sense of connection between people is vitally important. Smiles and laughter help us to connect socially; the touch of a caring hand or gentle embrace, can lift the spirit and diffuse anxiety, agitation and distress.

Social activities can also help people living with advanced dementia maintain positive connections with others. Objects designed for individual use can stimulate conversation, both verbal and non-verbal with carers or visitors. Designs can incorporate aspects of a person's life story, family interests, cultural motifs and familiar places to help rekindle positive and affirming emotional memories on which conversations can be based.

Objects are also vital for maintaining an outward connection from the body into the world. They provide a person with a sense of autonomy, opportunity for interaction and a self-determined choice about whether to respond. These activities, although small, can be highly significant for maintaining the personhood of someone with severely impaired mental capacity.

HUG by LAUGH

Compassionate Design was developed and tested through LAUGH research, a design research project that investigated ways to support the wellbeing of people living with advanced dementia through the development of playful objects. This three-year international interdisciplinary research brought together a team of researchers from three universities, in UK and Australia, and involved over 170 participants representing 70 organisations, including people living with dementia.

LAUGH research

LAUGH research sought to understand how playfulness, positive emotion and hand-use contribute to a sense of wellbeing for people in the advanced stages of dementia. Using participatory and co-design approaches underpinned by Compassionate Design, a set of six key themes were developed that were later used to shape six bespoke handheld playful objects designed for residents living in specialist dementia facilities in two Pobl Gwalia Care homes in South Wales (Treadaway, Taylor and Fennell 2019). Personal profiles (called 'Portraits') were developed to collect information about resident's individual preferences, lifestyle choices, favourite music, colours, favourite smells and family histories using qualitative interviews with family members, carers and the person living with dementia. The portraits were used as the starting point for design concepts. The 6 key themes identified from data analysis of the participatory workshops with health and care professionals, relatives of people living with dementia, also informed each design concept.

LAUGH playful objects were evaluated via a process of deep observation by researchers and carers. Each person who received an object was in the advanced stages of dementia and unable to communicate verbally. They were visited by the research team on three occasions over the three-

month period during the evaluation. The analysis also included qualitative interviews with professional carers, who knew the residents well, and could observe them every day. These interviews were used to corroborate the observational data from the evaluation.

One particular prototype design was found to have a significant positive impact on the health and wellbeing of the person it was designed for. HUG by LAUGH® is a soft wearable doll-like object that is designed to soothe and reduce anxiety (Fig. 2). It was created in response to the theme 'Nurturing', one of the six key themes that had emerged from the participatory design workshops. HUG® is designed to nurture the user via the experience of its weighted limbs (that provide a hugging sensation), while simultaneously providing an opportunity for the user to cuddle (nurture) the object. HUG® contains electronics, which provide a simulated beating heart and can also be programmed with a playlist of a person's favourite music.

LAUGH EMPOWERED

HUG by LAUGH® was designed for Thelma, a person living with advanced dementia who was on end of life care. She could no longer communicate verbally, was bedbound, unable to socialise and constantly fell when out of bed. At the end of the three-month evaluation, there was a significant improvement in her general health and quality of life. She began to speak again, was no longer in bed all day, her appetite returned and, after being given HUG, she had no further falls. Her carers considered that Thelma believed she had a child to care for and so a purpose to continue to live.

Interest from NHS in Thelma's story led to follow-on research (funded by Welsh Government ERDF), to evaluate HUG® via a larger study, in both hospital and residential care home settings. The LAUGH EMPOWERED PSCI is currently on-going

and includes qualitative evaluation using the Pool Activity Level (PAL) tool and Bradford Dementia Wellbeing Scale and involves 40 participants. The early findings from the study corroborate the earlier LAUGH research evaluation with Thelma and shows significant positive benefit of using HUG for people living with cognitive impairment. HUG by LAUGH is currently in the early stages of manufacture and is being developed via partnering with Alzheimer's Society through their Accelerator Programmeⁱⁱⁱ.



Figure 2: HUG by LAUGH®

Discussion

Compassionate Design methodology was used to underpin the design of HUG by LAUGH® and the three key themes of sensory, personalised and connecting were prioritised in its development. Textiles were used to provide a variety of tactile experiences and materials selected that were soft and comforting to touch; the music and rhythmic heartbeat contribute to HUG's® sensory qualities. The potential to upload a person's favourite playlist onto the magic box enables HUG to be personalised. It connects with the person physically on the body and also provides opportunities to stimulate conversations with others and so connect the person socially to those around them. The LAUGH and LAUGH EMPOWERED projects

have tested Compassionate Design methodology in design practice, through concept development to manufacture. It has resulted in a product that is having a significant positive impact on the quality of life of people living with dementia and cognitive impairment, both in hospital and living in residential care. The methodology is now part of the design curriculum, being taught to undergraduate and post-graduate students at Cardiff School of Art and Design, Cardiff Metropolitan University.

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ⁱ<https://www.who.int/features/factfiles/dementia/en/>

ⁱⁱhttps://www.lexico.com/definition/well_being

ⁱⁱⁱSee: www.laughproject.info



PHARMACY OF THE FUTURE: FROM MEDICATION TO PATIENT

Lorena Trebbi

Sapienza University of Rome, IT

Abstract

We are living an era of great social changes: progress in medicine led to increased life expectancy and ageing population, and the advent of digital fabrication technologies revolutionized the way we use and produce objects, expanding nowadays its range in the field of medications, 3D-printing drugs and cosmetics. This opens new perspectives for the future pharmacy, which in the last years has been witnessing a growing tendency toward self-diagnosis and self-care that reduced pharmacists to mere sellers. Moreover, there is a strong demand for better adherence to treatments and monitoring of chronic diseases, as well as for customization of therapies and devices. The future pharmacy will be grounded on hyper-personalization, getting closer to the laboratory dimension taking back the production stage. Hyper-personalization won't affect just aspects related to physiological user's need – with multiple-dosage and controlled-release drugs – satisfying also aesthetic requirements able to turn medical devices into fashion accessories. This scenario has been implemented into the “Craft Pharmacy” concept, within the project

‘Inspiring the Future Pharmacy’ (Scanu 2019). The research – based on Design Thinking and Metadesign methodologies – started from a preliminary activity involving focus groups and surveys, culminating in a workshop with PhD and MS design students. ‘Craft Pharmacy’ places itself between innovation and tradition grafting new technologies on traditional galenic, twisting the figure of ancient apothecary with a new pharmacist-maker, and reevaluating his role since personalization requires expertise. It is organized around three main services – display, consultation, production – with the open laboratory as core of the retail space. Future is a multiplicity of ideas embedded in today's practices (Kjaersgaard et al. 2016); through design then, acting as interpreter of a dynamic and complex reality (Antonelli 2008), is possible to bring qualitative improvement in the traditional pharmacy system, shifting the overall attention from medication to patient.

Keywords: hyper-personalization, new-craft, 3D-printed drugs, processes

Ageing Humanity and Future Healthcare

Humanity is ageing, elderly people are going to overcome children in the next future and there are more people at extreme old age than ever before. In 2010, eight percent of the world population was aged 65 or older, by 2050 this rate is expected to rise up to sixteen percent (WHO 2011).

This is the result of progress in medicine, and the consequent declines in death rates among older people. Moreover, this means also a shift in the leading causes of disease and death: from infectious and acute diseases, to chronic, degenerative and non-communicable ones. These factors have highlighted new needs, issues and opportunities, as a strong demand for the monitoring of such diseases, as well as better adherence to treatments, up to the customization of therapies and devices.

On the other hand, Internet has enabled a wider part of the population to easily access information about health and diseases, as well as the development of websites that aim to provide potential diagnoses based on self-reported symptoms. This fostered a growing tendency toward self-diagnosis and self-care, through the purchase of over-the-counter remedies or prescription drugs from web pharmacies.

Such condition, affected in the first place the pharmaceutical sector, turning the pharmacist – who historically had a well-defined status and recognisability, a trustworthy person, somebody to turn to and to rely on – into a mere seller of products from famous brands. A tendency that reflects upon the physical retail space of the pharmacies too: overcrowded with advertising posters and signs, saturated by the visual communication of pharmaceutical brands.

'Inspiring the Future Pharmacy' Research Project

Starting from these considerations, the research project 'Inspiring the Future Pharmacy' was born, in order to push pharmacists to rethink and redesign their pharmacy following the design concept proposed, adapting it to the evolving scenario both from a cultural and a technological point of view (Scanu 2019). The project stems from an idea of Banca IFIS in collaboration with CREDIFARMA, and involves two different design teams, one from Sapienza University of Rome coordinated by Prof. C. Martino and M. Scanu, and one from Polytechnic University Milan coordinated by Prof. S. Maffei and F. Foglieni. As regards the Sapienza team, it was made up of PhD students in Design from the Department of Planning, Design and Technology of Architecture (PDTA), and a selection of the best students from bachelor's and master's degrees in different design fields – Product, Service, Exhibit and Communication.

The research question was to imagine functional and strategic scenarios to innovate the system of Italian Independent Pharmacies, investigated through the Design Thinking approach, able to face complex issues with the tools of metadesign (Van Onck 1965), in order to rapidly develop innovative concepts and solutions. With the Design Thinking approach – first theorized by Herbert Simon in *The Sciences of the Artificial* (1969) – design becomes a tool for thinking and activate iterative processes to understand the users' perspective, challenge assumptions, and reframe problems with the aim of identifying alternative strategies and solutions. The envisioning ability of design, moreover, allows to translate the latest results of scientific research into real products and services available to society, 'culturalizing' technological innovations (Manzini 1990).

The scenarios developed within the project, are deliberately taken to extremes to show their potential, and presented in the form of metadesign concepts that can be declined within specific contexts implementing only part of the ideas proposed, as well as combining elements from the different concepts. The research project started with a preparatory phase articulated into both desk and field research and culminated in a workshop. The first phase consisted in Focus Groups discussions with pharmacists held in different Italian cities (Rome, Milan and Venice). Subsequently, surveys have been conducted in several pharmacies in Rome, selecting different areas from the city centre to the suburbs, and administering questionnaires to a sample of more than a hundred users, in order to analyse their behaviours. Finally, all the data collected were used to structure the workshop, intensive stage of confrontation, debate, and metadesign development. The workshop in turn, was organized according to the following steps: thematic keynotes through which depict the state of the art of pharmacies from the perspective of Materials and Technologies, Retail, Service and Communication Design; collective brainstorming; definition of the research matrix, with the identification of problems, opportunities and areas of intervention; final concept development.

Trend topics and new opportunities

Over the last decade, digital fabrication technologies have enabled hyper-customization and on-demand micro-production, revolutionising the way we use and produce objects. Nowadays, are expanding their range in the field of medications with the 3D-printing of drugs and cosmetics, allowing the customization according to dosage and patient biology.

The first experiments on 3D-printed pills were carried out at MIT – dropping precise drug doses onto thin layers of powder to

form a tablet (MIT Tech Talk, April 16, 1997) – and allowed an unprecedented dosage control as well as more precise time control of drug release. In 2015 the first 3D-printed drug – Spartiam, a drug to treat epilepsy seizures – was approved by FDA and released on the US market in 2016.

In 2017 the University of Michigan developed a new method for 3D-printing custom medication called Organic Vapor Jet Printing, through which layering multiple drugs on a single surface by spraying them as a fine gas (Shalev et al. 2017). In the same year BioLogic FabLab in Cava de' Tirreni, in collaboration with the Italian Institute of Technology (IIT) in Naples and the National Council of Research (CNR), developed Galeno, a first prototype of 3D-printer specifically designed for drugs microproduction (Fuschetto 2017). The technology developed allows the production of tailor-made controlled-release and multiple-dosage drugs, thanks to the specific design of the drug shell: subdividing the volume into multiple compartments and acting on the shape of compartments and on the thickness of their external shell, is possible to program the release of different drugs at specific times of the day. In this way a patient following a therapy with multiple drugs to assume during the day, is eased and assisted. Having to take just one pill appears way much simpler, especially for elderly people, with no need for complex pillboxes and daily reminders.

The 3D-printing technology has reached also the field of dermocosmetics: in 2018 Neutrogena designed maskiD, a tool for personalized skincare able to scan the user's face and produce an accurate micro 3D-printed treatment mask, specifically designed to fit each individual's characteristics. Users we'll be able to select separate ingredients for six different areas of their face – forehead, eyes, cheeks, nose, chin, and nasolabial folds. However, the first healthcare application of 3D-printing and scanning technologies has been in the field of orthotics: the digital

fabrication of orthopaedic devices lowered costs and production time, ensuring a better personalisation as well as a better support. Some examples are the 3D printed cast+ultrasound by DK Design, where the integration of low-intensity pulsed ultrasound (LIPUS) causes solicitations at the cellular level, resulting in an improved exchange of nutrients between cells; the Parametric Brace by Studio Bitonti instead, through algorithmic personalisation of the brace makes the therapy more effective, bypassing at the same time the high constriction of traditional braces; PIT insoles by RS group, can measure the plantar pressure and analyse the gait through scanning, in order to determine the specific resistance and flexibility of the printed structure.

The trend towards customization of medicines concerns not only humans but also other species. Often veterinary treatments are based on the consumption of standard drugs, which are very difficult to administer, resulting in a stressful condition both for humans and pets. Many pharmacies nowadays provide Veterinary Compounding, realising customized drugs turning tablets and pills into liquid preparations. Moreover, to the preparation is added a specific flavouring according to the taste of each animal species to which is intended, so facilitating their consumption.

Customization has hit the healthcare world starting from the need for better therapies specifically designed for the unique physiology of each patient but is also opening up the possibility to design the aesthetics of medical devices. An example is Anura by G. Califano, decorative-curative patches with controlled release of active principles, made from biomaterials using additive printing techniques. Moving further and reaching the more futuristic and technological advanced outputs, we find the Adaptive Skin Suits by C. Cooper, a concept for future metabolic suits – inspired in their morphology by organic tissues – that once worn can treat damaged organs

or body parts. Medical devices are so turned into fashion accessories, as happened in the past century with prescription glasses, and in some cases can become part of the body itself: the DermalAbyss project, from a collaboration between MIT and Harvard Medical School, is a proof-of-concept that explores the possibilities of substituting tattoo's inks with Biosensors – liquids able to change colour reacting to alterations in the blood flow – turning the body surface into an interface, an interactive display which measures and communicates from the inside out of our body.

Craft Pharmacy

Craft Pharmacy is one of the five design concepts developed by the Sapienza team as a result of the workshop¹, focused in particular on the aspects and opportunities related to the latest techno-scientific innovations previously described.

Despite grounded on technological innovation, the proposed scenario is developed from a human-centred perspective with a shift of attention from medications to patients, allowed by the high level of customization enabled by new technologies that, thanks to their ubiquity and ease of use, brought a democratisation of production processes. Technology then is in the service of society, in a pursue for a social-driven innovation more than a technological-driven one.

Moreover, new technologies are here grafted on traditional techniques, giving rise to the convergence between tradition and innovation. 3D-printing techniques are twisted with craft skills and galenic formulations in the new figure of the hybrid pharmacist, who stands between an ancient apothecary and a pharmacist-maker. The pharmacy gets closer to the laboratory dimension of fablabs taking back the production stage, self-producing 3D-printed drugs and cosmetics, other than traditional galenic and veterinary compounding.

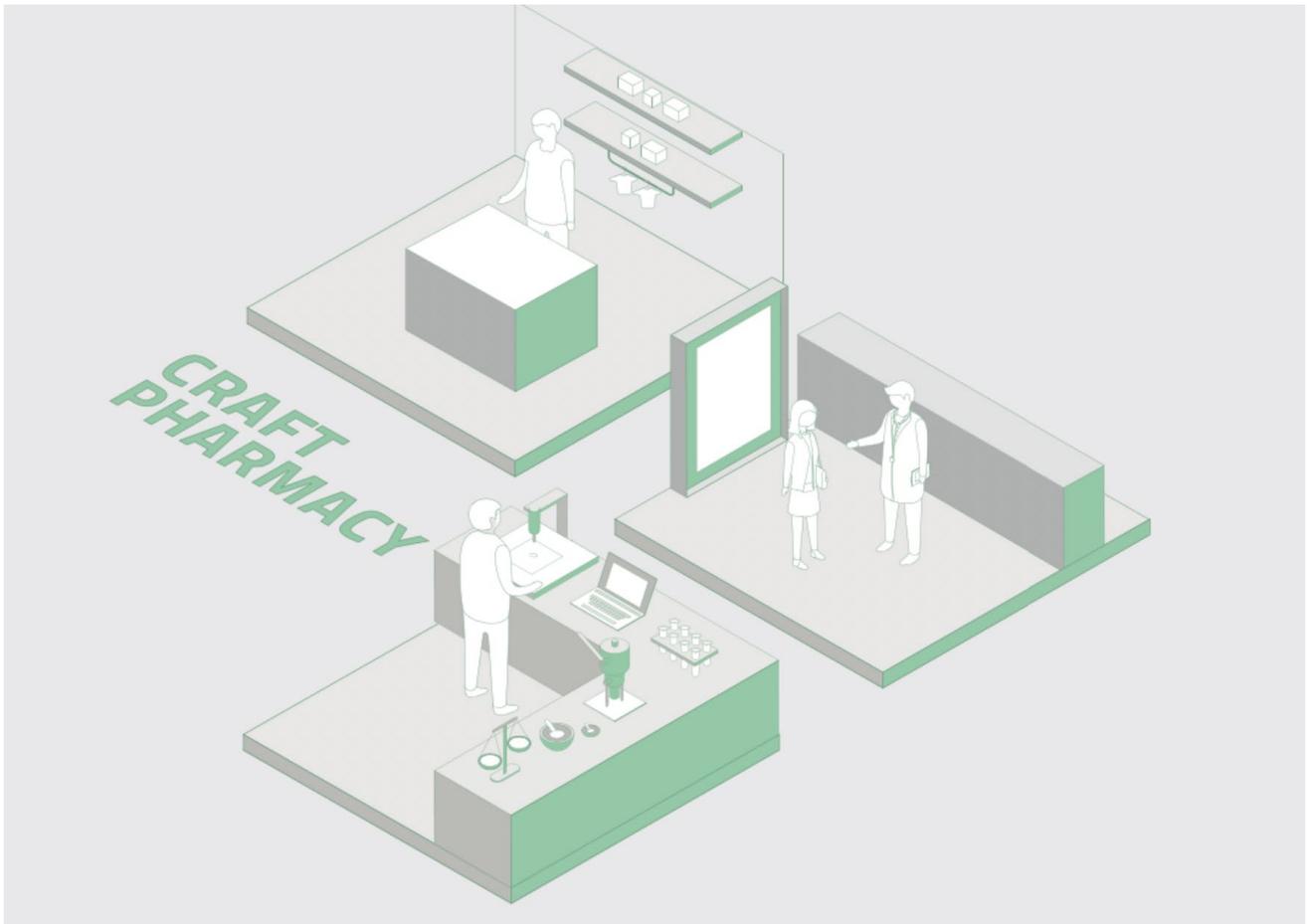


Figure 1: Craft Pharmacy's services – display, consultation, production

Customization concerns not only aspects related to the physiological needs of the patient, but also meets aesthetic requirements that turn medical devices – orthotics, bandages, wearables, up to futuristic metabolic suits – into fashion accessories, envisioning the future pharmacy as an actual boutique where to buy curative clothing and accessories.

The pharmacy is structured around three main services: display, consultation and production. The display is for the showcase of products that can be selected for customization, as well as for the ingredients used in the galenic formulations, allowing patients to know and select the most suitable for their wellbeing assisted by the pharmacist. Within the consultation, expert advice from external professionals – medical doctors, orthopaedists, dermatologists, nutritionists – is made available for the patient, in order to provide a deeper insight

on the services offered. Finally, there is the production of 3D-printed controlled-release and multiple-dosage drugs, customized cosmetics and orthotics, tailor-made galenic preparations and veterinary compounding. The centrality of customization processes is reflected also in the retail space of the pharmacy, whose cornerstone is the laboratory – emphasized by glass walls which allow the user to visually connect both from the inside and from the outside of the pharmacy – around which is revolved the display area, together with a private space for the consultation.



Figure 2: Craft Pharmacy – Display. Patients can look at and select products available for the customized production, which takes place in the adjacent production Lab

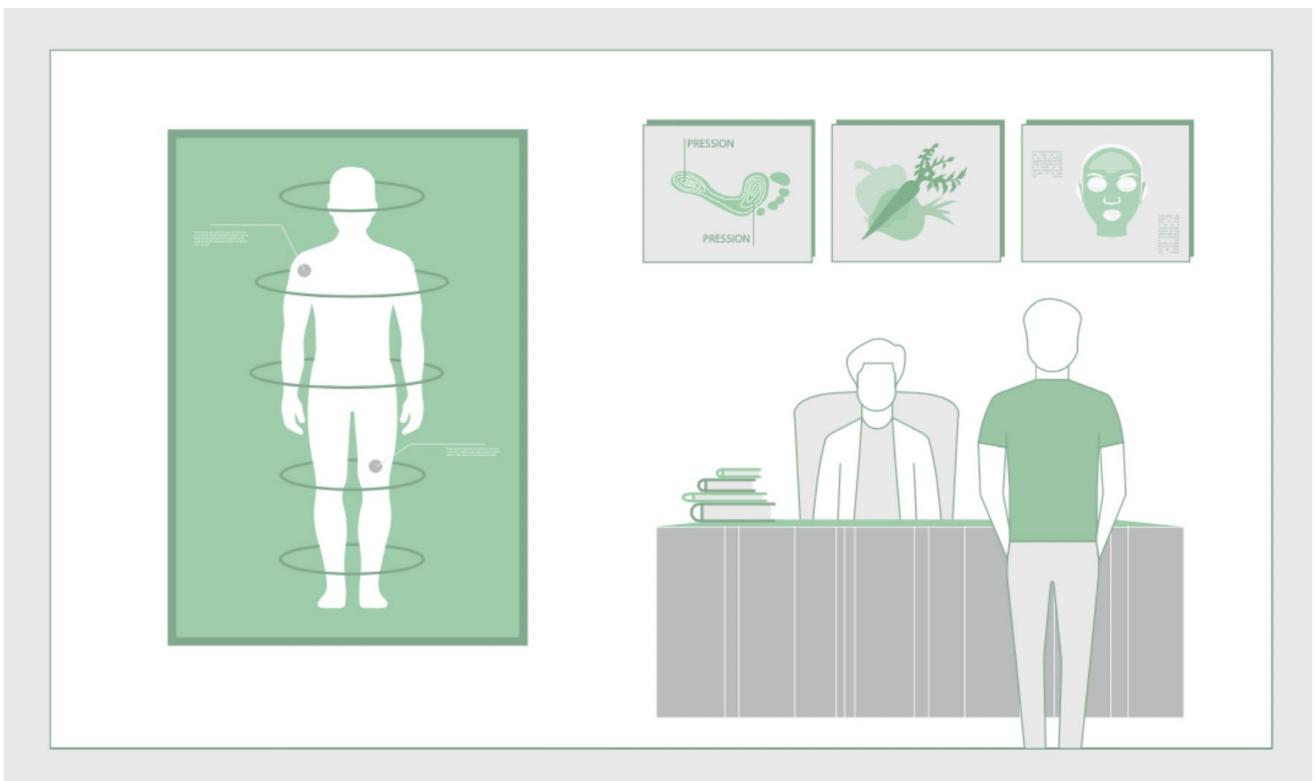


Figure 3: Craft Pharmacy – Consultation. Part of the retail space is dedicated to consultation with experts from the clinical field, to analyse patients' specific needs and offer them tailor-made and effective treatment

Conclusions

In the proposed scenario, the Craft Pharmacy will require an update of the specialized knowledge of the pharmacist, who will have to be able to manage the whole production process, including 3D-modelling, printing and scanning. University education will be responsible for the training of such professional figures, while confronting with experts in the field of 3D manufacturing. Moreover, relying on the availability and state of development of the technologies involved, is possible to outline a feasibility timeline with the services that can be activated in the short, medium and long term. Galenic, veterinary compounding and tailor-made cosmetics are all currently available services, while 3D-printing and scanning for drugs and orthotics production, could be implemented in the medium term. When all this has become easily accessible, the production of metabolic clothing and curative accessories will be introduced in the Craft Pharmacy, that will be so complete in all its parts.

The high level of customization of 3Dprinted drugs, hardly fits the current regulations based on standardization of processes and will require different strategies in order to assure safety and quality control. Technology changes quickly, making it often difficult to keep up with laws and regulations, which need to become more proactive, dynamic and responsive. Despite the novelty of such matter however, risk-based control strategies are feasible, as shown by the FDA approval of a 3D printed drug back in 2015 (Norman et al., 2017). Through data driven regulatory intervention and a principle-based approach (Fenwick et al., 2017), is possible to develop strategies to assure quality control in every step of the process – raw materials selection, 3d-model, software, manufacturing process, and final product – (Marzuka et al., 2016), enabling the implementation of the Craft Pharmacy concept in real life.

The centrality of processes entails a renewed idea of work culture, characterized by the rediscovery of a stronger relationship between individuals and their jobs, and a social recognition of crafts (Micelli 2011). This however does not mean a return to the past, but a reinterpretation of the craftsman's features into the contemporary scenario. According to Sennet, the craftsman is the one who pursues for a work done to perfection, who is committed in the achievement of higher standards, driven by the desire to improve quality through technique and exercise (2008).

Taking the production stage back, makes that the skills and responsibilities of the pharmacist get valorized and enhanced. The customization according to specificities of each patient, will require a high level of expertise which pharmacists have already acquired, and can now implement and put into action within the Craft Pharmacy.

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LESSONS LEARNED FROM CO-CREATING A PERSONAL WAYFINDING APP WITH PEOPLE WITH A VISUAL IMPAIRMENT

Joey van der Bie¹, Christina Jaschinski² and Somaya Ben Allouch¹

¹Amsterdam University of Applied Sciences, NL

²Saxion University of Applied Sciences, NL

Abstract

Travelling independently in an urban environment is challenging for people with a visual impairment (PVI). Current Wayfinding-apps lack detailed environmental information and are often not fully accessible. With the aim to design a wayfinding solution that facilitates independent travel and incorporates PVI needs and wishes, we deployed a co-creation design approach with PVI and professionals as co-creators. Our combination of different co-creation techniques and iterative prototyping expands the related research on wayfinding solutions and allowed us to zoom-in on specific features. Our approach started with a user-requirements analysis through self-experience sessions, observations and focus groups. This was followed

by iterative prototyping with user evaluations in controlled indoor and outdoor environments. Over a period of two years we created an accessible wayfinding solution in co-creation with 31 PVI and 19 professionals. This resulted in an optimized accessible interface, a personalized route, personalized wayfinding instructions and detailed orientation and environmental information. Lessons learned for co- design with PVI included setting up an accessible workshop environment, applying diverse evaluation methods and involving reoccurring participants.

Keywords: co-creation, co-design, visually impaired, assistive technology, wayfinding, navigation, urban space, smartphone



Introduction

To overcome difficulties with wayfinding, people with a visual impairment (PVI) use wayfinding-apps. Current apps often lack detailed environmental information and are not fully accessible. To design a wayfinding solution that facilitates independent travel, we deployed a co-creation design approach. Our approach built on related research, expanding and combining common techniques, leading to an adapted co-creation approach for PVI. This allowed us to zoom-in on specific features and to create an accessible wayfinding app. This paper presents our iterative design approach and the lessons learned.

Related Research

Earlier research has involved visually impaired users in designing wayfinding solutions. For each phase we describe the user's influence using this method.

Need Analysis

For gathering requirements and generating ideas, techniques as observations, interviews and group discussions have been used.

Atkin et al. (2015) explored limitations and improvements of wayfinding signing with a digital layer through observations. This method allowed for real-time detection of shortcomings. Petrie et al. (1997) gathered user requirements through interviews and group discussion with users and professionals. This approach gave participants the opportunity to express their problems, desires and ideas without having to consider the limitations of the technology.

Prototyping

Williams et al. (2015) explored the design of new navigation technology using workshops. In a small group setting participants and facilitator crafted a new navigation wearable using available

hardware components. By changing the material and activity, the sessions gave insight into design considerations that typically do not arise in group discussions or are easily overlooked by designers.

Both the MOBIC system (Petri, 1997) and the Navcog system (Brady, 2015) were explored via Wizard-of-Oz prototype studies. Wizard-of-Oz studies allow the researcher to evaluate the implementation of an idea before the system is fully developed. In these studies, proof-of-concept prototypes are presented to the user as a working solution, when actually the functionality is simulated by a person (wizard).

Brady et al. (2015) combined multiple designs in their prototype evaluation. This allowed them to expand the influence the user can have over a design in one test session. Atkin et al. (2015) evaluated prototypes with PVI and professionals over multiple iterations, allowing the design to evolve. The iterations allowed the user to get familiar with the prototype and influence the design step-by-step. The Navcog app was evaluated in a shopping mall while accompanying the user (Ahmetovic, 2016). This outside-the-lab, but relative safe environment, allowed for testing while the app was not fully implemented.

User Involvement Activities in Our Study

Designing a wayfinding solution for PVI is challenging due to variations in visual limitations and accompanying symptoms. To incorporate their perspective we involved 31 PVI with various visual impairments and 19 professionals as co-designers. Our co-creation approach started with the context specification and needs analysis followed by iterative prototyping and user evaluations in controlled indoor and outdoor environments.

Phase 1: Context Specification and Need Analysis

Through self-experience sessions, observations of an orientation and mobility training, and a series of focus groups, we specified the context, identified the main problem areas and formulated the user requirements.

To empathize with the PVI's experience, we participated in a wayfinding exercise with special glasses that simulated visual impairments. This self-experience session helped us to understand common problems, fears and frustrations PVI encounter while navigating.

To further empathize with PVI's experience and explore the design space of wayfinding applications, we observed two PVI (male, age 41 and female age 43) during an orientation and mobility (O&M) training with smartphone apps. The session consisted of route planning, wayfinding and an evaluation of the navigation experience.

Building on the insights from these earlier sessions a focus group study was set up. We conducted four focus group sessions with a total of 16 PVI (7 male, 9 female; age 43-72) with various visual impairments (e.g. blind, limited sight and milder visual impairment). Group sizes were small, to create a comfortable and noise free environment. A fifth focus group was organized with 9 care professionals who support PVI with navigation and accessibility. During the focus groups four themes were explored: (1) current navigation problems (2) experience with navigation aids (3) preferences for a new wayfinding technology and (4) exploration of an initial concept for the wayfinding app. The application concept was presented as a scenario (user journey story). The scenario described route planning, different route situations, app functionalities and feedback modes.

Table 1. Iterative prototyping sessions in chronological order

No.	Session Type	Participants	Activity
1	Clickable prototype test on route preparation (smartphone)	10 PVI (age 46 – 63, 3 male, 7 female), all PVI participated earlier	App walkthrough
2	Clickable prototype test on route preparation (smartphone), Wizard-of-Oz test on multimodal communication (smartwatch)	4 PVI (one male, three female) (age 46 – 57), 4 PVI participated earlier	App walkthrough followed by indoor navigation task
3	Co-creation workshop with clickable prototype 1 & 2 (smartphone)	6 PVI, 5 care professionals, 1 ICT professional and 4 Interaction Design professionals, 4 PVI participated earlier	(1) Discussion of a user journey map to validate the wayfinding problem experience (2) Evaluation of prototypes.
4	Case study on route preparation and clickable prototype test on wayfinding (smartphone)	1 PVI female, age 71, 1 O&M professional	(1) Design app and route with the participant and professional (2) App walkthrough, and outdoor navigating task
5	Clickable prototype test on route preparation (smartphone)	6 PVI (3 male, 3 female, age 50 – 80)	App walkthrough
6	Wizard-of-Oz test on multimodal communication (smartphone, smartwatch, bone conducting headset)	2 PVI (female, age 30 and unknown)	App walkthrough, and outdoor navigation task (in a safe environment)
7	Wizard-of-Oz test on wayfinding messages (smartphone, bone conducting headset)	6 PVI (4 male, 2 female, age 44 – 69), 6 PVI participated earlier	App walkthrough, an outdoor navigation task with expanded and condensed wayfinding messages
8	Wizard-of-Oz test on multimodal communication (smartphone, smartwatch, bone conducting headset)	4 PVI (3 male, 1 female, age 25-48), 2 PVI earlier participated	App walkthrough, followed by outdoor navigation task with expanded wayfinding messages and multi-modal communication.

Phase 2: Iterative Prototyping

In the second phase we developed our wayfinding solution with PVI and professionals as co-designers through iterative prototyping. The input from phase 1 served as the groundwork for this phase. The app matured from clickable prototypes, to Wizard-of-Oz prototypes, to a working prototype (Figure 1 and 3). We applied different test setups with different stakeholders (Table 1). We slowly expanded the app functionality and focused on different aspects, including route

preparation, communication methods and personalization. By applying a hands-on approach through clickable prototypes, user interface design was a factor that was improved through each iteration. User feedback was gathered via the think-a-loud method and a questionnaire

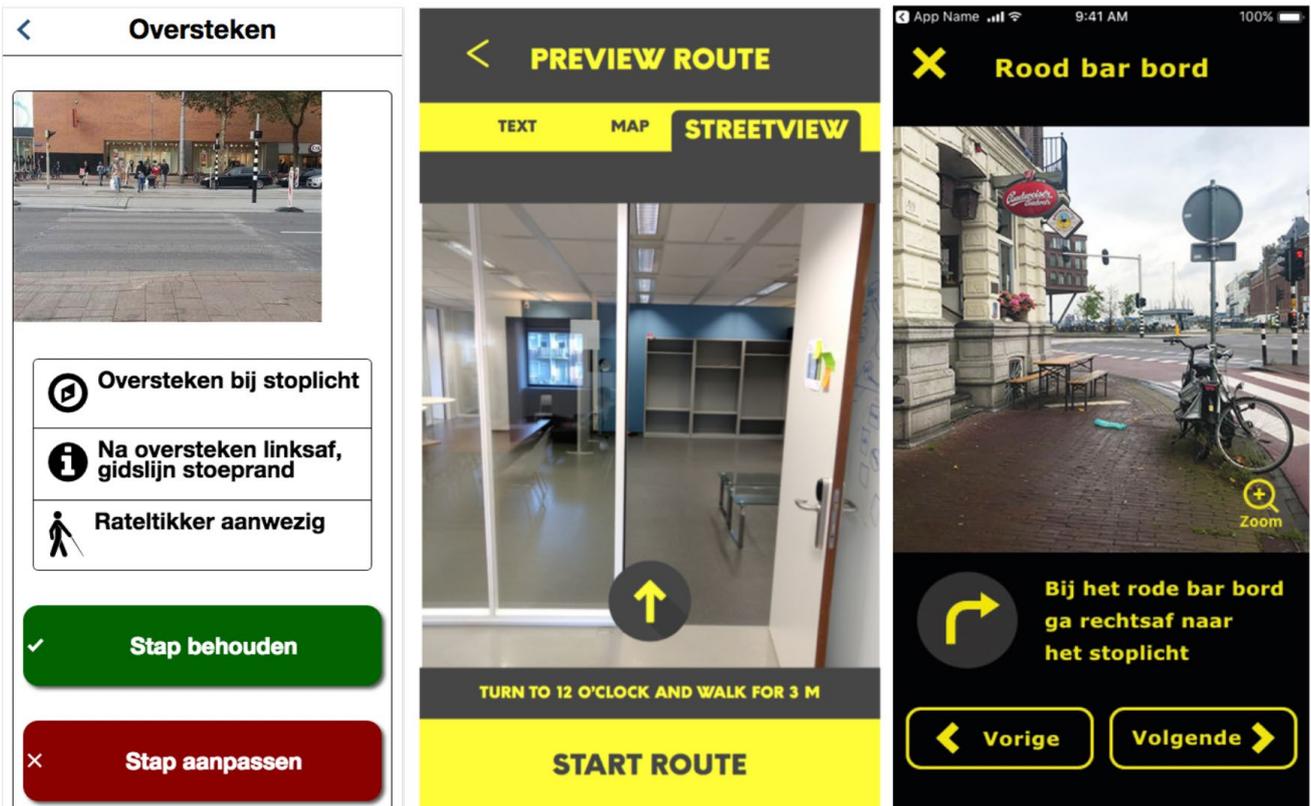


Figure 1: Clickable prototypes for route preparation and wayfinding. From left to right: a) Session 1 web-app, b) Session 2 web-app, c) Session 4 iPhone app

Clickable Prototypes

The first clickable prototype (sessions 1 and 3) was a web-app for the smartphone (Figure 1a). Route information was provided via categories and could be customized. The second clickable prototype (sessions 2 and 3) was a web-app for the smartphone with Android smartwatch app (Figure 1b). Route information was selected via a wizard interface. With both designs, participants encountered accessibility issues but were very positive.

The third clickable prototype (session 4 and 5) was a native iPhone app (Figure 1c). The app allowed the participants to trigger voice messages during wayfinding. The participant of session 4 wanted to use the app in daily life. Participants of session 5 encountered accessibility and navigation issues and were not satisfied with the inconsistency of the wayfinding message structure.

Co-Creation Workshop

The effectiveness of design 1 and 2 were compared in a co-creation workshop (session 3) (Figure 2). The participants were divided into four groups with PVI and care professionals in each group. Interaction Design professional acted as facilitators for each group. Participants used their own smartphone or provided devices, next to an App print-out on A3 paper. Both apps were considered an improvement over existing wayfinding apps. However, the customizable app was preferred over the wizard-style app.



Figure 2: Co-creation workshop with prototypes, accessible tools and facilitators.

Working Prototype

The working iPhone app prototype (Technology Readiness Level 6) was used in sessions 6, 7 and 8. An Apple watch app and bone conducting headset allowed for multi-modal communication during wayfinding. Messages were provided via vibrations, message type icons and short instructions on the smartwatch accompanied by audio tunes and voice messages on the bone conducting headset (Figure 2). For session 7 and 8, a route of 1 km in urban Amsterdam was set out, including obstacles that are typically encountered outdoors. The wayfinding messages were triggered via Bluetooth beacons, activated by a researcher, ensuring that at messages were presented by the app at specific locations. When the route is provided online the app could be used on an iPhone in any location where Bluetooth beacons or GPS are available.



Figure 3: Bone conducting headset, iPhone and Apple watch app prototype for wayfinding via multi-modal communication. A message used in session 7 and 8 is displayed on the devices.

In session 6, one participant who had little experience with wayfinding apps, had difficulties with navigation and the content and structure of the wayfinding messages.

A new wayfinding message structure was integrated in the app and evaluated in session 7 (van der Bie, Jaschinski and Ben Allouch, 2019). Despite some remarks all participants found the new app and messages an improvement over the existing wayfinding solutions they used.

The full multi-modal wayfinding system with smartphone app, smartwatch app and bone conducting headset was evaluated in session 8 (van der Bie, Ben Allouch and Jaschinski, 2019). Although not all vibration patterns were detected, participants were positive about the new multi-modal system.

Lessons Learned

Over a period of two years we created an accessible wayfinding solution in co-creation with 31 PVI and 19 professionals. The combination of involving users through different phases and prototypes allowed for the detailed evaluation of different aspects of the navigation app resulting in an optimized and accessible interface, a personalized route, personalized navigation instructions, and detailed orientation and environmental information.

Lessons Learned Phase 1

In Phase 1 we performed self-experience sessions to empathize with the user's wayfinding experience. Although this was very valuable, the designer's experience does not reflect the broad spectrum of wayfinding issues the visual impaired community experiences. Therefore, we advise to use self-experience sessions in combination with other requirement gathering methods.

From the observation sessions we learned about the limitations of currently available software regarding accessibility and interface design. Also, we got a first impression of what type of information is useful and how this could be communicated to PVI.

We performed focus group sessions with a diverse sample of PVI and professionals. The PVI shared what users want from a wayfinding app. The professionals confirmed these requirements and provided new and interesting aspects that PVI did not discuss or forgot to share. The user story provided a fast way of receiving feedback before an actual app was created. User experience sessions can take up multiple hours, limiting the number of users that can be involved. Through our group setup and by involving professionals we included multiple perspectives and gained initial feedback in a time-sensitive manner.

Lessons Learned Phase 2

Co-Creation Workshop

The workshop gave insights into missing features and necessary design adjustments. The tools used in the workshop facilitated the process and should be selected carefully and be adapted to the PVI participants. The online clickable prototypes worked well for the user evaluation. Although the PVI participants were often not able to read the enlarged printouts, they still served as a valuable tool to collect feedback. The group facilitator allowed the discussion to continue while organizing the feedback.

We also learned that, despite forming subgroups the session was too crowded and noisy, resulting in extra stress and fatigue for the PVI participants. One participant left due to the noise. For new co-creation workshops with PVI we would recommend arranging only one group per room.

For most sessions we provided participants with detailed travel instructions and a pick-up from public transport. They were used and appreciated by the participants. Still, despite the accessibility of the location, for the workshop and focus group sessions we encountered participants cancelling the meeting at the last moment. To still get valuable results, we recommend to account for a one-in-five cancellation factor.

Case Study Design

The case study design allowed zooming-in on specific parts of the app and receiving fast feedback from one representative of the user base. The difference in experience between the case study participant (session 4) and other participants (session 5) showed that when designing an app for one person, directly generalizing for the full target audience can be difficult. Still, combining this design method with an evaluation by a larger user group allowed for detecting important features that were missing, as the inconsistency of wayfinding messages.

Iterative Prototyping

Through iterative testing with mostly reoccurring participants, we explored different user interfaces, various communication methods (with wearables), and slowly transitioned from save indoor environments to urban Amsterdam. New participants showed that the learning curve of new technologies such as wearables can be high. A short explanation was not sufficient for participants to familiarize with the multi-modal system. The inclusion of participants that were familiar with the system from previous sessions allowed for a smaller learning curve and a more authentic setup.

We found value in changing variables slowly towards real-life situations. We tailored our wayfinding message structure through sessions 1,2,4,5,6 and 7, starting our experimental setup with app walkthroughs, followed by lab and enclosed outdoor wayfinding sessions, finishing with outdoor wayfinding sessions. The transition to a more challenging environment resulted in finding new errors in message structure and content. By creating a user test for the wayfinding message feature (session 7), we could zoom-in on the effectiveness of our solution.

Conclusion

By involving the users as co-designers of our wayfinding solution, we were able to create an accessible design for PVI. Our approach differs from earlier approaches with regard to the methodological diversity and many iterations. This allowed us to focus on specific features such as the structure and communication of the wayfinding messages.

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KNEEHAB: A SYSTEM FOR SELF-MONITORING KNEE OVERSTRETCHING

Sanne van der Linden^{*,1}, Huizhong Ye^{*,1}, Shiyuan Huang^{*,1}, Panos Markopoulos¹, Wouter Hoens², Ton de Lange²

**Authors contributed equally to the paper*

¹Eindhoven University of Technology, NL

²Libra, NL

Abstract

Knee overstretching, a condition where the knee bends too far backward, requires treatment and proper guidance otherwise it can deteriorate causing pain and knee instability. Patients may overstretch their knees because they lack awareness of their knee posture. Here we explore how to address the need for tele-rehabilitation and self-tracking of knee posture throughout the day.

Kneehab is an at-home wearable system consisting of a small knee brace with sensors, a pocket-size module connected to the brace which collects the data, and a smartphone application providing feedback and personalized reminders that apply a

persuasion profiling approach. An initial evaluation by four physiotherapists, two knee overstretching patients and nine domain experts, is encouraging regarding the perceived potential of the Kneehab system as a therapeutic aid. Preliminary user tests (N=4) show a sensor accuracy of 5 degrees. Future research will seek to empirically validate the efficacy of the system as a therapeutic aid and to explore its potential in enriching the communication between the therapist and the patient.

Keywords: rehabilitation, behavioural change, wearable technology, data visualization, personalization



Introduction

Knee overstretching, also called knee hyperextension or genu recurvatum, pertains to the extension of the tibiofemoral joint (the knee) beyond the zero degrees or neutral position (Loudon, Goist and Loudon 1998). This behaviour is very common in rehabilitating patients, especially those with neurological diseases, muscle tone diseases or trauma accidents. Hyperextension due to sports injuries are excluded because it is treated differently. Without timely treatment and proper guidance, it will develop into more serious knee diseases in the long run, causing pain and knee instability (Loudon, Goist and Loudon 1998).

Patients experiencing hyperextension need to learn to keep their knee in the right position. At rehabilitation clinics, physiotherapists help patients recover by making plans, guiding them in training sessions, and reminding them not to overstretch their knees. The rehabilitation should ideally continue at home. We seek to develop technical means which will allow patients to be aware of their knee posture and to be reminded to correct it when necessary. The contribution of this design driven research is an initial proof of concept and an initial evaluation of a wearable system for self-monitoring knee posture through immediate and long-term feedback.

Understanding the User Group

We interviewed a physiotherapist, two patients, and three domain experts and observed a physiotherapist session to gain a first-hand impression of the target user group and their context. We found that most adults with knee overstretching are between 45-65 years old and have physical conditions, like muscle deterioration or neurological disorders. In the specialized clinic we visited, patients stay initially for four weeks, after which they visit the clinic three times a week for eight weeks to increase strength, condition, balance and coordination. After 12 weeks the patient is referred to a general physiotherapist.

Patients in this group are quite motivated, since they are less able than before to walk, hindering their family, social, and work life. Often, they do not realize they overstretch their knees and relapse into old habits, especially if they are focused on other activities. For them overstretching feels like they are walking or standing naturally. On the contrary, walking or standing normally feels like falling and costs them a lot of effort. During rehabilitation training the physiotherapist helps patients realize when they overstretch their knee and why they should not. Unfortunately, when patients find themselves back at home they still overstretch their knees and could use reminders to increase their awareness of their knee posture and triggers to correct it. For this purpose, we set out to provide a wearable device to self-track the knee angle.

Related Work

There are various techniques to measure angles on the body. Shen et al. (2016) and Papi, Bo and McGregor (2018) measured the angle of fingers using rubber bands. Gibbs and Asada (2005) and Gioberto, Compton and Dunne (2016) used conductive thread to measure angles. There are also several commercial products which most typically use IMU (Inertial Measurement Units) to measure the angle (Vitaly et al. 2017), such as the Rover (as of December 9, 2019, the Rover home page on <https://rover.health/>) for remote patient monitoring with the focus on gait and balance. This can be extended to also using a bend sensor together with an IMU, such as Claris Reflex (as of December 9, 2019, the Claris Reflex home page on <https://clarisreflex.com/overview/>) to measure knee flexion and body postures. There also are laboratory products, such as BioStampRC (Lonini et al. 2017), which are able to retrieve data about muscle activation and movement by utilizing EMG. However, none of these systems target knee overstretching.

The Design of Kneehab

We approached the design of the system as a case of a behaviour change support technology. We carried out two design workshops. In the first, a Com-B analysis was carried out based on Michie's behaviour change wheel approach (Michie, van Stralen and West 2011). Based on this we decided to provide support for patients to be aware of their knee (increasing their psychological competence for the desired behaviour) and persuasive communications to act as triggers for them to adapt their knee posture. The resulting application consists of a wearable device for tracking, and a web application to provide the relevant feedback which are described below, see Figure 1.

The **homepage** displays basic information, aiming at providing the user with an overview of their rehabilitation and knee overstretching situation. The four cards on the bottom link to four main pages separately.

The **'Rehab Diary'** page is in the form of a chatbot, providing personalized triggers and feedback as well as helping users reflect on the day. In the morning, a persuasive message is sent to trigger users to change their behaviour framed according to the social influence strategies by Cialdin (2009). However, since it is known that individuals respond very differently to these strategies, we adopted the persuasive profiling approach by Kaptein et al. (2015), where the system selects from a pool of 67 persuasive messages that implement a strategy to which the patient responds most favourably. The implicit profiling is based on objective measurements of differences in knee overstretching over days, e.g., if the knee overstretching improved the strategy implemented in the persuasive message on that day is weighted more favourably. Over time a persuasion profile is built allowing to distinguish which strategies work best for this persona and which not, and thus select messages appropriately. The messages in the pool are based on four of

the six influence principles, see Table 1. For rehabilitation goals to be effective, users need summary feedback about progress in relation to their goals (Locke and Latham 2002), so a daily summary message is sent at the end of the day, see Table 1. After the summary message, some questions are presented to guide users to reflect on their behaviour and emotions of the day. They can choose an icon or type their experiences.

The **'Statistics'** page shows the last 7 and 30 days data of knee overstretching in order to increase the user's self-liberation (Prochaska and Redding and Evers 2015). Below the detailed data is the trend of knee overstretching related to context (time and activity) based on the last seven days data. With the 'Statistics' page, the users can explore cause-and-effect relationships between their life routine and knee situation.

The **'Set Your Goal'** page allows goals to act as commitments of the users in the action stage of behaviour. An overview of the goal process is at the top of the screen to increase the effectiveness of the goals (Locke and Latham 2002). Below is the editing area where the users can set their (sub-) goals by themselves or together with their physiotherapists.

Table 1. One example persuasive message per principle and examples of the summary messages (the ... should be filled in based on the patient data).

Category	Principle	Message
Persuasive messages	Authority	Try not to overstretch your knee today. According to the physiotherapist, this is a good way to rehabilitate.
	Consensus	9 out of 10 patients who exercise at home reduce their knee overstretching. You can do it!
	Consistency and Commitment	You can do this! Finish this rehabilitation process. See how far you have come already!
	Scarcity	There is only one chance a day to reduce knee overstretching. Take that change today!
Summary messages	Condition: Not on the first day of usage	In comparison to yesterday to overstretch your knee ... times less/more
	Condition: At least 1 goal is finished	Congratulations, you already completed ... goals in the last ... weeks.

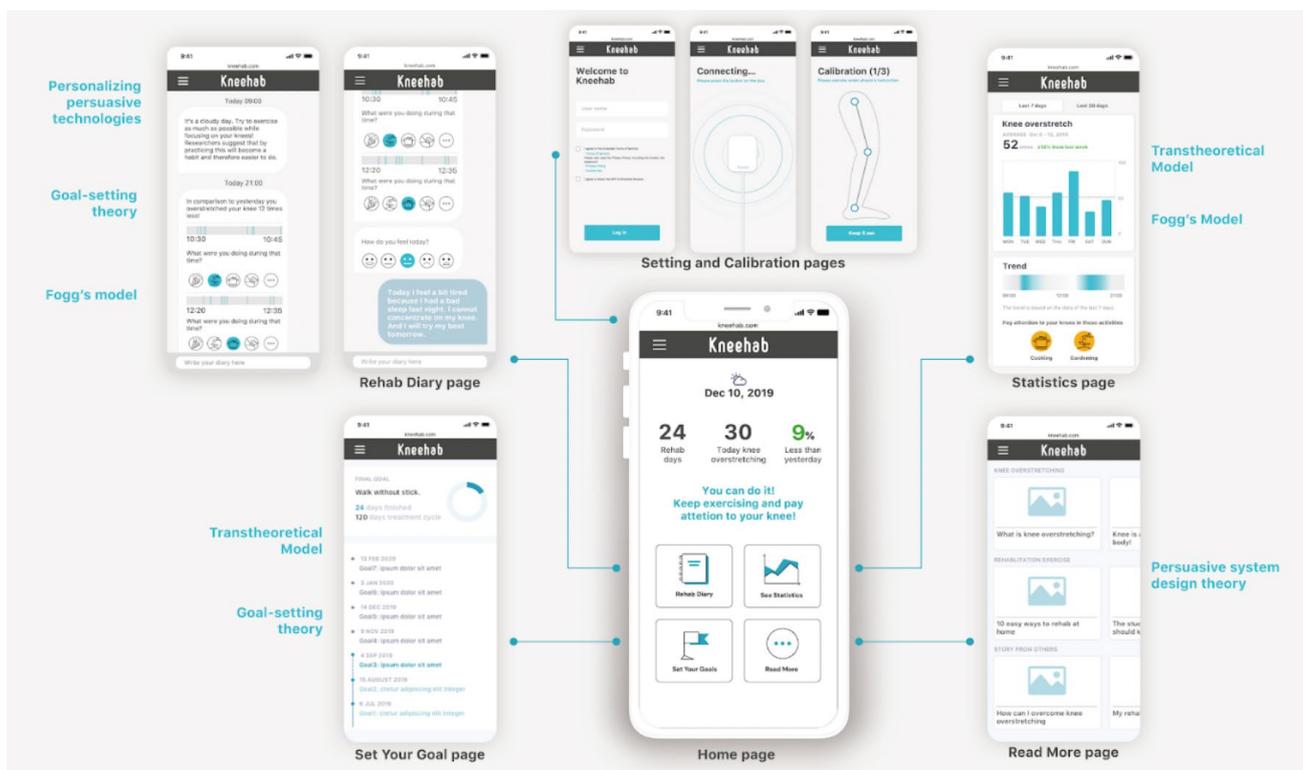


Figure 1. The Behavioural change application.

The 'Read More' page provides the users with articles and videos about rehabilitation and knee health. And more pages were designed for settings and calibration when users use it for the first time since everyone's knee is different.

Kneehab System Overview

The system overview of Kneehab is illustrated in Figure 2. The web application displays the data from the brace. The brace

consists of a box and a knee brace, which are connected by a flat cable. Users can put the box on their belt or in their pocket, see Figure 3. The box (69*54*20 mm) contains an ESP8266 mini which sends the data to the database and a lithium-ion battery to power everything. The brace consists of a vibration motor which starts buzzing if the user overstretches and a flex sensor (4.5") to measure the angle of the knee, due to the change in resistance if the sensor is bent.

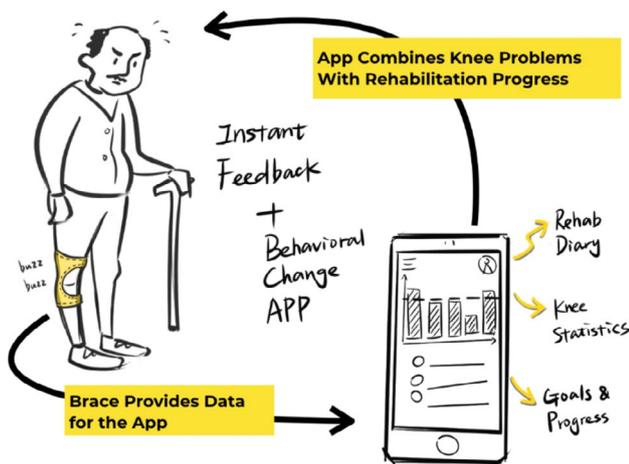


Figure 2. System overview.



Figure 3: User wearing the brace.

Preliminary Evaluation of Kneehab

Method

The user test involved patients, physiotherapists and domain experts. Four participants (one with overstretching) tested the brace. They were asked to put on the brace, and do five in-place steps with knees in normal position (set A) and knees extending as far back as possible (set B). This was repeated twice. The resistance of the sensor was recorded and hip-knee-ankle angles were measured manually by using a screen angle measurement tool on the recorded video. Then the resistance was mapped to the correct measured angle.

First the system was demonstrated, then participants filled in the CEQ (credibility and expectancy questionnaire) and after they gave detailed opinions. Interviews were transcribed and analyzed using thematic analysis (Braun and Clarke 2006). The CEQ (Deville and Borkovec 2000) was filled in by four physiotherapists, two knee overstretching patients and nine domain experts.

Sensor Evaluation

For every person the data was plotted as in Figure 4. It can be seen that in the local minima the red line has a lower sensor value than the green line, this could indicate that it should be possible to identify knee overstretching. For this person, a window size of 18 deci-seconds is used to capture the local minima of the filled lines, which resulted in 80 data points. The relation between those points in the local minima and the sensor value are plotted in Figure 5. The R-squared value, 0.8695, is quite reasonable (the R-squared values of the 3 other participants were 0.8767, 0.590 and 0.489). It was also noticed that when people wore slightly wider clothing it was harder to get an accurate angle and this might explain the lower R-squared values. The accuracy ranged from approximately 5 to 20 degrees. The slope for the value-degree function is different for every person, probably due to the different shapes of the knee.

Step patient

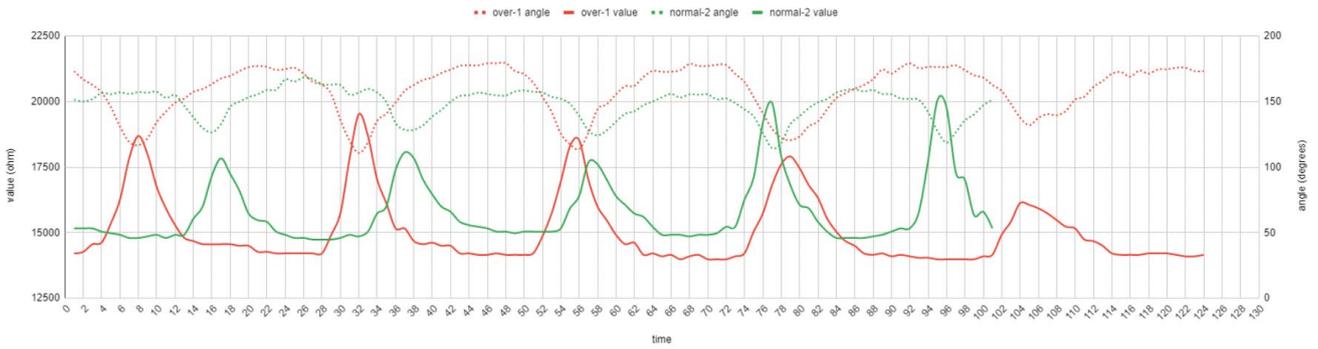


Figure 4, Patient data while stepping, the sensor data over time (deci-seconds) in the filled line (left y-axis) and the actual angle of the knee are the dashed lines (right y-axis). The red lines are with overstretching and the green lines are without overstretching.

Step value patient

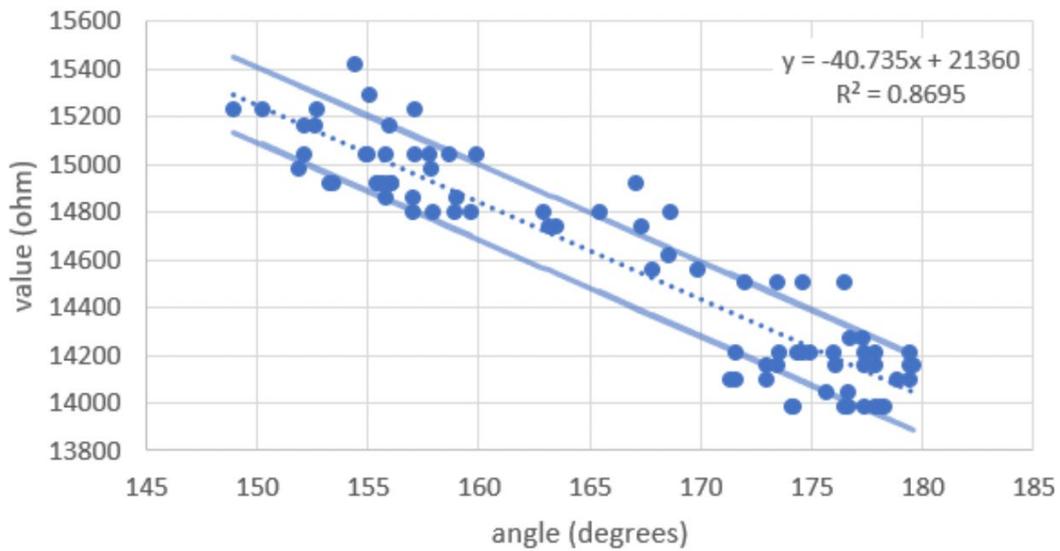


Figure 5, Relation between the value and the angle for patient data. The dashed line is the trendline based on the least squares method and the blue solid lines are the error margin based on adding or subtracting the standard error of regression from the trendline.

User Perspective: CEQ and Interviews

Table 2: The result of the CEQ, score ranged from 1 (no trust in system) up to 9 (trusts system completely).

Category	SET-1 Think				SET-2 Feel	
	question-1	question-2	question-3	question-4	question-5	question-6
average (all = 15)	7.33	7.33	6.87	6.67	6.92	6.62
standard deviation (all = 15)	0.90	1.05	1.25	1.23	1.61	1.61
average (patient & physio = 6)	7.83	7.83	8.17	7.33	8.00	7.83
standard deviation (patient & physio = 6)	0.75	1.17	0.75	1.21	1.26	1.17

First of all, the system is believed to be **effective**, because it monitors the knee constantly and therefore the system collects detailed information. In the CEQ results, see Table 2, the average score of all questions is 6.96, which indicates users' positive expectations of the proposed system. It's worth noting that the scores from patients and physiotherapists are higher than the average. Besides, during the interview, patient 2 said:

'I believe that this kind of brace can help you learn it quicker. Since you carry it all the time. ... You are 24/7 able to learn how to walk right.'

Also, domain expert 1 mentioned:

'This system also gives you more detailed information on what is happening and if you want to know more.'

Second, closely related to this is that the users and experts experienced the system as '**clever**', **easy to understand** and the **personalized feedback** as very beneficial. Patient 1 said:

'The information is very clear. Everybody is on the app.'

This is due to the type of questions being asked (for example, they think that taking emotions into account is beneficial), the immediate feedback and the information being displayed. The physiotherapist pointed out that the system is very useful, especially the app, because patients can gain more information about their behaviour.

Third, they also think the brace is **comfortable** and **easy to use** after they experienced wearing it. Patient 1 mentioned:

'It's comfortable, it's not heavy ... It's very easy-going.'

Also, Patient 2 said:

'It is very easy to put on the brace.'

Fourth, they believe the system will also **benefit the physiotherapists** by reducing the number of reminders and repeated explanations they have to give to the patients. The physiotherapist mentioned:

'As a physio, I have to give this information every time. When it is in the app the patient can read the app ... then I can do other things.'

Conclusion

This paper has introduced a persuasive system designed to help track and reduce knee overstretching for patients in tele-rehabilitation. The proposed system helps patients see their knee overstretching data and can help share rehabilitation progress with the physiotherapists. Future work could focus on the interface for the physiotherapist to support tele-rehabilitation practices, and could provide more evidence regarding the reliability of the sensor readings. The efficacy of the system in changing knee posture should be established with more extensive field testing. Improving sensor reliability could be supported by combining multiple flex sensors.

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HOW SUPERMARKETS CAN HELP THEIR CUSTOMERS TO BECOME AND STAY HEALTHY

Veerle van Engen, Marina Bos-de Vos

Delft University of Technology, NL

Abstract

Preventing or decreasing chronic health conditions by healthy eating is increasingly seen as a shared responsibility. Defining what is healthy is person-specific, depending amongst others on a person's health and responses to food. Supermarkets, which are considered highly influential in shaping the diet of customers, are starting to serve customers based on their health needs. This study explores how supermarkets can tailor their service provision to the dietary needs of individual customers and what business and design implications this involves. Through a service design approach involving participants with elevated blood glucose levels,

thoughts and emotions during the process of dietary change were translated into a customer journey that reveals multiple opportunities for service delivery to support healthy eating. The customer journey can be used by supermarkets to shed new light on their positioning and customer segments. The study also provides inspiration for how supermarkets and other organizations can support customers with specific health needs to eat healthy via group-based and personalised services.

Keywords: diet, health, supermarket, service design, customer journey, co-creation



Introduction

Supermarkets are considered highly influential in shaping dietary choices (Waterlander et al. 2018). While they are typically seen as organizations that seduce customers to make unhealthy choices, they can also support customers in adopting and maintaining a healthy diet. However, how they can effectively support individuals in healthy eating is unclear. Using a service design approach, this study investigates how supermarkets can tailor their services to specific dietary needs of individual customers, and thereby contribute to their health. As this approach to serve customers based on their health needs is still nascent, this study answers the following research question: How can supermarkets facilitate and support their customers in dietary change and what business and design implications does this involve?

The focus of the study is on reducing the consumption of refined carbohydrates, which are eaten in abundance globally (Nelson et al., 2018). The excess intake of carbohydrates causes insulin resistance and elevates blood glucose levels (Zeevi et al. 2015). People with elevated blood glucose levels risk developing diabetes type 2, which causes them to live in suboptimal health and simultaneously puts pressure on the care system (Gibney 2002).

Studies have shown that reduced carbohydrate intake as a nutritional strategy has beneficial effects on blood glucose levels of both healthy people and people with diabetes type 2 (Westman et al. 2007). At the same time, research shows that people have unique blood glucose responses to food (Zeevi et al. 2015), implying that there is no 'one-size fits all' diet (Szakály, Fehér, and Kiss 2019). This indicates that generic food recommendations need to be replaced by advices tailored to specific groups and characteristics of individuals by means of precision nutrition (Palmnäs et al. 2019).

Method

A service design approach was taken as both services and dietary change involve a sequence of interactions over time (Polaine, et al., 2013). Data were collected and analysed via two activities with people who adopted a carbohydrate-restricted diet to lower their blood glucose levels. With the exception of one participant, all participants underwent the dietary change recently and were therefore capable of recalling their thoughts and describing vivid situations. Due to the focus on service opportunities for supermarkets, the participants are referred to as 'customers' instead of patients. Each activity was performed with the participants individually, and took between one to two hours. The activities resulted in written documentation created by the participants and notes taken by the researcher. These notes were developed further immediately after the activity.

Activity 1. Constructing and exploring the 'thoughts & emotions' customer journey

The main author constructed and explored a customer journey with five participants who followed a carbohydrate restricted diet. At the start, the purpose of the study – the exploration of how supermarkets can serve customers in healthy eating – was explained. Subsequently, via a three-step process, participants were invited to share their experiences during the process of dietary change by describing the thoughts and emotions which they deemed potentially relevant or of interest for supermarkets to establish new services.

First, participants shared the process from being diagnosed with elevated blood glucose levels to adopting a carbohydrate-restricted diet. The Product Emotion Measurement Tool (Desmet 2019) in combination with a timeline, helped participants to express the thoughts and emotions that they experienced over time (see Figure 1). Participants were asked to map their thoughts on the timeline with a brief verbal description of the situation,

and enrich each thought by picking a sticker that best reflected their emotion during that specific thought. The participants were instructed to place the sticker and explanation on a fitting position of the timeline, with the y-axis ranging from an intense positive emotion (top), via a neutral emotion (middle), to an intense negative emotion (bottom); and the x-axis representing the chronological order of their thoughts and emotions. The diagnosis of elevated blood glucose levels marked the start of the journey. The ending of the timeline was left open for the participants

to describe their current state. Afterwards, the participants were asked to indicate which stages they considered as critical. A critical moment was defined as an important moment with impact on the person's next steps, either in a positive or negative way. Finally, the participants were asked to write down the support (e.g. consultation with medical professionals and patient-to-patient platforms) that they used during the transition, and indicate during which moments the desired support was absent or ineffective.

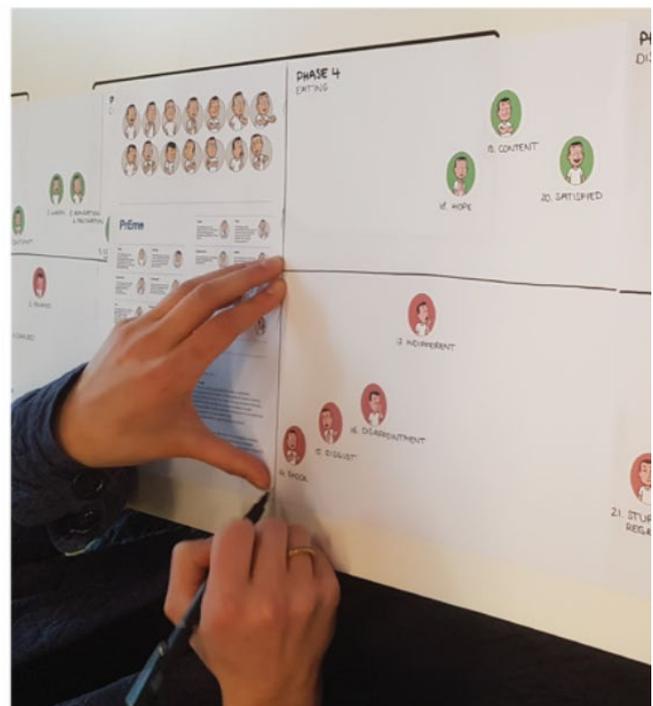
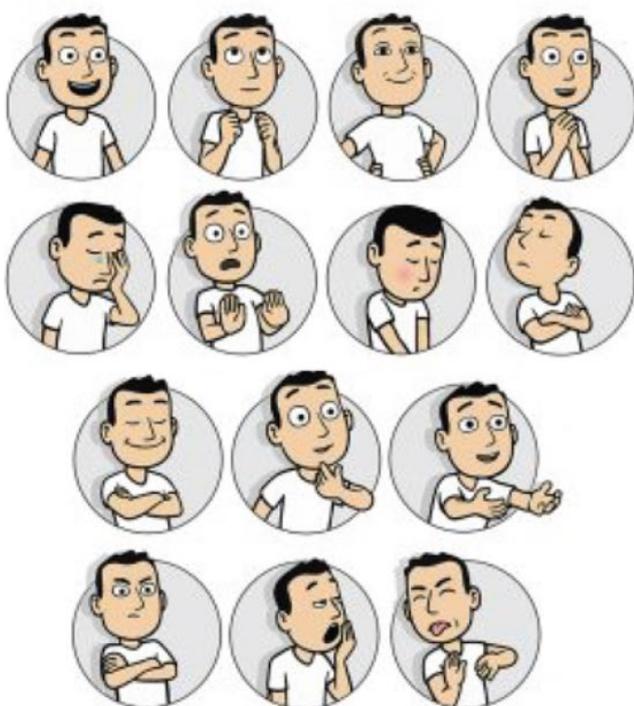


Figure 1: The emotion stickers by Desmet (2019) (left), used by a participant to construct a 'thought & emotion' customer journey (right).

Activity 2. Opportunity finding with a synthesized customer journey

The customer journeys participants constructed served as a basis for the creation of a synthesized journey. First, the individual maps were analysed for overlapping thoughts, emotions and critical aspects. The resulting synthesised customer journey includes a combination of reoccurring concepts, such as sadness to give up on enjoyable foods; and less obvious thoughts and emotions that were

considered critical by individuals, such as the concern of eating more fat. In case of variability in participants' thoughts and emotions, the extremes were integrated in the journey. The synthesised map, which is shown in Figure 2, contains four phases: 1) Awareness and Consideration, 2) Preparation, 3) Doing, and 4) Evaluating.

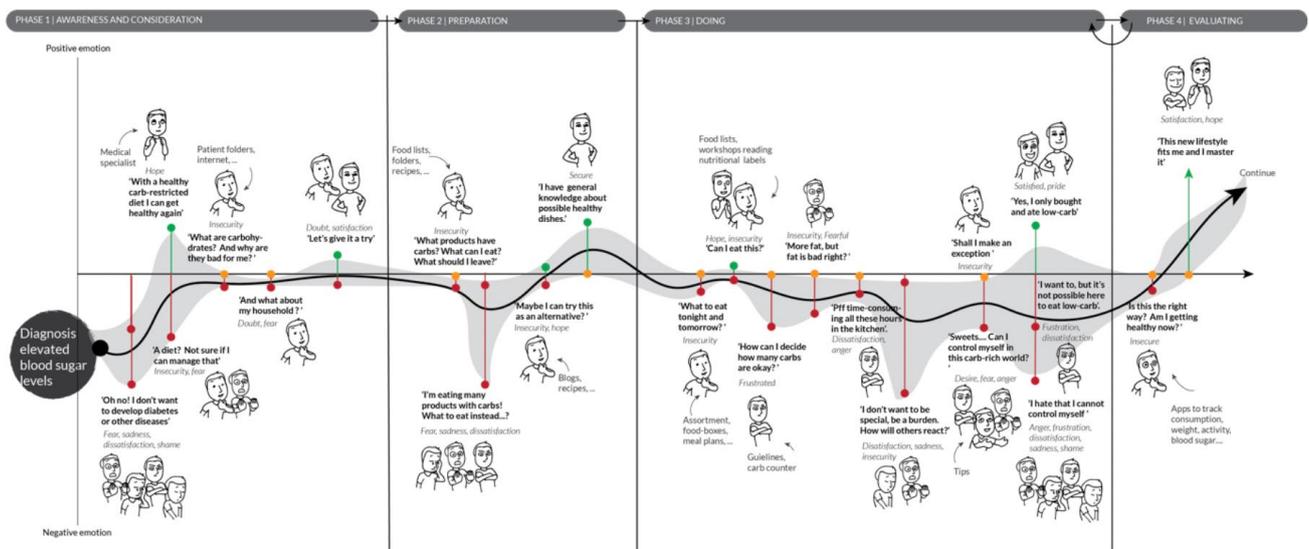


Figure 2: The synthesised customer journey reflecting thoughts and emotions during dietary change.

Then, two people with diabetes were engaged in opportunity finding by discussing the synthesised customer journey. Both participants (a founder of a patient-to-patient diabetes platform and an ambassador of a diabetes patient organisation) work with different types of diabetes patients on a daily basis. They could therefore contribute valuable input from the perspectives of different patient profiles. To find windows of opportunities, participants were invited to share ideas that could support a person with elevated

blood glucose levels in (stages of) the dietary change. Each idea was discussed to find the underlying need or desire, which represented the opportunity. The participants were asked to cluster the needs and desires and describe the overarching opportunities (see Table 1). The main author helped the participants in this process by asking questions and summarizing insights. To arrive at a final clustering, participant two also reflected upon the results of the session with participant one.

Table 1. Fragment of the clustering that led to the fifth opportunity.

OVERARCHING OPPORTUNITY	DESIRE/NEED CLUSTER	DESIRE/NEED
Creating a supportive environment	No seduction	<ul style="list-style-type: none"> No promotion of carb-rich products (e.g. discounts, recipes) Low-carb routes or sections
	Self-initiated restriction	<ul style="list-style-type: none"> Shielding carb-rich products during online purchase Setting personal restrictions related to carb-quantity
	Stimulating healthy choices	<ul style="list-style-type: none"> Incentives to buying low-carb Rewarding good behaviour
	Social acceptance	<ul style="list-style-type: none"> Low-carb party and dining assortment National educational campaign

Findings

The activities resulted in two generic observations and five windows of opportunities.

Generic observations

The first observation is that an opportunity can reinforce positive emotions or improve negative emotions, and thereby enhance customer experience and motivation. An example of reinforcing a positive emotion was to strengthen pride after successfully withstanding seduction. To enlighten a negative emotion, a participant suggested avoiding the word 'diet' as this word has a negative connotation. The second observation is that opportunities are present throughout the complete customer journey and do not limit themselves to existing touch points and interactions with supermarkets.

Opportunity 1. Facilitating evaluation of diet-related health

The first opportunity describes the use of health check-ups, in this case assessment of blood sugar levels, to: 1) enable supermarkets to offer targeted and personalised health-driven services, 2) enhance customers' receptiveness to dietary change, and 3) establish a feedback loop.

An initial health check-up is required to identify customers with elevated blood glucose levels, and thereby enable supermarkets to offer these customers targeted services to improve their health via diet. Moreover, the test outcomes create awareness and enhance customers' receptiveness to change. A participant described: 'by seeing the outcomes I realized that I really needed to change'.

Participants also sought follow-up tests to evaluate the effectiveness of their diet and make changes if necessary, empowering them in self-management of their health. Furthermore, participants expressed the desire to evaluate other diet-related health metrics, such as cholesterol and

blood pressure, as these metrics should be integrated to offer a truly personalised diet.

Opportunity 2. Encouraging a positive attitude towards dietary change

The second opportunity is to encourage customers in developing a positive attitude towards dietary change by enhancing knowledge and skills, and facilitating them to experience the new diet as a way to combat negative prior experiences and prejudices.

Participants mentioned to be hesitant to commit to a diet. Reasons for this hesitance were negative prior experiences with dieting, having prejudices about dieting, lacking knowledge and having low perceived self-efficacy. One participant explained that he does not like to commit to unfamiliar things, as he does not know what he will commit to. These reasons imply that customers may not even consider dietary change.

Interestingly, the participants expressed that their perception of the diet changed after experiencing it and seeing positive health outcomes, such as weight loss and improved blood glucose levels. People described a transition from being insecure and hesitant to feeling convinced, satisfied, proud and in control. Despite describing their new diet as having less variety, the participants also described it as tasty, easy and healthy. This shows the importance of making people attempt the new diet.

Opportunity 3. Exploring opportunities for dietary improvements

Third, supermarkets can support customers to 1) structurally evaluate the healthiness of their diet and 2) provide healthier alternatives accompanied by evidence.

First, participants desire support in evaluating the healthiness of their current diet. Participants mentioned that reflection on one's diet remains important as carbohydrate-rich foods may be present in a 'hidden' form, product ingredients may change and healthier alternatives may emerge.

Second, participants seek support in finding alternatives to the unhealthy products in their diet or the 'healthier' options. This exploration was described as an emotional rollercoaster, driven by successes and failures in finding healthy and desirable foods. However, participants mentioned to experience distrust towards supermarkets and manufacturers and their dietary advices. Participants said that supermarkets should proof if, and how, their proposed alternatives are better compared to other products. Collaborations with experts and research institutes were mentioned as possible ways to enhance trust.

Opportunity 4. Supporting implementation of the new diet

A fourth opportunity is to provide customers practical support to implement the new diet. Participants described the desire for support during day-to-day actions related to their diet. For example, they seek meal inspiration and support in reading nutrition labels as this is considered effortful and complex. Furthermore, a participant described the inner-conflict of consuming more fat. He desired guidance in determining the right quantities. Moreover, some participants wished to reduce the time they spend in the kitchen to make low-carb foods such as seed crackers.

Opportunity 5. Creating a supportive environment

The fifth opportunity is to create a fully supportive environment that accommodates and stimulates a healthy diet by redesigning the food ecosystem and enhancing knowledge and acceptance in society.

Participants described to experience various negative emotions caused by their environment. The first problem occurs when the social environment does not accommodate the diet, for example during catering of events. This can also happen unintentionally as described by a participant: 'a friend who invited me for dinner failed to offer a low-carb meal due to her lack of knowledge'.

Seduction was the second problem that was voiced. Some participants perceived the sight of unhealthy foods as challenging. One participant described a strategy for self-control by only shopping in the outer ring of supermarkets; the vegetables, dairy and meat and staying away from the inner part. Another participant wished to adapt the visibility of products during online shopping. He described that: 'interventions to eat healthy make no sense if supermarkets simultaneously seduce you to buy unhealthy products'.

Conclusion & discussion

The aim of this study was to explore how supermarkets can tailor their service provision to the dietary needs of their customers and what business and design implications this can involve. The contribution, which is primarily focused on commercial organizations that already do or wish to engage in designing for health, is twofold: 1) it describes how a customer journey can be used to shed new light on their positioning and customer segments, and 2) it presents five opportunities to support healthy eating and associated business and design implications.

The results outline five service opportunities that supermarkets can use to enhance their social responsibility by supporting a healthy diet and thereby contribute to preventing and reducing the occurrence of diet-related diseases: 1) facilitating evaluation of diet-related health, 2) encouraging a positive attitude towards dietary change, 3) exploring opportunities for dietary improvements, 4) supporting implementation of the new diet, and 5) creating a supportive environment.

These five opportunities have several implications for supermarkets and designers who work on stimulating healthy eating. First, precision nutrition (i.e. moving from generic services to group-based and personalised services) is important to take into account (see Figure 3). This is in line with earlier research, which highlighted the

potential of precision nutrition to optimize health (Palrnäs et al. 2019; Szakály et al., 2019). It means that supermarkets need to transition from serving the population to serving individuals. Diet-related health needs of customers can be used to identify new customer segments. Customers with elevated blood glucose levels represent one example of such new customer segment. Services may target the needs of customers in this segment and can be personalised by integrating the lifestyle, dietary preferences and context of individual customers. Another option to personalise services is to include individuals' unique responses to specific foods. Personalised services are important to satisfy customers and thereby enhance customer retention.

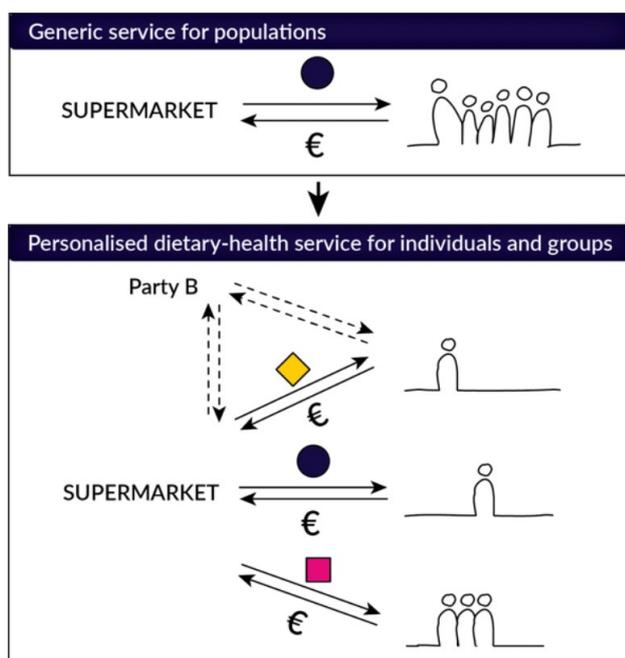


Figure 3: Changing from serving populations to offering personalised and group-based services, possibly in collaboration with other parties.

Second, dietary behaviour of customers is not limited to the moment of shopping. This means that a supermarket can also create value for customers prior to, and after, the shopping activity itself, as illustrated by the opportunity to facilitate health check-ups. As suggested by Waterlander et al. (2018) achieving healthy eating requires a holistic approach. Thus, when designing for healthy

eating, it is important to consider the entire time span that may be relevant for the actors involved, instead of focussing only on the obvious moments. Consequently, this triggers changes in communication channels, core activities and also introduces the possibility for new collaborations.

Third, supermarkets will establish a new relationship with their customers. Collecting health-data of customers is expected to increase the level of intimacy with them. This raises the question what relationship a supermarket aims to pursue: being a facilitator or an involved partner? Related to this is the question to what degree a supermarket engages customers to co-create new services. Co-creation allows services to respond to customers' desires and concerns, which is suggested to enhance customer acceptance of precision nutrition services (Szakály et al., 2019). Collecting health data also introduces opportunities for data mining. For example, the combination of customers' purchase- and health data can explore consumption determinants of good health. To create a good overview of the possibilities and constraints for health-driven nutrition services, designers need to identify and assess the different values that play a role in such new relationships, such as privacy, well-being, but also economic value.

Due to the limited number of participants, this paper can be best interpreted as a first exploration on how supermarkets can contribute to the health of customers with elevated blood glucose levels. To examine to what extent the findings are generalizable to different customer groups, the 'thought & emotion' customer journey approach can be used with participants undergoing other types of dietary change. Future work may also address the perspective of supermarket chains to include the lenses of viability and feasibility (IDEO 2015). For example, future work can explore how the opportunities described in this paper can be aligned to the commercial stakes of supermarkets and how to utilize available customer data.

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CO-DESIGNING BEHAVIOUR CHANGE PROTOTYPES WITH PAEDIATRIC PHYSICAL THERAPISTS: INTEGRATING INSIGHTS ON BEHAVIOUR AND SOCIAL SYSTEMS IN A PARTICIPATORY DESIGN PROCESS

Anita van Essen¹, Sander Hermsen^{2,3}, Eline Bolster², Manon Bloemen²,
Christa van Gessel¹ and Remko van der Lugt¹

¹Co-Design Research Group, Utrecht University of Applied Sciences, Utrecht, NL

²Lifestyle and Health Research Group, Utrecht University of Applied Sciences, Utrecht, NL

³One Planet Research Center, Wageningen, NL

Abstract

('Co-)Designing for healthy behaviour greatly benefits from integrating insights about individual behaviour and systemic influences. This study reports our experiences in using insights about individual and systemic determinants of behaviour to inform a large co-design project. To do so, we used two design tools that encourage focusing on individual determinants (Behavioural Lenses Approach) and social / systemic aspects of behaviour (Socionas). We performed a qualitative analysis to identify 1) when and how the team applied the design tools, and 2) how the tools supported or obstructed the design

process. The results show that both tools had their distinctive uses during the process. Both tools improved the co-design process by deepening the conversations and underpinnings of the prototypes. Using the Behavioural Lenses under the guidance of a behavioural expert proved most beneficial. Furthermore, the Socionas showed the most potential when interacting with stakeholders, i.e. parents and PPTs.

Keywords: co-design, behaviour change, social systems, participatory design, physical therapists

Introduction

Designing for healthy behaviour greatly benefits from integrating theory and evidence on individual behaviour change (Hagger & Weed, 2019) and socio-systemic influences on behaviour (Dahlgren & Whitehead, 1999). Unfortunately, using theory and evidence to inform the design process remains exceedingly difficult: they are often seen as 'impenetrable' (Pettersen & Boks, 2008), suffer from limitations in applicability (Hermsen, Renes, & Frost, 2014), and tend to limit 'designerly drifting' (ibidem). Designing for the tension between individual behaviour and its context (e.g. the social system) remains especially problematic (Tarquino et al., 2015).

The past years have seen a range of efforts to support designers in using behavioural scientific theory and evidence in their work (cf. Tromp, Daalhuizen, & Renes, 2018). Most of these methods lack rigorous evaluation, however (Hermsen, 2019; Tromp & Hekkert, 2016). Furthermore, there are as yet no studies looking into the possibilities of combining insights on both individual and socio-systemic aspects of behaviour change.

The current paper contributes to bridging this gap by presenting a case study in which a method for designing for individual behavioural change (Behavioural Lenses Approach; Hermsen et al. 2019) is combined with a method for designing for social-systemic influences (Socionas; Postma, 2012). To answer our main research question, whether these tools contribute to the design process and outcomes of the case study, we assess three aspects of design performance (Tromp & Hekkert, 2016): design quality (DQ), process quality (PQ), and process efficiency (PE). DQ refers to the extent the design outcomes are effective in addressing the intended behaviour change and social dynamics; PQ refers to the extent the design team uses the behavioural insights and social dynamics provided by the tools throughout the design process; and PE refers to the extent the design team works efficiently when applying the tools.

Case Study: 'Wat Beweegt Jou'

'Wat Beweegt Jou' ('What moves you') is a participatory design project to develop a toolkit for paediatric physical therapists (PPTs) to promote a physically active lifestyle in children with physical disabilities. The project consisted of a range of design activities, centered around four five-day design sprints and three four-hour co-creation sessions. The sprints were performed by an interdisciplinary design team consisting of two design practitioners, two design researchers and two PPT's. The first two sprints focused on the development of tools to improve PPTs' physical activity coaching; and stimulating children's physical activity in their own life settings, respectively, resulting in eight prototypes. These were mid-fi prototypes, i.e. testable plywood or paper artefacts made with a laser cutter and color printer (see Figure 1 for an example) to represent an early model of a product.



Figure 1: An example of a physical prototype; the plywood prototype 'question dice'

The third and fourth sprint aimed at the development of a tool for establishing contact and cooperation between PPTs and social care workers, resulting in a concept for a mobile application. After the first two sprints, the mid-fi product prototypes were distributed among 14 PPTs for usability testing. 10 PPTs tested the usability of the mobile application (Sprint 3 and 4) with a clickable mock-up. Subsequently, during a 2-day session, the mid-fi product prototypes were adjusted accordingly and combined in a final 'toolbox'.

Tools used in the case study: The Behavioural Lenses, Socionas

The Behavioural Lenses Approach (Hermsen et al. 2019) supports designers in integrating insights on individual determinants of behaviour in design activities. It consists of several tools, based on five so-called 'lenses' that represent different subsets of behavioural determinants (see Figure 2). A complete overview of all available tools, background texts, and scientific publications is available from Hermsen, 2019.



Figure 2: The five Behavioural Lenses

The Socionas (Postma, 2012) are an approach to help a design team build understanding of social structures and their influences on people's daily lives. The current project uses an iteration on the Socionas approach proposed by Van Gessel, Van der Lugt and De Vries (2018). While the original approach relies heavily

on play acting as a means for designers to develop insight in social dynamics, Van Gessel et al concentrate on developing visual descriptions of the systemic dynamics of people in different social roles, using basic personas as building blocks to capture variations in prototypical dynamics (see Figure 3 for an example).

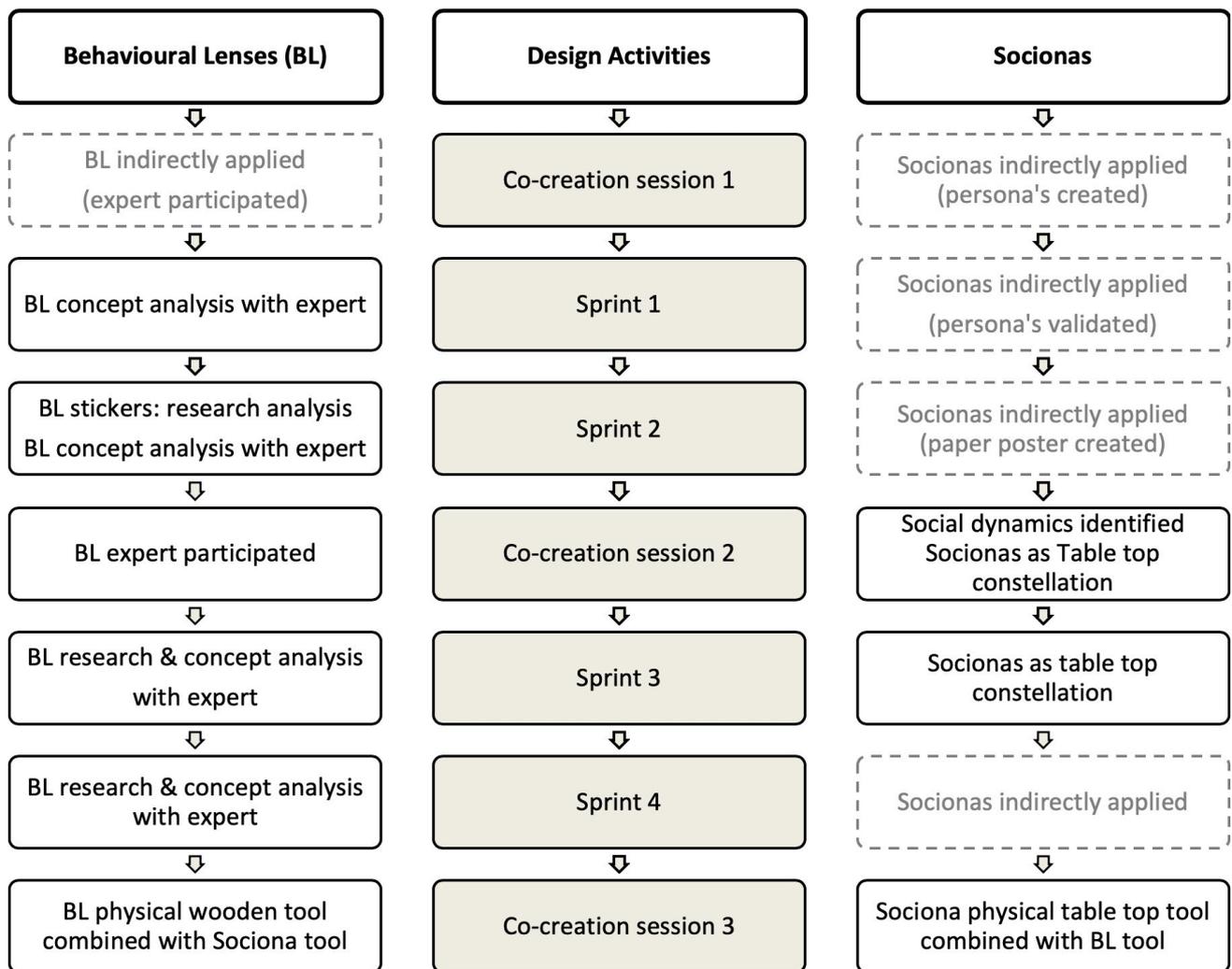


Figure 3: Overview of the design process and the application of the Behavioural Lenses and Socionas

Behavioural Lenses

The Behavioural Lenses (BL) were ready to use in the design process, a feat aided by the availability of a behavioural expert during the sprints. At the start of the project this expert presented the tool to the design team. Every third day of the sprint the expert helped the team review their prototype concepts using the BL. The BL also invited the development of new design tools. To deal with lacking time for extensive user research analysis, the team created a sticker set in the second sprint, which helped speeding up the analysis of user insights. In the third sprint, the team developed a physical tool (figure 3) to make the BL more usable for PPTs in their practice.

Socionas

It took more time to develop the Socionas into a form that was applicable in the sprints. During the first co-creation session and sprint, the design team constructed 'static' Socionas consisting of three Personas (parent, child, PPT) in a network. The results of this approach felt overly simplistic and not representative of real life. In the third sprint, the design team developed a new tool to create dynamic, table-top Persona constellations. This physical Sociona tool (Figure 4, customizable wooden puppets and cards with generic social dynamics) turned out a lot easier to apply, and also capable of generating valuable insights, especially in combination with the wooden BL tool and tiles representing potential prototypes.



Figure 4: the combined physical BL and Sociona tool

Behavioural Lenses: design performance

Process Quality

By offering a framework, the Behavioural Lenses helped the team review concept storyboards, brainstorm ideas, and prototypes. Furthermore, this framework also provided insight in underlying mechanisms, which informed a critical discussion of the behavioural goals of the prototypes and their expected effects on the user.

Having the behavioural expert in the design team proved a key factor in the application of the Behavioural Lenses tool. Even though consulting the expert did not always radically change the concepts, it helped the team to 1) improve and strengthen the underpinnings of the ideas and prototypes, (2) make underlying mechanisms explicit, and (3) increase confidence in decision making during the sprints. All this meant that the design team felt the Behavioural Lenses, combined with expert availability, were sufficient to integrate insights from behavioural sciences in the design process.

Process Efficiency

Application of the BLs showed to be compatible with the design sprints, improving their efficiency. Developing the stickers helped the team to apply the BLs without the expert in analysing user research insights quickly. Performing an review with the BLs guided by the behavioural expert improved decision making and thereby guaranteeing the high pace of the sprint.

Design Quality

During the expert review of the prototypes, the experts sometimes assigned more and different BLs to the prototypes than the design team had. The experts assigned lenses referring to the behavioural effects of the prototypes, whereas the design team assigned lenses referring to the behavioural goal that the prototype would contribute to. Overall, the experts indicated that the prototypes fitted the behavioural goals of the project only partially, supporting deconstruction and reframing of problematic situations (e.g. the BCTs 'framing and reframing', 'information about

antecedents', 'self-monitoring of behaviour'), but potentially lacking in strategies to establish new behaviours. The fact that the experts assigned substantially more lenses to the prototypes than the design team may indicate that the BLs alone are not enough to replace expert knowledge in behavioural change; the experts saw potential behavioural effects that the designers were not aware of.

Socionas: design performance

Process quality

As mentioned before, the design team felt that the preliminary Socionas tool (using paper persona constellations) was too static to be helpful in the sprints. When the design team developed the table top constellations tool, this enabled a dynamic setup which proved easy to use for PPTs, parents and other stakeholders. This tool helped review concepts and their potential impact on existing social dynamics.

The design team felt the need to use different approaches to take the social systemic aspect into consideration, such as inviting different stakeholders for focus groups. This may serve as indication that the Socionas, especially in their former, paper form, were not sufficient to capture systemic dynamics.

Process efficiency

In the first part of the project, constructing Socionas by combining personas and identifying social dynamics hindered sprint progress rather than enhance it. A key factor that delayed the process during the sprints was determining the scope of the social system, and decision making on which dynamics seemed most valuable. In the more slow-paced co-creation settings, where participants had more time to identify social dynamics, Socionas proved more useful, but even then, the allotted timeslots were not enough for in-depth discussions.

Design quality

The expert review showed that some of the prototypes succeed in explicitly involving the social network (caregivers and social care workers) when using them (for instance; the 'conversation placemat', the 'question dice' and 'looking glass', and the 'photo frame'). This was also reflected by the assigned BCT 'restructuring the social environment' in some prototypes. The experts recognized that some tools might address and disrupt existing social dynamics (such as 'parents being overprotective of the child'), however they were not convinced that the prototypes could adjust the dynamics to support the desired behaviour change.

Discussion and Conclusion

This paper reports a case study of how insights on individual and systemic aspects of behavioural change can be incorporated in a (co)design process. To do so, the paper analyses a design process in which a design team developed a toolkit with Paediatric physical therapists (PPTs) stimulate physical activity in everyday life settings of 6–12yo children with physical disabilities. For each aspect (individual and systemic), the design team used a design tool and input from experts. The study shows that the design process benefitted from applying the two tools; each tool with a different application and design performance.

Firstly, the usability of the two tools for design sprints and co-creation sessions differed. The Behavioural Lenses showed to be applicable and efficient in the sprints, whereas the Socionas proved to be more beneficial and suitable during co-creation sessions. This could be explained by: 1) the presence of a trained Behavioural Lenses expert, 2) different maturity of the tools at the start of the project, 3) different origins, as the Socionas come from an 'empathic design' perspective and the Behavioural Lenses from a behavioural science background.

Secondly, the tools had a different process quality. The Behavioural Lenses mostly enhanced the underpinnings of the design decision during the sprints. The Socionas mostly enhanced the conversation with users and stakeholders and the identification of social dynamics. Interestingly, the design team returned from the chosen approach based on Van Gessel (2018) to the original, more theatrical, approach of Postma (2012). An explanation for this change could lie in the co-design nature of the project. The interactive and customizable form facilitated the conversations with end-users better than the posters.

Thirdly, the difference in efficiency of both tools points towards having a defined 'end-point' or criteria in a design method that describes when to take the next step. The Socionas differed from the Behavioural Lenses in that the design team had no way of knowing when sufficiently rich information was obtained. This hindered the design process by repeatedly reopening the discussion between users, stakeholders and the design team.

With respect to the design quality, all experts agreed that the prototypes mostly focused on breaking through current behaviours and less on supporting new behaviours and social dynamics. However, from the review itself an essential difference between the two tools transpired. Namely, the Behavioural Lenses tool was developed to make existing insights about behaviour change accessible. Reviewing the design quality was thereby easily linked back to theory by using the BCT taxonomy. Socionas do not represent a set of theoretical insights but makes an insight (social dynamics play a role) tangible. Thus reviewing this could not be linked to a specific theoretical model, which makes it hard to define underlying mechanisms for behavior change. Until the prototypes are tested for efficacy, it remains unclear whether the application of the tools results in better prototypes to change social dynamics.

Lastly, an important notion is that these two tools separate two perspectives (individual and social) that designers naturally integrate simultaneously. This project made a first attempt to integrate both in a final physical tool, yet this is still very premature. Further research should focus on integrating both perspectives in a method to improve design performance in practice.

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GUIDED BY LIGHTS: STIMULATING PHYSICAL ACTIVITY THROUGH AN ADAPTIVE PERSONAL LIGHT SYSTEM

Loes van Renswouw¹, Carine Lallemand^{1,2}, Bodi Fok¹, Maaïke Jetten¹,
Ayu Ritzema¹, Heleen Smeets¹ and Steven Vos^{1,3}

¹Department of Industrial Design, Eindhoven University of Technology, NL

²HCI Research Group, University of Luxembourg, LU

³School of Sport Studies, Fontys University of Applied Sciences, NL

Abstract

Increasing physical inactivity and its subsequent health concerns have made promoting healthy and active lifestyles an important endeavour for many governing agencies. In this paper we focus on the influence of the environment to encourage people to move more. As a second iteration of an existing 'Smart Exercise Route', a 1.8 km walking and running path consisting of LED tiles in a public park, we designed a system that supports runners or walkers to set personal goals and gain intrinsic motivation to be physically active. The design focuses on aspects that positively impact

motivation and/or performance: personalization, goal setting, and feedback mechanisms. An initial evaluation of a prototype placed in three public parks, showed that participants (N=35) appreciated the personalization of the route and its goal-setting opportunities. While one third of participants indicated the prototype as directly motivating, these positively experienced features are expected to indirectly increase motivation to be more active even further.

Keywords: exercise motivation, physical activity, urban environment

Introduction

Physical inactivity is a major public health concern for many governments. Amongst interventions at the individual or social level, urban planners and policy makers have started reflecting on the design of active urban environments, supported by technology. To increase physical activity and social cohesion, the Slimme Beweegroute (Smart Exercise Route) was installed in Eckart Park in Eindhoven (Netherlands) in 2017. This running and walking route resulted from co-creation sessions with the neighbourhood. It consists of LED tiles on the ground, powered by solar energy. Users can choose one of four preset speeds by stepping on a coloured tile. The LEDs will light up sequentially, matching the selected speed. The system aims to motivate people to keep their pace and exercise frequently.

Interviews with municipality representatives and citizens showed that the route has had technical issues from the start, which led to a bad reputation and low usage rate. The main issue identified when the route was functioning were the fixed speeds, not matching the user's desired pace. Interviewees also indicated the LEDs were hardly visible and some had trouble understanding how the route works, despite the information board.

We thus researched how this route could be improved to stimulate the motivation of people to run or walk in a park, focussing on making the light system adaptive and personalized. This paper provides insights in how an intervention in the environment can influence people's behaviour and stimulate them to be more physically active.

Related Work

Urban environments have the potential to strongly contribute to physical activity through their design (Sallis et al. 2016), especially with possibilities of evolving and increasingly integrated technology continuously adding new opportunities (Stephanidis et al. 2019). Technology

also enables new and enhanced ways for tailored design and personalization, which are typically more impactful in design for motivation and sustained behavioural change than universal designs (op den Akker, Jones and Hermens 2014).

The research presented in this paper explores the value of a more interactive and personalized running experience. There is ample research available on personalization through interactive technology in the Human Computer Interaction (HCI) community (Stephanidis et al. 2019), that argue personalization plays an instrumental role in motivation (Sebire, Standage and Vansteenkiste 2009). Here, we position our work in research that relates specifically to physical activity and running.

Looking into enhancing advanced amateur runner's experience, Knaving et al. (2015) proposed design guidelines for future runner support technology. These include the importance of allowing runners to define personal and social goals to strengthen internal motivation. Regarding feedback, they urge designers to use non-intrusive interfaces that minimize distraction during a run.

Enhancing interest for an activity, goal setting can increase motivation, especially when the motivation is intrinsic (Sebire, Standage and Vansteenkiste 2009). The strategy of goal setting was used by another interactive running route, located in Oosterpark, Amsterdam. Bluetooth beacons with a connected app tracked a runner's speed and position. Messages via the app suggested exercises, goals, to the users (Dallinga. et al. 2016). These goals, however, are set by a system, while autonomously set goals result in better performance (Sebire, Standage and Vansteenkiste 2009).

Reflection on goals creates more awareness, helping to set the right goals and improve skills and motivation (Lee et al. 2015). Additionally, allowing goal progress monitoring promotes behaviour change (Harkin et al. 2016). GoalLine and GoalPost

are research probes used to investigate physical activity motivation using goal setting, rewards, self-monitoring, and sharing (Munson and Consolvo 2012). Using primary and secondary goal setting resulted in increased motivation of participants. However, the reward system and sharing feature relied on extrinsic motivation and did not have the desired effect.

To measure achievements and recognize reached goals, system feedback is important. During a run, haptic and visual feedback by light could motivate people to persist (Wozniak et al. 2015). The interaction can become more effective when varied feedback is used (Arroyo, Bonanni and Valkanova 2012).

Feedback systems for runners should provide simple visual output, being more effective than auditory feedback and requiring little cognitive effort during a run (Wozniak et al. 2015). Providing visual feedback for self-monitoring through an app is effective for increasing physical activity (Murray et al. 2017). However, while smartwatches and smartphones can present large amounts of data, these interfaces are not optimal for in-run feedback (Colley et al. 2018). Exploring other ways of presenting data, they developed a shoe that gives feedback on running pace through light signals. Similarly, the interactive shoe Pediluma lights up when walking as immediate positive feedback (Lim et al. 2011). It had a positive effect on the step

count, yet users felt uncomfortable with the light at night and preferred a goal-reward system.

For our design, we build on the successes and recommendations of this previous work to create a lighted path that motivates people to be more active.

The Design

To research the influence of personalization of the designed route, we created a prototype of the new light route, including an improved and brighter light system and a shorter distance between the lights. The system is now tailored to each user; aware of his/her pace and lighting up accordingly. Additionally, this lets users track their progress and set goals.

The prototype-setup is 55 metres long. The user's speed is measured within the first five metres. After another five metres, a LED matrix displays their speed, allowing personal goal setting and progress tracking. The display turns off when the pace reaches the first light. From here, five poles with LEDs are placed every ten metres. These lights guide the journey of the user and provide feedback every ten metres. The lights turn on when the user should be next to it, based on their speed in the measuring section. The LEDs are red, as this colour showed to be most visible in contrast to the green park and was seen the brightest in sunlight.

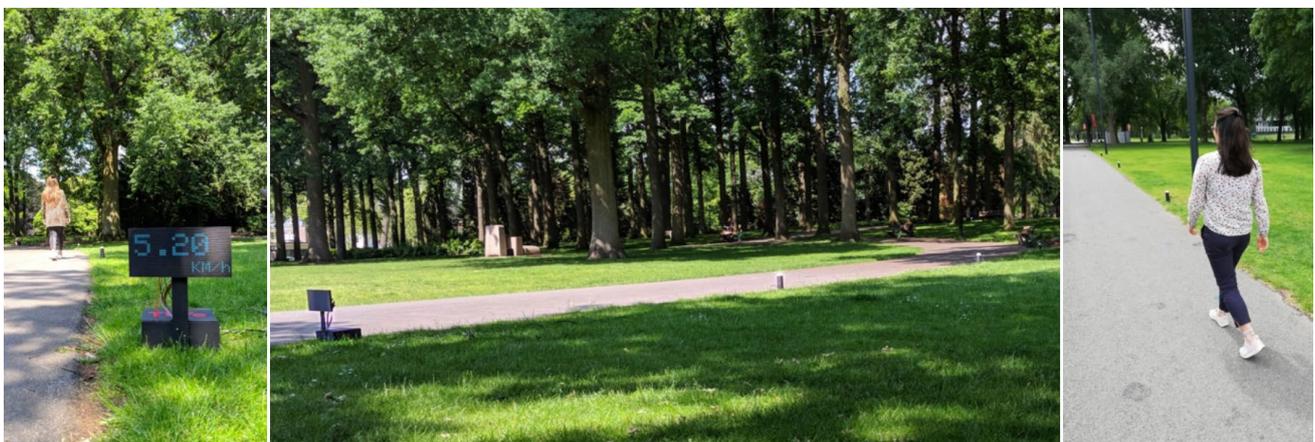


Figure 1: System Setup

Method

As inspiration for this research we used the Experiential Design Landscapes approach, where design propositions are placed in people's everyday lives. Using sensors and smart technology, their experiences and behaviours are captured and analysed, identifying patterns and creating new design opportunities (Peeters et al. 2013).

Pilot Study

Eighteen interviews were conducted with park visitors, to understand their mindset regarding exercising and running in this environment. Questions about the current light route were included to investigate people's pre-existing knowledge about the route and if they used it.

Research Setup

After the pilot interviews, two observation studies of 3.5 hours each took place in Eckart Park and Stadswandelpark. A third experiment took place on the Eindhoven University campus.

The goal of the first observation studies was to observe if park visitors would spontaneously use the system and how they interact with it. Researchers observed from a distance without interacting with participants. Users that adapted their pace (N=2) also filled out subscales of the User Experience Questionnaire (UEQ) (Rauschenberger et al. 2013) related to attractiveness, perspicuity, stimulation and novelty of the system.

The third experiment was focused on motivation for physical activity and the design's appearance. Twelve participants, all students (18-25 years old) and unfamiliar with the smart exercise route, were given information on the original route and the design before filling in part of the Physical Activity and Leisure Motivation Scale (PALMS) questionnaire to measure their motivation for physical activity (Zach et al. 2012). Only the physical and individual subscales were used. Next, participants were asked to use the course at their preferred pace. Observations were made on pace and attention paid to the display and lights. After the test, participants filled out the UEQ subscales. Open questions were added to better understand participants' replies.

Results

During the first observations 23 people passed the testing area. Eight of them (34%) interacted with the adaptive light route and only two (9%) adapted their pace to the route. Mostly young people (up to ca. 20 years old) interacted with the route. Observation showed that the novelty of the setup at the second location did not significantly influence the results.

The UEQ shows that although the design is not perceived as very novel or innovative (Novelty subscale: $M= 0.6$; $SD= 1.4$), respondents found it attractive ($M= 1.1$; $SD= 1.2$) and somewhat stimulating ($M= 0.9$; $SD= 1.3$). The design scores highest on perspicuity ($M= 1.4$; $SD= 1.6$), meaning it is understandable and easy to use.

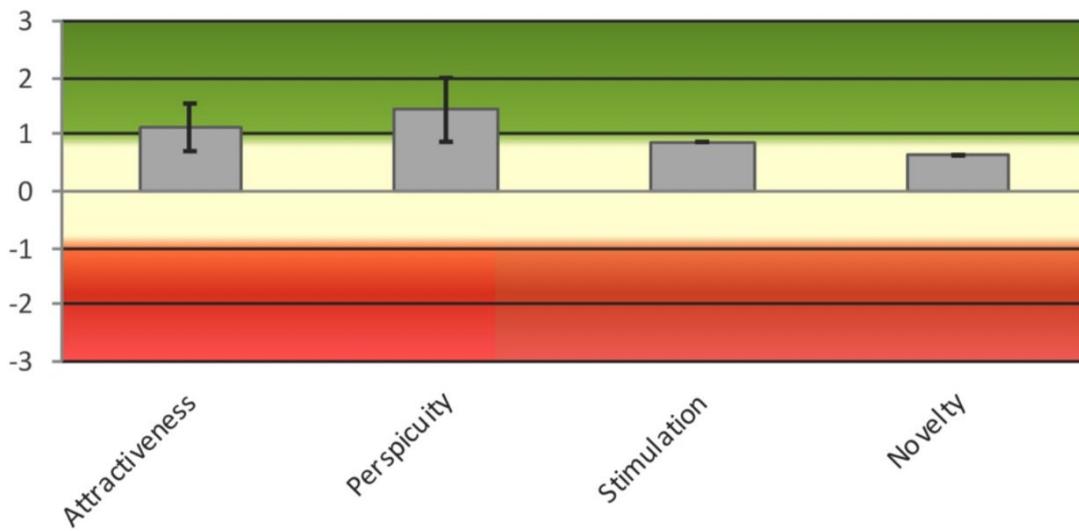


Figure 2: UEQ Scales (Mean and S.D.)

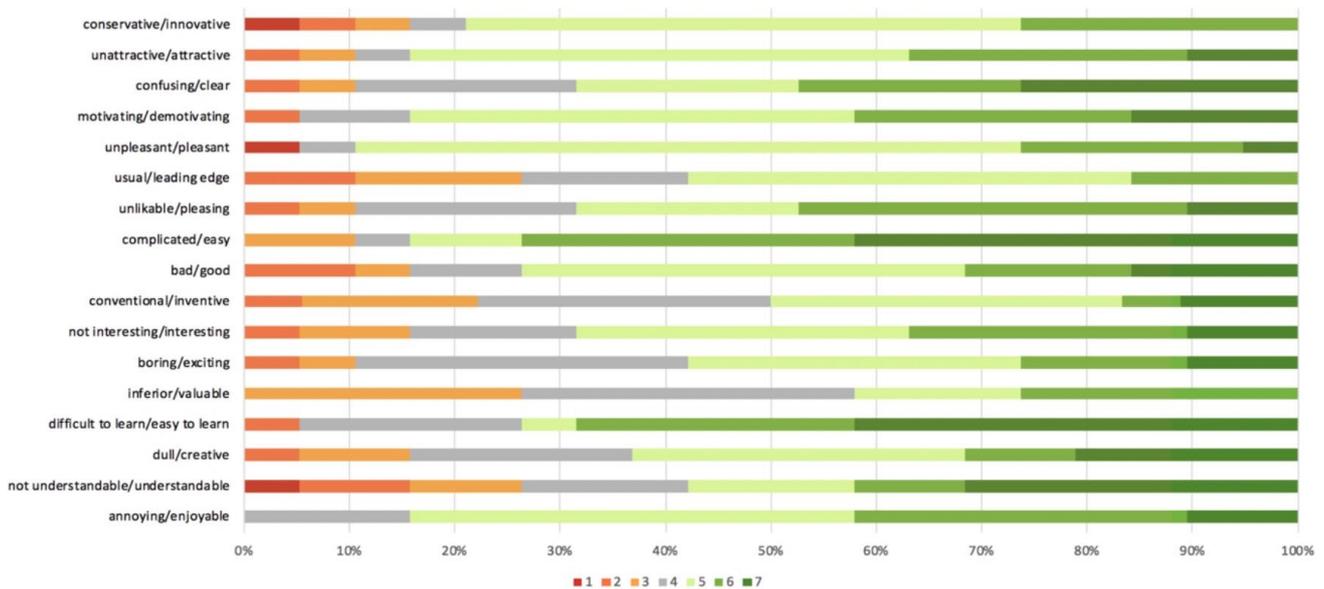


Figure 3: UEQ Answer distribution per item

Regarding motivation, responses to the open questions (N=12) can be sorted into three categories. Two participants did not find the route motivating at all: 'I'm not a running fan, design could be more innovative or fun' (participant 1). Five participants found it potentially motivating but were not sure based on this test: 'I can imagine the whole route can be motivating. The user test was such a small part that I find it hard to say anything about this' (participant 12). Five others found the route motivating and positively experienced the personalization of speed: 'nice to complete a milestone with each light' (participant 2).

People found the best time to encounter the route would be when walking, running or playing sports, especially in the evening. The most mentioned motivations to use the system were to improve oneself and using the lights for guidance during so there's no need to think about directions. Main points of feedback were the length of the prototype route and the visibility of the lights. Suggestions were given to provide more information at the start of the route, to make the design more remarkable and to further personalize the route with colours; people indicated that controlling the light colour or pattern would make them feel more connected to the system.

Discussion

Motivating people to become more active is a complex challenge, because motivational factors differ per person. Other influencing factors are uncontrollable, such as the weather. For our design, we focus on personalization, goal setting, visibility and understandability.

Personalization

In line with the literature review, the main reason for the increased motivation was the personalization of the route. However, the 55m of prototype setup was not long enough for all participants to form a clear opinion about the effect of the system on a longer circuit. Observations also showed that five metres are not enough to measure the user's speed. People did not have a constant pace, resulting in many participants not finishing alongside the light indication.

Goal setting

The related work showed that goal setting and appealing to intrinsic motivation, can increase motivation to be active, while not being forced to do so. The new system depends on the user's memory and willingness to improve their speed. Yet, some people indicated they may still need an extra push to exercise.

Because of the small sample size, generalization of this research is less reliable. While being the target users, people living near Eckart Park were already familiar with the original light route. This possibly influenced their opinion or interaction with the design during the first experiment. To get a more objective view on the project, another observation was done at the Stadswandelpark, where the visitors and participants largely represented the target users. All participants in the experiment on university campus were 18-25 years old. Even though these ages are part of the target group, this group does not fully represent the residents of the neighbourhood.

Because of ethical regulations, a sign informed people that anonymous data would be collected if they proceeded along the route. This clearly influenced the results, as people intentionally avoided the area and were less inclined to interact with the design.

While we conclude that personalization creates more motivation for people to run/walk, this does not yet show a direct relation between increased motivation and actually using the route.

Visibility

The design was enhanced to improve visibility of the LEDs and, based on conclusions from related work, also give them more meaning for the user. Observations showed that the new system was noticed more in the park setting and drew the attention of people passing-by. However, they were not always visible in bright sunlight, making the user test inconclusive for some participants.

Understandability

Despite a positive score for the system's understandability on the UEQ, it is not clear from these results to what extent this only lowers the threshold for using the design or actually affects the motivation for physical activity.

Conclusion

To increase people's motivation to run or walk more through design, multiple aspects need to be taken into consideration. The personalization of the route; adjusting to the user's speed, is experienced as more pleasant and creates a connection with the design. It also provides the opportunity to set and check personal goals. Additionally, the Guided by Lights design is more visible than the original system and efforts have been made to make it more self-explanatory and understandable. When designing for behaviour change, this combination of personalization, goal setting, visibility and understandability is essential for any similar

system to boost motivation and physical activity.

Future Work

To improve the personalized running route concept, further research needs to show the effects of a longer route and the impact of repeated speed measurements along the track. A next iteration of the design should be longer to test the effect more thoroughly. A longer run-up and speed measuring in multiple places can help staying connected to the user's pace and allow for personal training variations. Brighter lights or colour patterns can increase visibility. Next to that, patterns or a connected app could enable further personalization or a playful element in the route, motivating people to use the lights in a new way. Additional studies can also help to determine in which stage of a run this design is most effective. These iterations would create a better connection to the user, providing new and improved ways to motivate people to walk or run.

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VIRTUOUS DESIGN FOR E-HEALTH: FIRST SKETCH OF AN ETHICAL FRAMEWORK ACTIONABLE IN PRACTICE

Stéphane Vial¹, Marie-Julie Catoir-Brisson²

¹*École de design, Université du Québec à Montréal, CA*

²*PROJEKT Lab (EA7447), Université de Nîmes, FR*

Abstract

Mobile health apps are booming but they raise complex ethical issues. Research on ethical issues in e-health is usually focused on the downstream part of the design process. This paper focuses on the upstream part and explores how we can embed values into digital health artefacts at the early stages of the design process, in a virtue ethics perspective specific to e-health. What does a virtuous design for e-health consist of? How to design for e-health virtuously? In order to address these questions, existing ethical frameworks in design are of limited interest. For that reason, we developed a first sketch of an ethical conceptual framework that is specific to the challenges of e-health and that is actionable in

practice. It is made of 12 virtues to be considered at the early stages of any e-health design project that claims to be 'good'. This paper aims to introduce the framework and open a discussion on it. First, we present our theoretical approach by defining design ethics and exploring actionable values. Second, we describe two e-health design cases through the lens of these values and we extract from them other values. Third, we introduce the first sketch of our ethical framework in design for e-health as a work-in-progress tool for framing design-led innovation in e-health.

Keywords: e-health, ethical design, virtuous design, ethical framework, design for e-health.



Introduction

Digital health is a major transformational force today in the health sector (Meskó et al. 2017). Mobile health apps are booming, including mental health (Anthes 2016). However, they tend to be controversial because they raise complex ethical issues, such as privacy, accessibility, or free informed consent (Wadhwa and Wright 2013). Research on ethical issues in e-health is usually focused on the downstream part of the design process, exploring ethical impact assessments or intertwined ethical and legal challenges (George et al. 2013). This paper focuses on the upstream part and explores how we can embed values into digital health artefacts at the early stages of the design process, in a virtue ethics perspective specific to e-health. What does a virtuous design for e-health consist of? How to design for e-health virtuously? In order to address these questions, existing ethical frameworks in design are of limited interest, because they are either very general and not specific to the health sector (Van den Hoven, Vermaas and Van de Poel 2015), or very restricted to targeted issues (Harris 2014). For that reason, we developed a first sketch of an ethical conceptual framework that is specific to the challenges of e-health and that is actionable in practice. It is made of 12 virtues to be considered at the early stages of any e-health design project that claims to be 'good'. This paper aims to introduce the framework and open a discussion on it.

Theoretical approach

Ethical design

Ethics is commonly defined as a system of values, principles and rules that guide action towards the good. A principle or rule is used to frame the decision that leads to action (e.g. 'treat others as you would like others to treat you') by referring to a value

(e.g. reciprocity). Applied to design, ethics can be defined as follows: an approach or a process¹ is used to frame the project that leads to an artefact (e.g. biomimicry) by referring to a value (e.g. sustainability). It means that values can be expressed and embedded into artefacts (Van den Hoven, Vermaas, and Van de Poel 2015). Therefore, ethical design requires identifying values to be incorporated into artefacts, and ethical design for e-health requires identifying values that are specifically relevant to be incorporated into e-health artefacts. For instance, as the right to be left alone and to be free of surveillance, privacy is a typical value to be incorporated into a mobile health app. But what does it mean to incorporate values?

Virtuous design

Among the different types of ethics, virtue ethics appears to be the most suitable ethics for any design that seeks to embed values into artefacts at the early stages of the design process. In virtue ethics, a good action depends on a virtuous person. Applied to design, it means that a 'virtuous designer' carries out a 'good design'. For instance, to be incorporated into a mobile health app, the value of privacy can be early integrated into the design process only if it is expressed from the outset by the designer or the design team as an essential requirement AND materialized in the process through actionable design principles, such as those of Privacy By Design (Cavoukian 2009). In other words, virtuous design for e-health can only be achieved if the design process is guided by predefined values that are specifically relevant to an e-health context, consciously claimed as such by the designer/design team, and actionable in practice. However, one is not born, but rather becomes, a virtuous designer/team, especially in healthcare: it's something to be worked on and built on.

¹ We consider here that the equivalent in design of a principle or rule is an approach or a process.

Exploring values

This sub-section is an attempt to explore existing frameworks and to identify in them values that are *specifically relevant* and *actionable in practice* in design for e-health.

Design for Values (DfV)

Design for Values is a broad approach to the ethics of design that is not specific to the health sector (Van den Hoven, Vermaas, and Van de Poel 2015). However, it offers a framework of interest based on 11 values that can help us identify values that are specifically relevant in design for e-health. The 11 values of the DfV approach are the following:

- 1) Accountability and Transparency,
- 2) Democracy and Justice,
- 3) Human Well-Being
- 4) Inclusiveness,
- 5) Presence,
- 6) Privacy,
- 7) Regulation,
- 8) Responsibility,
- 9) Safety,
- 10) Sustainability,
- 11) Trust.

Among them, we will keep the following values in order to embed them in our framework. *Inclusiveness, Privacy, Safety* and *Trust* are already well known in existing research on e-health (George et al. 2013), so we consider them as obviously relevant in design for e-health, since they are already admitted as such and related to actionable approaches in practice (e.g. inclusive design, Privacy by Design, engineering design...). *Accountability, Transparency, Democracy, Justice* and *Sustainability* are relevant for any kind of ethical design, including design for e-health, and they are also related to actionable approaches (open design, participatory design, ecodesign...).

However, we will not keep the values of *Human Well-Being* and *Responsibility* because we consider them tautological in a health context. We will not keep the value of *Regulation*, because we consider it related to legal and governance challenges more than ethical ones. We will not keep the value of *Presence*, because we consider it encompassed in *Trust*.

To be noticed: already known in existing research on e-health, the value of *User Autonomy* is missing in the DfV approach.

Design for social innovation (DfSi)

Design for social innovation has emerged over the past two decades as a new paradigm for design (Bason 2012; Mulgan 2014; Manzini 2015), that is today more broadly called 'social design' and based on the central value of the *Common good* (Tromp and Hekkert 2018). In that sense, DfSi can be seen as a value-based design approach, intertwined with ethics. Often based on citizens' local initiatives involving a large range of participants, it is driven by 4 main values: the value of *Common Good* (designing for collective ends to improve the society at large), the values of *Democracy* and *Justice* (participatory design with stakeholders on equal terms) and the value of *Sustainability*. Only the value of *Common good* is new here, compared to the DfV approach. However, we will not keep it since we consider it very broad, tautological in a health context, and not specifically relevant in design for e-health.

Responsible innovation in health (RIH)

Responsible innovation in health has been characterized through the integrative RIH framework by Pascale Lehoux and collaborators (Pacífico Silva et al. 2018). It is of interest for us because it is specific to the health sector. It is comprised of 9 dimensions organized within 5 value domains.

Table 1. Overview of the values from the RIH framework

Value domains	Specific values (dimensions)
Population health	Health relevance; Mitigation of Ethical, legal and social issues; Health equity
Health system	Inclusion (of stakeholders); Responsiveness; Level of care (compatibility)
Economic	Frugality (greater value using fewer resources)
Organizational	Alternative business models (that benefit more society)
Environmental	Eco-responsibility

Although the RIH framework is specific to health, several of the values it offers are quite similar to those that we have found in the DfV and the DfSi approaches. *Health equity* is a health version of Justice. *Inclusion* of the health system stakeholders is a variant for *Democracy*. *Frugality* and *Eco-responsibility* are variants for Sustainability. The only new values here are those related to the Organizational and Health system domains. They are highly relevant in design for e-health considering the strong business and public health components of e-health (Eysenbach 2001).

Summary of selected values from literature review

In order to build our framework, we will select the following set of 10 values that we consider both relevant and actionable in design for e-health:

- 1) Accountability,
- 2) Transparency,
- 3) Democracy,
- 4) Justice (i.e. Health equity),
- 5) Inclusiveness,
- 6) Privacy,
- 7) Safety,
- 8) Sustainability,
- 9) Trust,
- 10) Inclusion of Health system.

Cases

Improving the follow-up of chronic insomnia

Som'Health is a project-grounded research focused on chronic insomnia. The aim of the project is to show that a digital service based on an app, and associated with a connected bracelet, can be useful for educating and monitoring insomniacs, if it is integrated into a care network supported by professionals and expert patients. The project revealed that several values were central and essential.

First, Privacy, because of personal sleep data collected through a sleep diary on a daily basis and possibly shared on digital social networks. Second, Democracy and Participation, since the digital diary was co-designed and tested with various stakeholders (patients, sleep specialists, nurses, secretaries, family doctors, psychologists) following a real shared-decision making process. Third, Trust and Safety, since patients expressed strong concerns regarding personal data, information systems and databases. All of these values (Privacy, Democracy/ Participation, Trust/Safety) are consistent with our literature review.

But there are two more values that appeared as central in the project. First, the value of Attention, in the sense of preserving the user's attention. It's not only

about avoiding distraction (Pang 2013) but also supporting the information ecology between the various tools offered through digital and non-digital solutions. Second, the value of Self-Representation, coming from the need for a visual language that could make sense for the patients. This value was identified by the researchers from the

analysis of patients and caregivers feedback at each iteration of the design of the sleep agenda, during the co-design workshop. As a subjective complaint, chronic insomnia requires a monitoring tool that allows patients to express their subjective lived experience (Figure 1).



Figure 1: Sleep timeline in Som'App

Improving access to psychotherapy

Psydia is a project-grounded research focused on psychotherapy. The aim of the project is to explore what design can do for psychotherapy in a digital age beyond the tendency to strengthen the false divide between the 'online' and the 'offline' (through preconceived ideas such as online therapy services). Conducted from Fall 2016 to Fall 2018 with five student cohorts who designed 69 prototypes of a mobile app, the project enabled a large range of ideas to be generated.

Considering the results, students did not give a great deal of attention to key values such as Privacy, widely neglected. Inclusiveness or Sustainability were even completely avoided. They focused more on Trust. For instance, the 'Explorapie' project aims to increase Trust in therapists that we browse online considering the lack of public awareness in therapies and the difficulty to rely on a therapist profile on a screen: it offers to match a patient with the right therapist after accessing relevant information about the therapy types, such as videos, testimonials... (Figure 2).

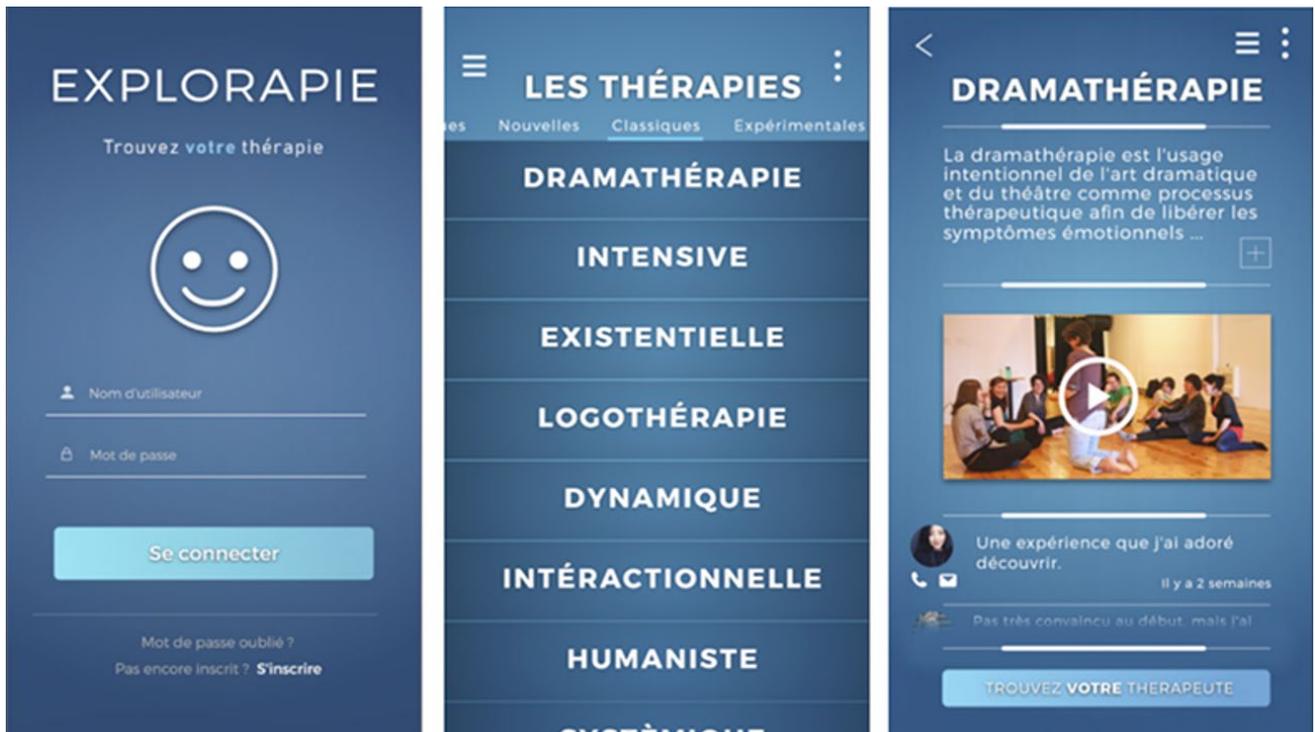


Figure 2: Screenshots of the project 'Explorapie'

As the students approached the project mainly with a patient focus, we also conducted codesign sessions with clinicians (psychologists). An unexpected value appeared during conversations with clinicians. It was phrased like this: *'It's up to you to decide if you need to see a therapist'*.

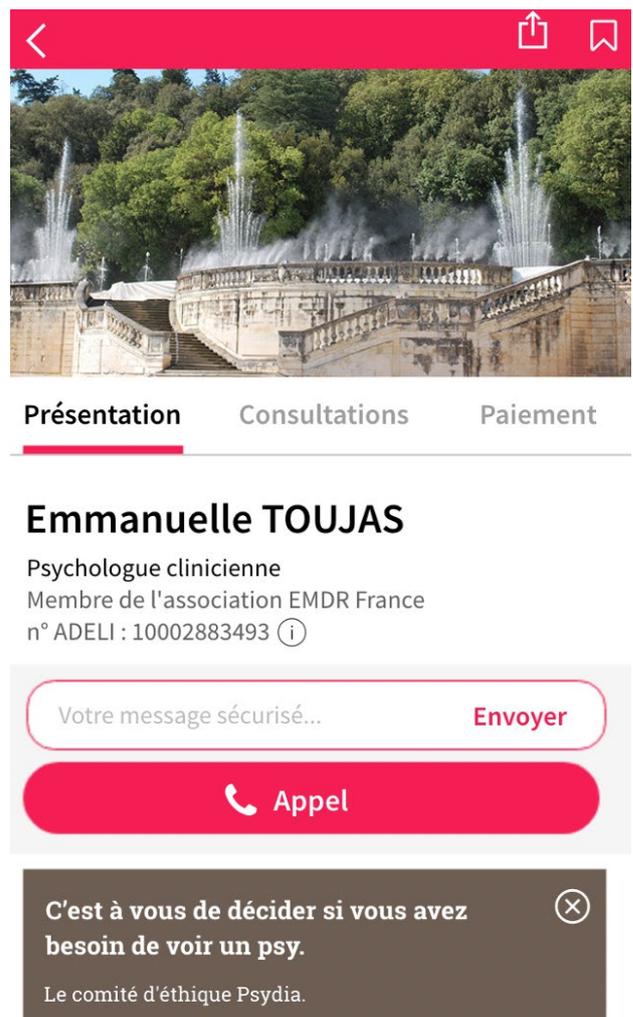


Figure 3: Codesigned therapist's profile (top of page)

We decided to embed it as it is into the interface, and to display it as a recommendation for patients coming from a sort of built-in ethical committee (Figure 3). The value that lies behind is Self-Determination. Clinicians always try to support patients' self-determination, which is widely recognized by the Ethics Codes of many psychological associations.

The virtuous design for e-health framework

General description

Inspired by previous work from both of us (Catoir-Brisson 2019; Vial 2019), this virtuous design for e-health framework is an attempt to frame design-led innovation in e-health through ethical concepts that are actionable in practice. The framework consists of 12 values and 12 series of related approaches (examples of appropriate methods/processes).

Values and approaches are distributed on both sides of a central axis and should be read from the bottom up along the axis in a three-level progression: individual, relational and systemic (Figure 4). Each level includes the values that must be incorporated into the e-health artefact from a particular design perspective.

The individual level corresponds to the perspective of the individual's relationship to himself or herself: it includes the values of the Self, Attention, Privacy, and Safety. The relational level corresponds to the perspective of the individual's relationship to other people, to groups to which he or she belongs, or to norms that act on the artefact: it includes Trust, Transparency, Accountability, and Inclusiveness.

The systemic level corresponds to the perspective of the individual's belonging to organizations, institutions, society as a whole and the planet itself: it includes Inclusion of Health system, Profit in second place, Justice, and Sustainability.

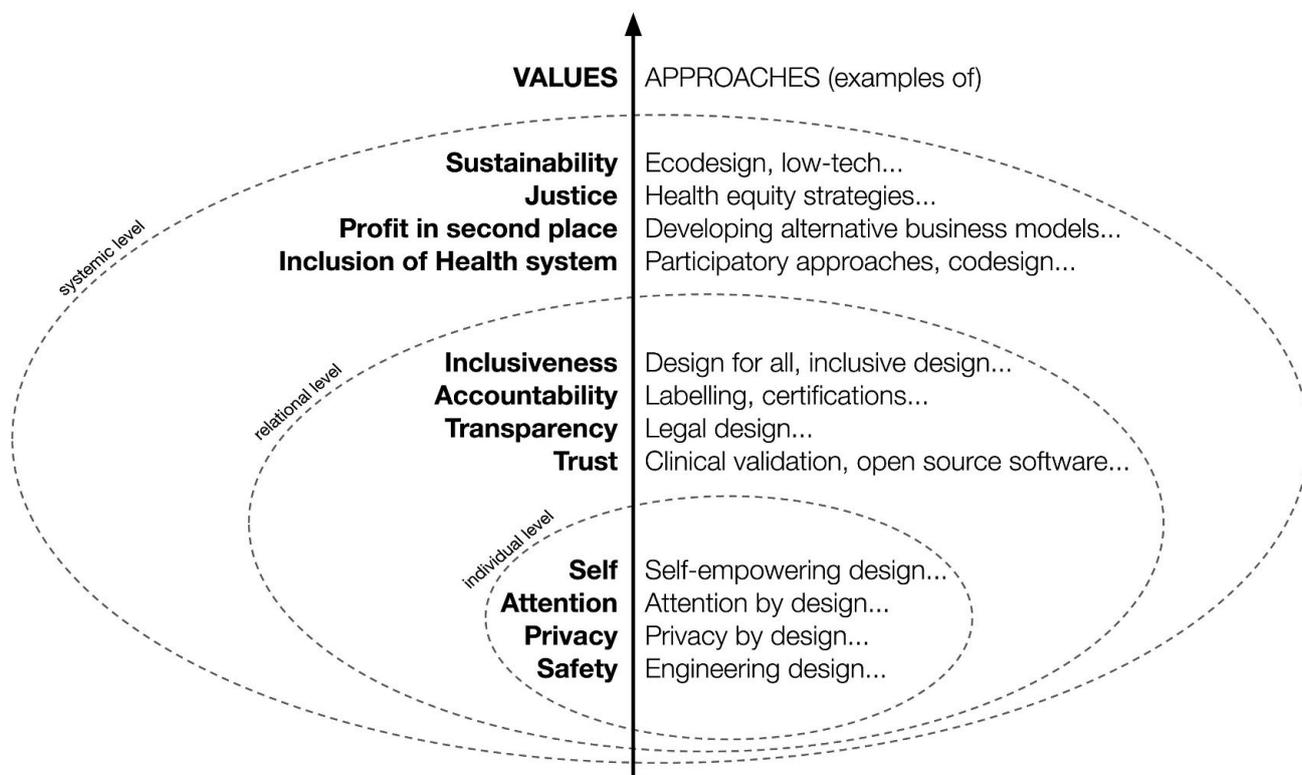


Figure 4: The virtuous design for e-health framework

Values

The values offered in the framework consist of a final set of 12 values: 10 values from our brief literature review and 2 additional values (marked below with an asterisk *) from our short cases studies. Although these 12 values are different, there may be some overlap between them.

Individual level

Safety is the value of doing no harm, physical (e.g. used materials) or mental (e.g. brain effects).

Privacy is the value of preserving confidential any personal data.

Attention * is the value of respecting the ability of users to freely apply their minds to something.

Self * is the value of respecting and supporting the patient's autonomy or self-reliance, it encompasses both Self-Representation (2.1) and Self-Determination (2.2).

Relational level

Trust is the value of reliance on the credibility, efficacy and morality of the service.

Transparency is the value of open communication to users, with no lies or dark patterns.

Accountability is the value of providing evidence of ethical commitment.

Inclusiveness is the value of including human diversity and various contextual situations of users.

Systemic level

Inclusion of Health system is the value of involving health stakeholders and considering health institutions.

Profit in second place is the value of developing business models that benefit society as a whole.

Justice is the value of including vulnerable groups and promoting equity in health.

Sustainability is the value of reducing the negative environmental impacts of health activities.

Approaches

The approaches listed in the framework are examples of possible relevant design methods and processes for incorporating related values into projects/artefacts. Most of them are well-known and do not need any definition. A few of them are our own definition and would need further inquiry, such as Health equity strategies or Self-empowering design.

It is important for us to highlight that the main contribution of this paper lies in values.

By mentioning possible design approaches, we want to underline the fact that those values are actionable. Of course, we assume that many other possible approaches must exist or are missing here. We would be interested in improving the approaches side of the framework in future work.

On the same note, this framework does not pretend to be comprehensive, it is a first sketch, a basis for opening discussion on these complex issues.

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DESIGNING SEXUALITY AND INTIMACY CARE FOR ADOLESCENTS AND YOUNG ADULTS (AYAS) WITH CANCER

Ruocha Wang¹, Bob Groeneveld¹, Leonore Albers² and Pieter Desmet¹

¹*Delft University of Technology, NL*

²*Leiden University Medical Center, NL*

Abstract

Adolescents and Young Adults (AYAs) with Cancer are making the transition from childhood to adulthood while handling the burden of cancer. During this extraordinarily challenging time in their growth and development, sexuality and intimacy, an important aspect of AYAs' wellbeing, are often insufficiently addressed by the healthcare providers, and AYAs are dissatisfied with the available information. The objective of this study was to develop objectives that could help design properly address sexuality and intimacy in AYA care along with a design prototype. The research investigated the big picture of sexuality and intimacy care for AYAs in the Netherlands and looked into AYAs' unmet needs through literature study,

interviews with AYA using the Q-sort method and interviews with healthcare providers. The list of design objectives was proposed based on the interviewees' opinions and insights, along with an iterative prototype designed by the researcher that reflected the objectives. Through a cyclic interview process, the list of design objectives was revised, and the prototype was refined as a possible solution in the end. Finally, a conclusion on the research findings and the design objectives is provided.

Keywords: Adolescents and young adults (AYAs) with cancer; human-centred design; sexuality and intimacy; sexual health; online intervention

Introduction

'AYA' stands for Adolescents and Young Adults (AYAs) with Cancer diagnosed at the age between 15 and 39 years old. When the burden of cancer is added during the transition from childhood to adulthood, it becomes part of a challenging time in AYAs' growth and development. The challenges present problems that neither paediatric nor adult-treating oncologists are fully comfortable in managing (Bleyer et al. 2017). The cancer as a disease, the diagnosis and the therapies can all have a negative effect on the quality of life on both the patient and the partner. The impact tends to cause a decline in the patients' level of functioning and their ability to maintain intimacy and a healthy sex life with their partner. On the patients' part, this will continue for many years even after the cancer treatment has come to an end (Reisman and Gianotten 2017).

While the impacts of cancer diagnosis and treatment are widely recognized and have been investigated in multiple studies (Dobinson et al. 2016; Olsson et al. 2018; Wettergren et al. 2016), inadequate support from physicians and lack of information regarding sexuality-related issues may contribute to AYAs' unmet needs. A national cross-sectional survey about sexuality and intimacy among AYAs in the Netherlands was conducted in 2018 among 56 AYAs. Nearly half of the respondents expressed that the subject of intimacy and sexuality is not sufficiently discussed by the healthcare providers, and there is dissatisfaction among AYAs about the information supplied (Albers et al. 2019).

To date, very few studies have been published that focus on finding solutions to fulfil the unmet needs of AYAs and that can help reduce the negative impacts on sexuality and intimacy. It is a missing part of the puzzle of the comprehensive AYA care in the Netherlands.

Research Aim and Methods

The purpose of the current study was to develop a list of design objectives that can properly address sexuality and intimacy in AYA care. The study investigated the big picture of sexuality and intimacy care for AYAs in the Netherlands and AYAs' unmet needs throughout the cancer trajectory, and translated the findings into a list of design objectives.

A literature study and interviews were conducted in parallel. Two books were the main reference: (1) *Cancer, Intimacy and Sexuality - A Practical Approach* (Reisman and Gianotten 2017) and (2) *Cancer in Adolescents and Young Adults* (Bleyer et al. 2017). Additional literature about roles of different healthcare providers, psychoeducation and the sexual healthcare intervention model was also studied.

Five interviews with two sexologists, two interviews with two oncology nurses and seven interviews with five AYAs were conducted in the period between March and June 2019. The AYAs were recruited from the National AYA 'Young & Cancer' Congress in March 2019. All interviews were recorded and transcribed for analysis. The Q-sort method (Brown 1996), a popular qualitative research approach, was used to understand the unmet needs of AYAs. With sexologists and oncology nurses, the patient-healthcare provider interaction and referral pathway were discussed.

The list of design objectives was developed in a dynamic way throughout the research process. An iterative prototype reflected the design objectives, and was shown to interviewees to generate discussions on the list of design objectives and further refine it.

Research Findings

The Big Picture of Sexuality and Intimacy Care in the Netherlands

The big picture view includes the possible intervention throughout the cancer trajectory regarding sexual consequences, the healthcare providers involved in AYA care and the referral pathway, as well as barriers and opportunities in the communication between the AYAs and healthcare providers.

Reisman and Gianotten (2017) listed the seven phases of the cancer trajectory and discussed the main sexual consequences in each phase. A summary of sexual consequences regarding AYAs and their partners in each phase is shown in Figure 1. In addition, in the interviews with Dutch sexologist Woet Gianotten, the possible interventions in an ideal situation throughout the cancer trajectory were discussed and summarized in Figure 1.

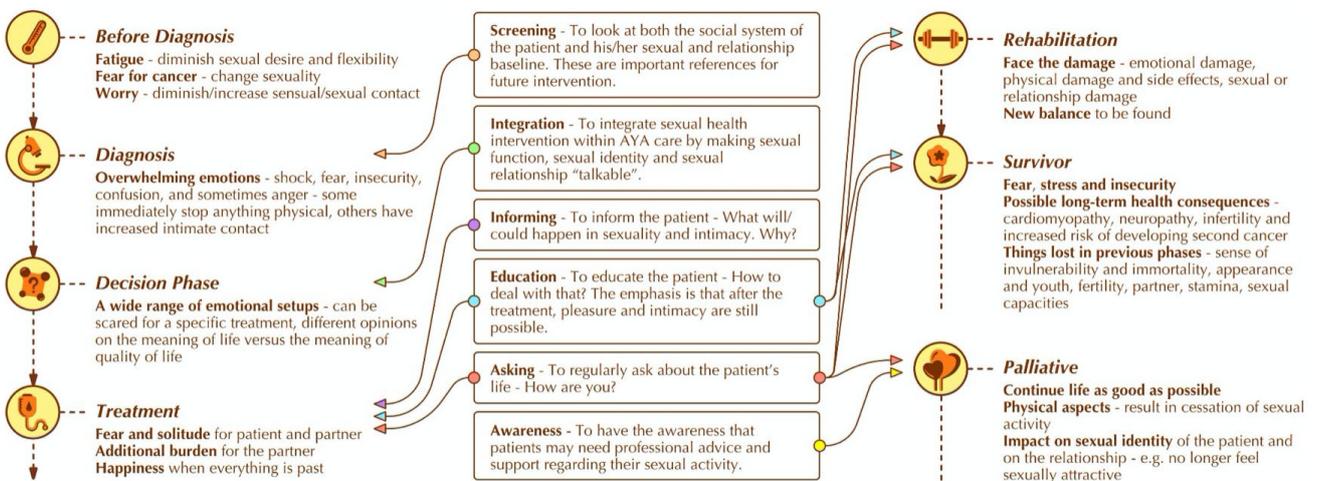


Figure 1: Sexual consequences in the seven phases of cancer trajectory and possible interventions

In the initial phases, it is important that the healthcare providers screen the baseline of the social system and relationship of the patient. It works as an important reference for future interventions where the patients should be routinely informed of what could happen, why and how to deal with this. Throughout the cancer trajectory, it is beneficial to integrate sexual health interventions within AYA care from making the topic 'talkable' (open for conversation) to regularly asking the patients 'How are you?'

The Dutch healthcare system has the resources to address a variety of concerns and disturbances that AYAs may face. It is provided by both 'primary contact' healthcare providers, the ones that AYAs always talk to, and the 'continuing support', those that the patients can be referred to. But AYAs do not always have the referral to address sexual concerns. Figure 2 maps out the different healthcare providers that may be involved throughout the cancer trajectory, along with the referral pathway from 'primary contact' to 'continuing support'. A referral here can be the recommendation or guidance to reach a relevant and reliable resource in any form, not necessarily a referral letter.

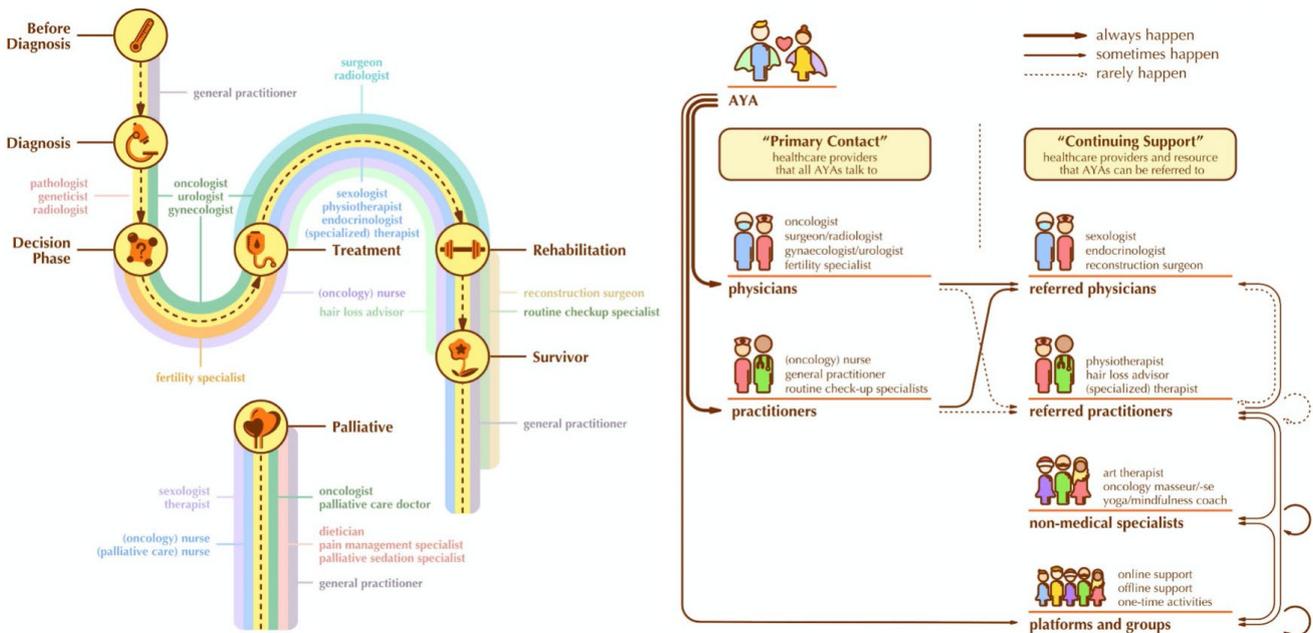


Figure 2: Different healthcare providers in different phases and in referral pathway in the Netherlands

In the referral pathway, AYAs are sometimes referred to physicians, such as a reconstruction surgeon in case of breast cancer. When AYAs communicate with the referred physician, they tend to talk more about sexuality and intimacy, and are sometimes further referred to other practitioners or non-medical specialists, where more referrals are available. When this pathway is unclear, it can take AYAs a lot of time to figure out how to approach the right expert, or even block them from finding support.

Sexuality and intimacy care is frequently not addressed by the oncology healthcare providers (Flynn et al. 2010) who are part

of the 'primary contact'. On the topic of possible omissions in the attention paid to sexual functioning in oncology care in the Netherlands, three papers revealed the barriers to discussions about sexuality and intimacy (Krouwel et al. 2015; Krouwel et al. 2015; Krouwel et al. 2015). The PLISSIT model is used as the structure to list the barriers found in these papers. This model Permission (P), Limited Information (LI), Specific Suggestions (SS), and Intensive Therapy (IT) was developed by the American clinical psychologist Jack S. Annon (1976) for the purpose of introducing the topic of sex into clinical conversations. Figure 3 summarizes the barriers in each layer of intervention in 'primary contact'.

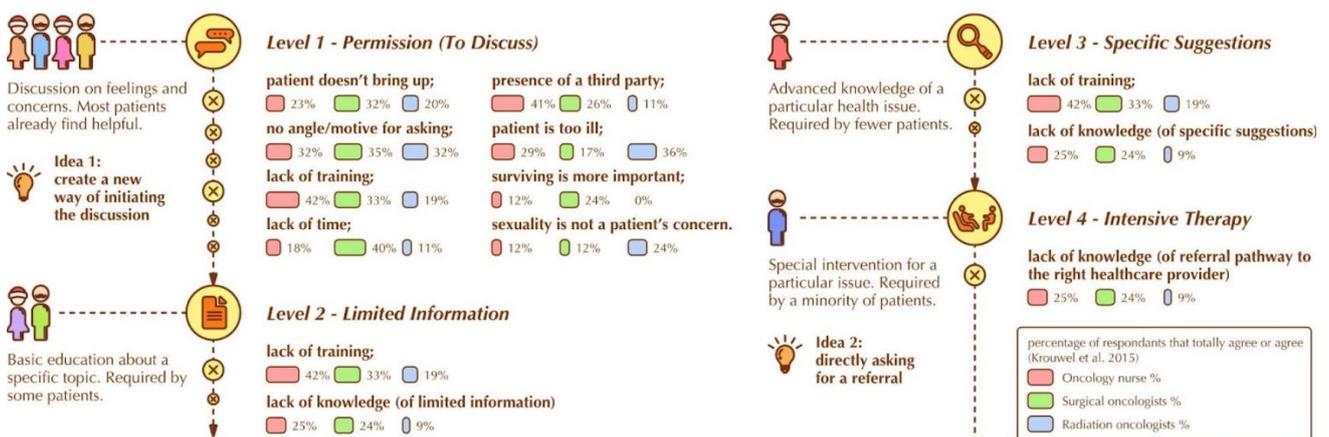


Figure 3: Barriers for oncology healthcare providers in addressing sexuality and intimacy in 'primary contact'

It is worth mentioning that most barriers can block the intervention at level 1 (Permission), that is, the basic discussion on feelings and concerns, which most patients would already benefit from. Some patients need further interventions, where the main barriers are a lack of training and a lack of knowledge. Oncology healthcare providers are not specifically educated to provide sexuality and intimacy care. Experts in 'continuing support' do have this specialized training and knowledge, but as discussed above, the referral from 'primacy contact' does not always happen, leaving AYAs' concerns and disturbances unaddressed.

Ideas about Crossing the Communication Barriers to Reach More Resource

To sum up, the main problem in the big picture of sexuality and intimacy care in the Netherlands is a lack of an effective referral pathway that bridges the gap between AYAs and experts specialized in sexual health. The ideal interventions are not offered by the healthcare providers that AYAs usually talk to because of various communication barriers, and they rarely refer AYAs to specialized experts.

If a new way of initiating the conversation can be created from the AYAs' side, and if

AYAs can ask for a specific referral, they can get closer to the support they need. On the healthcare providers' side, instead of being asked to offer sexual health intervention proactively, responding to the question and request of AYAs poses less burden on them.

The unmet needs of AYAs in sexuality and intimacy care

Research that studies the unmet psychosexual needs of AYAs seeks to understand what a design should provide through interviews. Dobinson et al. (2016) categorized these unmet needs into six categories: fertility concerns, sexual communication, dealing with side effects, dating and disclosure, relating to other AYAs, and reconciling identity conflicts. Albers et al. (2019) listed AYAs' satisfaction with received information of eight items concerning sexuality and intimacy care. Based on these two resources, the unmet needs in sexuality and intimacy care for AYAs were clustered and rephrased into ten items as a material to facilitate discussion in the interview.

Figure 4 shows the ten unmet needs and the Q-sort board used in the interviews with AYAs.

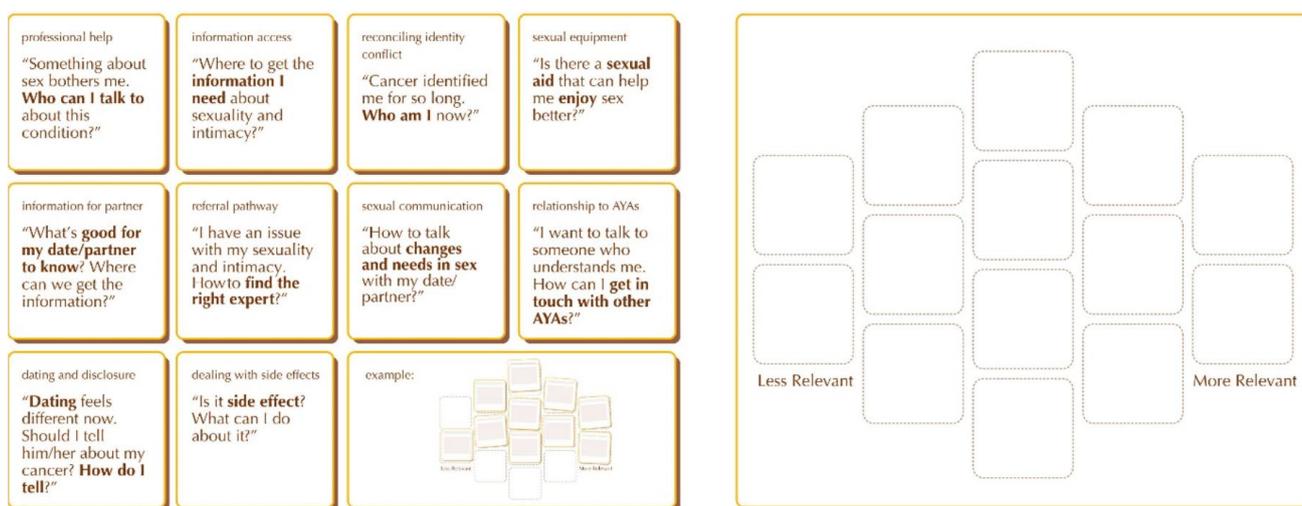


Figure 4: Material used for discussing AYAs' unmet needs using Q-sort method

Based on the thoughts and experience shared by the AYA interviewees, a summary of the insights is drawn below.

Needs for Reassurance

The feeling of reassurance is fundamental when AYAs try to reach support. They want to be reassured that seeking help about sexuality and intimacy is an appropriate action to improve the quality of life, not overreacting, it is normal to have disturbances, and that there is always someone or something that can help them.

Emotional support throughout the cancer trajectory is crucial. Some AYAs feel lost after the treatment. For them, it is reassuring to hear that other AYAs went through similar hardships.

Needs for Reaching Professional Help

The need for professional help is unmet in AYAs' 'primary contact'. Because the feeling of reliance is important, nurses with whom they have extensive contact with are extra important for addressing sexual health, but they can find this a topic that is difficult to discuss. Short conversations would already be helpful, but this rarely happens. The AYAs do not know where to go to, or which expert to find for their concerns. With so much uncertainty, the first step of reaching for help is already a serious hurdle to take.

Insight about Current Information Supply

During treatment, AYAs sometimes feel uninformed about the sexual consequences. Meanwhile, the real impact on sexuality and intimacy starts after the treatment. But most information supplied to AYAs about sexuality and intimacy, if any, only focuses on problems during treatment.

Practical tips are important. For example, it is hard to find the right products that help AYAs to deal with sexual problems, such as lubricants that are safe for patients undergoing chemotherapy.

Insight about Online Information Resource

When trying to find information online, AYAs could not find what they need. There is limited practical information about disturbances. Moreover, the information that is available, is sometimes too medical, not reliable, and matching the individuals' particular situation in terms of age group, type of cancer, etc. In addition, searching in the poorly organized pool of information takes a lot of energy and requires a high baseline of prior knowledge.

Design Objectives and a Proposed Solution – New Me. New We.

The list of design objectives was developed throughout the research process and reviewed with the experts and AYAs in the interviews. Table 1 lists the final design objectives and a possible design solution.

Table 1. Consideration, design objectives and possible design solution

Consideration	Design objectives	Possible design solution
A) Reassurance	A-1) Convince users that seeking help is appropriate, having disturbances is normal, and there is always something/someone who can help. A-2) 'Light-hearted' vibe.	- 'Love notes' where AYAs can receive and write heart-warming words and share personal stories. - 'Expert words' that suggests there is always a way to get better. - Easy language with a personal touch.
B) Content structure	B-1) Intuitive and clear. Direct users to the information about the right expert or resource. B-2) Low barrier and personalization.	- Interactive eHealth platform. - Website provides one-time searching. - Mobile application provides tailored information.
C) Closing information gap	C-1) Address concerns in biological, psychological and social layers and information suits age group. C-2) Provide basic intervention of problem explanations.	- 'Body map' for information on biological and psychological disturbances. - 'Directory' for communication with partner, healthcare providers and fellow AYAs.
D) Communication	D-1) Prepare user to initiate discussion with healthcare provider. D-2) Help the user to ask for specific support.	- Explicitly show users how they can ask the question in text. - Show possible support on screen that can help users to discuss with their healthcare provider.

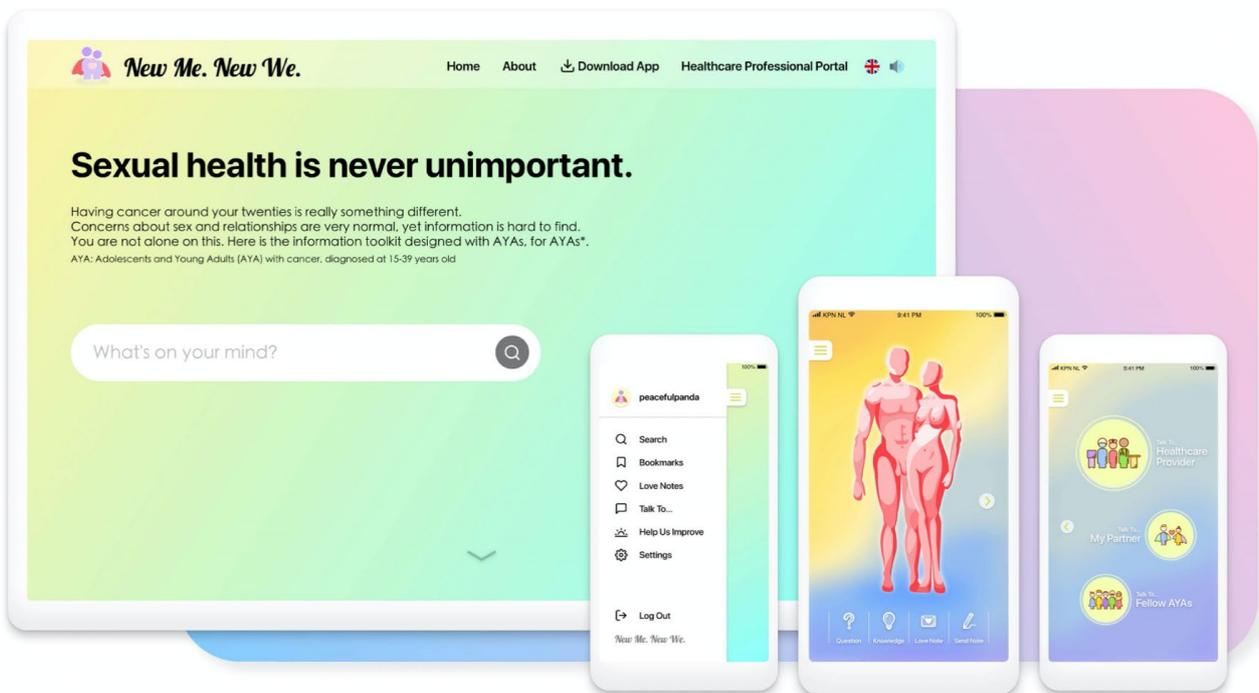


Figure 5: Interface design of New Me. New We.

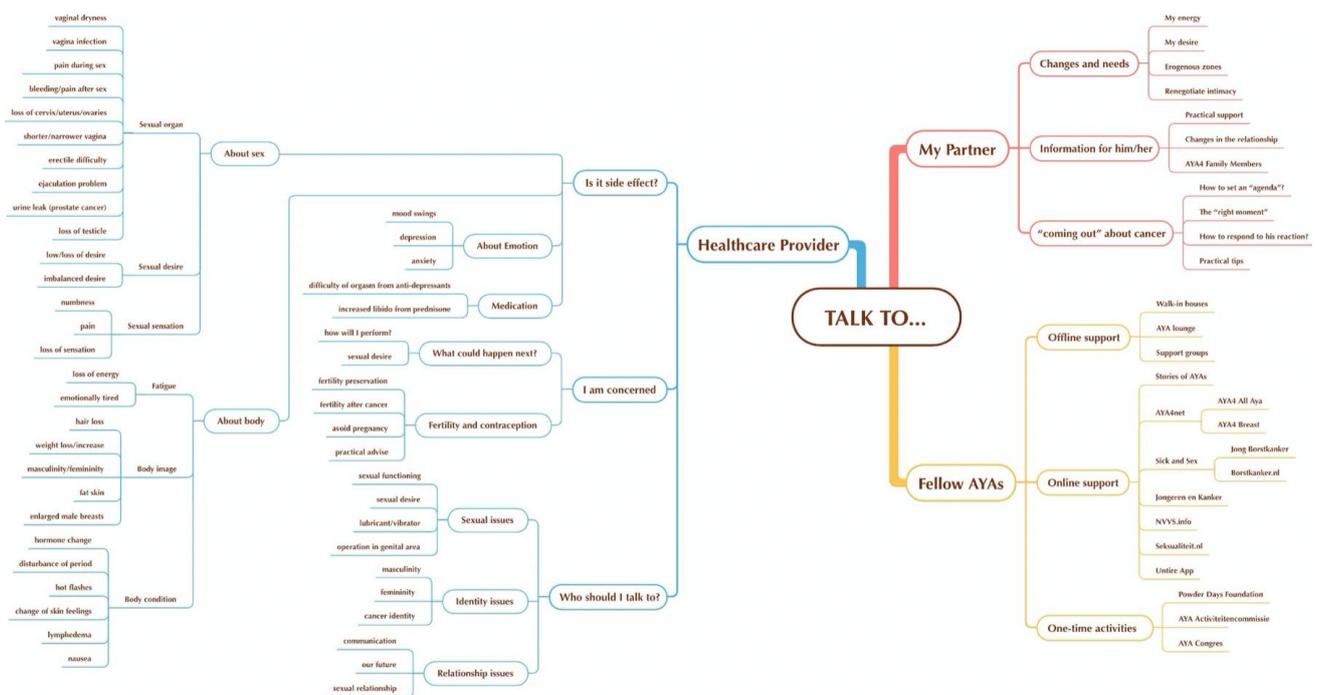


Figure 6: Information architecture of the directory of New Me. New We.

Conclusion

The study investigated the big picture of sexuality and intimacy care for AYAs in the Netherlands, where the main problem is the lack of an effective referral pathway to the right experts and resources. Based on the findings, we propose that AYAs can be encouraged to initiate the discussion and ask for specific support from the healthcare providers in their 'primary contact'. We also delved into the unmet needs of AYAs, and found that the need for reassurance and reaching professional help are fundamental. The gained insights about the current information supply and online resource were translated to a set of eight design objectives, including reassurance, content structure, closing information gap and communication. Finally, an application was presented that aims to meet the design requirements.

Some limitations of the research should be noted. Due to the small number of AYA interviewees and their above-average educational background, the insights and feedbacks may not fully represent the entire AYA group. Homosexuality, transgender people and polyamory were also not taken into account in the prototyping process.

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UNFORGETTING MUSIC: EXPLORING THE ROLE OF MUSIC IN THE DAILY LIVES OF PEOPLE WITH DEMENTIA LIVING AT HOME

Rik Wesselink¹, Marike Hettinga², Geke Ludden³ and Berry Eggen⁴

¹University of Twente, NL; Windesheim University of Applied Sciences, NL

²Windesheim University of Applied Sciences, NL

³University of Twente, NL

⁴Eindhoven University of Technology, NL

Abstract

People with dementia (PwD) risk a deterioration in quality of life (QoL) as the dementia progresses. A growing number of studies show that music can increase QoL. Unfortunately, loss of initiative and problems during product-use hinder access to music. In this paper we first depict a gap in knowledge on the needs of PwD in relation to listening to music in daily life. We then describe how we applied contextmapping to gain in-depth

insights in the role of music in the daily lives of PwD, using an 'activity case' and semi-structured interviews. Finally, we discuss the insights gained from a thematic analysis of these interviews and explain how these insights contribute to the current body of knowledge and provide pointers for future studies.

Keywords: dementia, music, home, daily life, contextmapping



Introduction

As the disease progresses, people with dementia (PwD) require more help in performing routine daily tasks and risk a deterioration in quality of life (QoL). Music can increase QoL (Elliott and Gardner 2018). Executing recreational, meaningful and pleasurable activities is an important need for PwD (Meiland et al. 2017) and music can meet this need. Unfortunately, impairment in executive functioning, apraxia and apathy are common amongst PwD and result in problems in product-use and loss of initiative. This hinders their access to music.

There is a growing number of studies that show the effect of listening to music on PwD. Listening to music can have positive effects on mood and quality of sleep (Chan, Chan, and Mok 2010), decrease symptoms of depression (Elliott and Gardner 2018), and increase activity in the 'rewarding system' in the brain (Snowdon, Zimmermann, and Altenmüller 2015). Other studies show that listening to preferred music can decrease agitation (Garland et al. 2007), anxiety (Sung, Chang, and Lee 2010) and pain (Park 2010).

A recent scoping review (Elliott and Gardner 2018) highlights three gaps in the existing body of knowledge. First, a narrow range of used methodologies. To study the effect of music on PwD, quantitative methods are used predominantly. These quantitative studies do not provide insights into how we can provide access to music for PwD, nor into the role music plays in their daily lives. Second, current studies predominantly focus on the context of care facilities and professionally led music interventions. This excludes a large population, for 60-70% of PwD live at home (Elliott and Gardner 2018). Studies that do focus on the home context, primarily look at the beneficial effects of music rather than at an implementation in the daily routine. Listening to music is an integral part of the daily lives of many people and could provide meaning and help holding on to one's

identity (Elliott and Gardner 2018). Third, the lack of input from PwD themselves: In most studies, caregivers acted as the voice of the PwD and they were the main source of information (Elliott and Gardner 2018). This is understandable since communicating with PwD becomes more complicated as the disease progresses, but it can lead to losing the perspective of PwD.

In current literature, knowledge on how to embed music in the daily lives of PwD living at home is still lacking. Therefore, improving everyday access of PwD to music requires knowledge on their needs and difficulties. This study aims to increase our understanding of these needs by exploring the role music plays in the daily lives of PwD living at home. Our study contributes to the three gaps by taking a person-centred qualitative research approach. Results inform future studies on how smart technology can support PwD to benefit from positive effects of listening to music in daily life.

Method

We used contextmapping (Visser et al. 2005) to gain in-depth insight into the role of music in the daily lives of PwD. The set-up of the study allowed PwD to actively participate and to do this at home, in their own time and at their own speed.

In contextmapping, data is gathered in two phases (Visser et al. 2005). The first phase is used to sensitize participants for the topic of the study. This is usually done in a period of two weeks and often involves a variety of creative assignments for the participants. For this phase, we developed an activity case (Figure 1) with assignments tailored to PwD and focused on music in daily life. Informal carers were asked to support participants in executing the assignments.



Figure 1 – A completed activity case. The case contains a booklet with creative assignments that take about five to ten minutes a day. They vary from taking pictures of music at home to creating a timeline of a day. The goal of the assignments is to sensitize participants for the interview.

The second phase is used to generate data, often through a generative group session. We did not use group sessions but interviewed participants in the safe environment of their home. This encouraged participants to share their perspective on music in their daily life, and it provided the possibility to show the spaces and objects that were discussed.

The overall process followed these steps:

1. Selecting participants: participants were selected by a dementia care professional based on our inclusion (recently diagnosed with dementia, living at home, informal carers can support

the participant in this study for two weeks) and exclusion (mentally not ready to participate, does not accept help from informal carers) criteria. Selected participants were approached by the dementia care professional and informed using an information brochure. If they wanted to participate, the researcher contacted them for the next steps. We included four participants in this study. They varied in age, gender, type of dementia and living situation. All participants were able to sign an informed consent and the informal carers were involved in the study.

Table 1 - Participant information

Participant	Age	Gender	Living situation	Dementia type
P1	65-69	Female	Alone	Lewy body
P2	80-84	Male	With partner	Mixed: Alzheimer's / Vascular
P3	70-74	Male	With partner	Alzheimer's
P4	80-84	Female	With partner	Lewy body

2. Sensitizing: We visited the participants, informed them in detail about the study and the purpose and content of the activity case. After signing an informed consent, the activity case stayed with the participants for two weeks. After one week we made a phone call to the participants to check on the status, and if required help them move forward.

3. Interview: After two weeks, we collected the activity case and interviewed the participants at home. These semi-structured interviews were recorded and transcribed.

4. Analysing: The interviews were analysed using a thematic analysis with an inductive approach (Boeije 2009) by the first author and a second researcher. Insights were compared to current literature.

Results

We first describe the needs uncovered, followed by a more detailed description of the two types of listening to music we identified.

Needs Relating to Music in Daily Life

In the thematic analyses we grouped the needs in three themes: needs relating to (1) emotional state, (2) content, and (3) products. The first theme (emotional state) represents needs that do not specifically relate to music (autonomy, dealing with negative emotions, enjoyment, social awareness, liveliness and distraction, reminiscence, and tranquillity). We found that music can play an important role in fulfilling these needs. Participants, for example, play music to overcome negative emotions (P1), purely for enjoyment (P1, P2, P3) and to make the home livelier (P2).

The second theme (content) represents needs that relate to the carrier of the music and their preference in music. Personalized music was an important content-related

need. P1, for example, explained she experiences an overload of digital radio channels, mainly with music 'that is just not for me, so much screaming'. This abundant offer of music she doesn't like makes it hard to find the channels that play music she does like.

The third theme (products) represents the needs relating to the design and functionality of the products they use to play music. Most reported issues in this theme relate specifically to the field of interaction design.

Needs relating to content and products reveal the 'music' barriers PwD run into in their daily lives. When these needs are not met, this has a negative effect on fulfilling the needs relating to emotional state. Autonomy, for example, declines when PwD cannot operate a music player. Difficulties in interacting with music players were reported often. P4, for example, could not turn on music at all, and P3 reported that he prefers listening to his CDs, but when he is alone, he cannot do this, so he turns on the radio. Remarkably, most participants required richer functionality than what is commonly considered in the design of music players for PwD. In our study PwD indicated they want to be able to play music from several sources, including records, CDs and YouTube (P1, P3). Furthermore, they like a remote control (P1), and when they live with a partner, they like to listen privately (P2, P3).

Ways of Listening to Music

We identified two ways of listening to music: music as background and listening to music as a focused activity. The reasons to turn on music, music sources, role of the music, and related needs vary between these two ways of music consumption.

Music as Background

The need for music as background varied between participants. One participant (P2) continuously played the radio during

the day. Reasons for this were eliminating the silence, adding liveliness to the room, and keeping up with what's happening in the world (P2). For background music, our participants only used FM radio and sometimes switched between radio channels. When other activities required them to focus, such as when they wanted to read the newspaper, the volume was lowered (P2). Other participants (P1, P4) explicitly explained they did not want the radio on all day, because 'those commercials make me crazy, and it all goes so fast!' (P1) or 'every now and then you hear a nice song on the radio, but it is followed by a lot of chatter and fuzz' (P4). Moreover, in contrast to P2 they liked the silence sometimes. It provided tranquillity.

Listening to Music as Focused Activity

P1, P2 and P3 described moments where they listen or want to listen to music. In these situations, they really focus on listening and enjoying the music. They assigned an emotional value to the music. P1 explained that music makes her happy when she is feeling anxious, and it helps her to get rid of all the negative thoughts. P2 emphasized he loves classical music. The moments of the day on which participants focused on listening to music varied between the participants. P1, for example, listens to music 'while drinking coffee' and she takes the radio to the shed 'There is a nice table there, with a big white towel on it. Garden chair with a pillow, so I can sit comfortably. And there I can enjoy listening to music. And smoke a cigarette.' For P2 this focused listening to music was done 'when I feel like it'.

In contrast to music as background, where radio played a dominant role, listening to music as a focused activity involved a variety of music sources. Participants explained they play their own music, referring to their collection of CDs, records, and even tapes. CDs and records were linked to their preference and stories of the past. Playing music from USB, YouTube,

Spotify and digital radio (via the TV) were also mentioned, occurred less often, but had its unique advantages (such as automatically playing related songs on YouTube).

Main Insights and Discussion

The insights we gained through this explorative study are based on activity cases and interviews with a limited number of participants. Although this limits the generalizability of the results, it does provide in-depth insights into the lives of the participating PwD and the role music plays in it. We compared these insights to what is known from prior studies and set a path for future research.

Insight 1: Participants actively use music for their mental wellbeing.

Music is used by PwD to prevent negative feelings and to actively deal with them when they occur. In studies that focus on the effect of music, music is mainly selected and initiated by therapists or informal carers (Elliott and Gardner 2018).

Insight 2: Problems in product-use limit the feeling of autonomy for PwD, and hamper listening to preferred music.

Maintaining autonomy is important for PwD (Meiland et al. 2017). Most participants owned music stored on sources they could not play by themselves anymore (records, tapes and CDs), making them dependent on others.

Insight 3: There are two ways of listening to music, namely *music as background*, and listening to *music as focused activity*. Most challenges are experienced in *music as focused activity*.

In related literature (Elliott and Gardner 2018), we see that *music as background* is often not considered. This might be because most studies used musical therapy, which always is a focused activity (Favilla and Pedell 2013; Chan, Chan, and Mok 2010; Sung, Chang, and Lee 2010).

For using *music as focused activity* the required functionality of the music player is quite extensive. Most products that provide this functionality, such as the possibility to play from various sources, are too complex to use for PwD.

Insight 4: PwD require interfaces that are in line with and can adapt to diminishing capabilities.

In our study, many of the reported difficulties relate to interacting with the music player or missing functionality. These insights provide a direction for future studies on better interaction design for PwD, which is crucial not only for improving access to music, but for all product design. Better designs could increase the autonomy of PwD in daily living.

In our view, future studies on interaction design for PwD should focus on creating interfaces that are in line with the capacities of PwD, can adapt to the declining capacities of the user, require a low cognitive load, are self-explanatory, and are tangible. Some recent studies already implemented some of these aspects (Seymour et al. 2017; Thoolen, Brankaert, and Lu 2019).

The tangibility and visibility of the music source adds value. Tangible sources such as records, CDs, and tapes make browsing for music intuitive. They can easily be identified, they show the songs they contain, they can carry an emotional value, and they are personal (and therefore often preferred music). Moreover, they fit in the mental model PwD have for music players.

From a functional point of view, and in relation to music, we suggest focussing on one music player to provide rich functionality, make it (or part of it) portable, have high quality sound, and allow for private listening by allowing wired and wireless headphone connection.

Conclusion

This study provided new insights that contribute to the current body of knowledge. We exposed a gap in knowledge on the needs of PwD in relation to listening to music in daily life. By getting input from PwD themselves, and by embedding this study in their home setting, we gained valuable insights into their needs in relation to music in their daily lives. We explain how these needs are currently not met and provided pointers for future studies to improve this. This paper aims to inspire others to include PwD as primary source for data and intensify studies on design for PwD living at home.

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TRANSLATIONAL CHALLENGES IN HEALTHCARE – THREE CASE STUDIES

Jonathan West

Helen Hamlyn Centre for Design, Royal College of Art, London, UK

Abstract

Design and innovation projects initiated by front line clinical research, without initial industrial or commercial focus, often fail to produce interventions which are adopted into front line practice. The well-covered concept of the ‘valley of death’ describes the difficulties which promising innovations face in the pursuit of translational benefit and front line adoption.

This paper discusses three case studies: a redesign of a resuscitation trolley, an innovative cervical collar, and outputs from the ‘Design Bugs Out’ project. These projects were funded by medical charities and public funds, and faced commercial, resource and end use challenges during the efforts to achieve more widespread clinical adoption. Although the research and design in each project followed best principles (and won awards), they all failed to produce significant front line impact.

Lessons from these failures are highlighted, demonstrating that factors such as market size and turnover, the changing landscape of clinical debate, and limited resources can all have a sizeable impact on

an innovation’s ability to cross the ‘valley of death’. Though many of these factors are typically regarded as downstream of the traditional design process, they point to a larger question concerning when the design process should end, and implementation/translational efforts begin.

Good inclusive design involves giving agency in the design process to stakeholders who are affected by the intended design output. Much focus to date has been on the inclusion of front line clinicians and patients in the process. These case studies reveal that such ‘downstream’ factors must also be considered within the design process in order to optimise innovation outputs and maximise the likelihood of adoption into front line clinical use. The aim is to benefit current inclusive design projects in healthcare and achieve greater impact from the design-led innovation in this field.

Keywords: human centred design, participatory research, design approaches, translation, commercialization



EXPLORING 'MEANINGFUL' OUTCOME MEASURES IN THE CONTEXT OF CHILD PROSTHETICS

Gemma Wheeler¹, Ursula Ankeny¹, Joe Langley¹ and Nathaniel Mills²

¹Lab4Living, Sheffield Hallam University, UK

²NIHR Devices for Dignity MedTech Co-operative, Sheffield, UK

Abstract

In 2016, the Department of Health (UK) released funding to establish The Starworks Network – a child prosthetics research network who bring young people, and their families, together with professionals from healthcare, industry and academia. There are recognised challenges to innovating for child prosthetics, for example low patient numbers compared to adult populations. Interestingly, a series of creative, collaborative 'sandpit' events with all stakeholders also highlighted another reason for this 'market failure' and subsequent lack of innovation in this area (or challenges in making small-scale innovations more widely available) - namely, a lack of 'outcome measures' that are meaningful to children and families. 'Outcome measures' are typically numerical grades of how effective a healthcare intervention is for a patient, often focussing on physical, functional aspects (i.e. walking distance) rather than a holistic view of the patient's life and context. When follow on funding was awarded to continue the network, researchers aimed to understand what 'meaningful' outcome measures might involve for this population.

Insights from literature will be combined with the perspectives of children, families and professionals from healthcare and academia, elicited using participatory design research methods (such as generative toolkits, card sorting activities and/or probes, dependent on the group). It is anticipated that such a multi-stakeholder, design-led approach is necessary to develop a meaningful, yet robust method of capturing less 'tangible' aspects of children's lived healthcare experiences.

If designing for future health aims to build on growing tradition of involving patients in healthcare, then attention must also be paid in understanding how patients can be involved in evaluating the real-world impact of that healthcare in their lives, and mobilising this knowledge. Whilst the complexity of this is compounded when these patients are children, the long-term health economics of involving children in their own healthcare from an early age cannot be underestimated.

Keywords: co-production, evaluation, paediatrics

CO-DESIGNING A SMARTWATCH APPLICATION WITH CHILDREN AND FAMILIES TO SUPPORT INDEPENDENT SELF-MANAGEMENT OF PAEDIATRIC INCONTINENCE

Gemma Wheeler¹, Peter Culmer² and Nathaniel Mills³

¹Lab4Living, Sheffield Hallam University, UK

²University of Leeds, UK

³NIHR Devices for Dignity MedTech Co-operative, Sheffield, UK

Abstract

Incontinence (a lack of voluntary control over bowel and bladder function) is most commonly associated with older adults, yet it is also estimated to affect 1 in 12 children. Whilst the impacts of paediatric incontinence can be significant (i.e. on a child's health, confidence, social participation and development), research in this area is uncommon.

The authors' previous work (Wheeler et al. 2018) explored the unmet needs of children living with incontinence, and their families, highlighting the potential for an alarm watch that better suited the needs of this population. This paper will describe subsequent research and development of a smartwatch application to address this need, working collaboratively and creatively with families at each stage of the process. This worked aimed to address both the practical questions of how to develop an appropriate smartwatch application for this group (i.e. specifying product interactions and functions), but also the more 'meta' questions of how to co-design with children and families (i.e. facilitating creative, collaborative activities that position children as experts).

Creative workshops were developed, building on previous experience of co-designing with children; using short activities that encourage self-expression and are playful in nature. Other activities that families would be familiar with, such as a 'treasure hunt,' were also found to be effective. In between workshops, the project partners consolidated the input from these sessions and developed prototypes in response.

The need for personalized eHealth technology in this area has been demonstrated in the high participant retention rate across all 3 workshops, but also in the positive feedback from families after testing the final, working prototype. The project has recently been awarded funding to develop the application further to make it widely and freely available on public platforms.

Keywords: co-design, paediatrics, incontinence, self-management, independence

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CO-DESIGNING A NECK STABILISING AID FOR CHILDREN WITH NARCOLEPSY

Gemma Wheeler¹, Heather Elphick², Joe Langley¹, Nathaniel Mills³, Ursula Ankeny¹ and Naomi Raszyk¹

¹Lab4Living, Sheffield Hallam University, UK

²Sheffield Children's NHS Foundation Trust, UK

³NIHR Devices for Dignity MedTech Co-operative, Sheffield, UK

Abstract

Narcolepsy is a disabling sleep disorder characterised by excessive daytime sleepiness and muscle weakness precipitated by strong emotions, known as cataplexy. Children with narcolepsy inevitably fall asleep on car journeys and the loss of head control causes immense parental anxiety as well as pain and discomfort for the child. There is currently no available, effective support for these children. As such, this research aimed to understand what a neck stabilising aid for these children should do, how it should look and feel, and how it should fit into a child's existing travel routines. Three co-design workshops were developed collaboratively by design researchers, clinicians and a MedTech Cooperative manager. They focussed on exploring unmet needs, testing existing commercial products and testing a range of new prototypes (developed by the research team in response to their input so far).

Participants attended from across the UK, including children aged 6-16 years, parents, siblings and healthcare professionals.

A range of bespoke co-design tools were generated to suit the emerging needs of the project and accommodate unexpected, but vital input from participants. Sketch ideas based on the collated input from children and families were generated, and sent back to the families for their feedback. Following this, nine prototypes were built based on the sketches described above. The prototypes were designed to be fully functional (although not safety tested) and were tested in the final workshop with children and families. This has given some early indication of which concepts warrant further development, with further funding being sought to do so.

Keywords: co-design, paediatrics, narcolepsy



Introduction

Narcolepsy is a lifelong neurologic disorder with onset commonly occurring in childhood or adolescence, and affecting approximately 0.025% of the general population (Plazzi et al. 2018). The symptoms of this debilitating condition, including excessive daytime sleepiness and attacks of muscle weakness (known as cataplexy), have a huge impact on a child's life in terms of emotional wellbeing and ability to reach academic potential.

Supportive aids ranging from a hand-held fan to help the child stay awake, to a wheelchair to aid transport when the child falls asleep unexpectedly, can help the child and family to function more easily day to day. However, some of the challenges faced by these children in daily life are less obvious to identify and understand. To design for such challenges requires close collaboration between families, healthcare professionals and designers.

This paper describes one such collaboration to develop a supportive aid to address a previously unmet need – head and neck support for children with narcolepsy when travelling in the car. The paper will provide the progress to date of this project, including practical findings (i.e. the challenges identified and potential solutions) as well as methodological insights into co-designing with a potentially vulnerable group.

Background

Literature

There are few studies available in the literature concerning the lived experiences of children who live with narcolepsy, and their families. Whilst some studies suggest that these children generally score lower on narcolepsy-specific quality of life scores compared to controls, and their parents experience higher levels of stress (Szakács et al. 2019), there is little insight available into the daily challenges these families experience.

The use of co-design (here referring to 'the creativity of designers and people not trained in design working together in the design development process,' [Sanders and Stappers 2008]) in healthcare contexts is becoming increasingly recognised for its ability to elicit and harness the knowledge and lived experiences of patients or 'users,' to better understand such challenges. A range of co-design tools have been developed in recent years to reposition 'users' as equal partners in a co-design process, contributing their unique expert knowledge alongside that of clinicians and professional designers, for example. Indeed, this project aimed to meaningfully involve families at each stage, adapting the aims and activities according to their insights.

The use of co-design approaches with children in healthcare is not as common in the literature, but extant examples demonstrate that it is worthwhile. Whilst previous work has highlighted some key principles that will be useful in this study, (such as enabling self-expression, and using short, sharp activities that have no 'wrong' answer [see van Rijn & Stappers 2008]) there is no readily available guidance on co-designing with children with narcolepsy. As such, the development of the co-design activities was guided by the insight of clinical specialists and previous experience of the design team.

Previous work

Two exploratory workshops with families of the Sheffield Children's Hospital (SCH) narcolepsy clinic explored unmet needs of children with narcolepsy. The 55 attendees (including children with narcolepsy, parents/carers, siblings, an adult with narcolepsy and sleep specialist staff) identified 20 potential problems that could be solved using supportive technology. A second workshop explored and prioritised these needs, where 'head and neck support in the car' was ranked as their greatest need by 32/39 participants. A literature search showed no references to previous work on

head and neck supports for children with narcolepsy in cars, nor any existing products specifically addressing this need. As such, further funding was sought to design and develop a neck stabilising aid for children with narcolepsy to use in the car.

Research aims & objectives

This study aimed to explore a range of possible solutions to the unmet need. It was anticipated that a range of concepts would be developed as speculative ideas, due to time and funding restraints. However, as will be discussed below, working prototypes of these speculative ideas were also developed and tested with families to guide future work.

The initial design and development of these solutions were informed by initial exploratory work with families, guided by three research questions:

- What are the lived experiences of children with narcolepsy, and their families, in regards to travelling in the car?
- What can be learned from current 'hacks' or solutions already sought by the families?
- What can be learned from commercial products already available, and family's views on them?
- As can be established by the questions above, an asset-based approach was taken – focussing on the strengths and expert knowledge of families to guide the project.

Method

Research team

Given that clinical staff from the SCH Narcolepsy clinic were key figures of the project team (alongside design researchers and a MedTech Co-operative manager), the team had established relationships with families. Patients aged 6-16 years were identified from the SCH narcolepsy clinic and responses were enthusiastic.

Research activities

1. Workshop 1 – Understanding lived experiences

Nine families attended a short (90 mins) session to reflect on and share their experience of car journeys, using 3 main activities:

- a. Car journey mapping – Families were asked to consider a journey they took often, for example going to school. After plotting each step of the journey on a timeline, the children were asked to attached an emotion to each of those steps. The negative emotions acted as prompts to better understand the challenges of travelling when you have narcolepsy (see figure 1).
- b. 'Hacks' – families were asked to draw or write the methods they currently use to make travelling more comfortable (see figure 1).
- c. Scorecards – a series of 'feature cards' were created (such as 'easy to clean,' 'soft,' 'looks good,') and families were asked to rank them in order or importance, elaborating where possible, or adding new features.

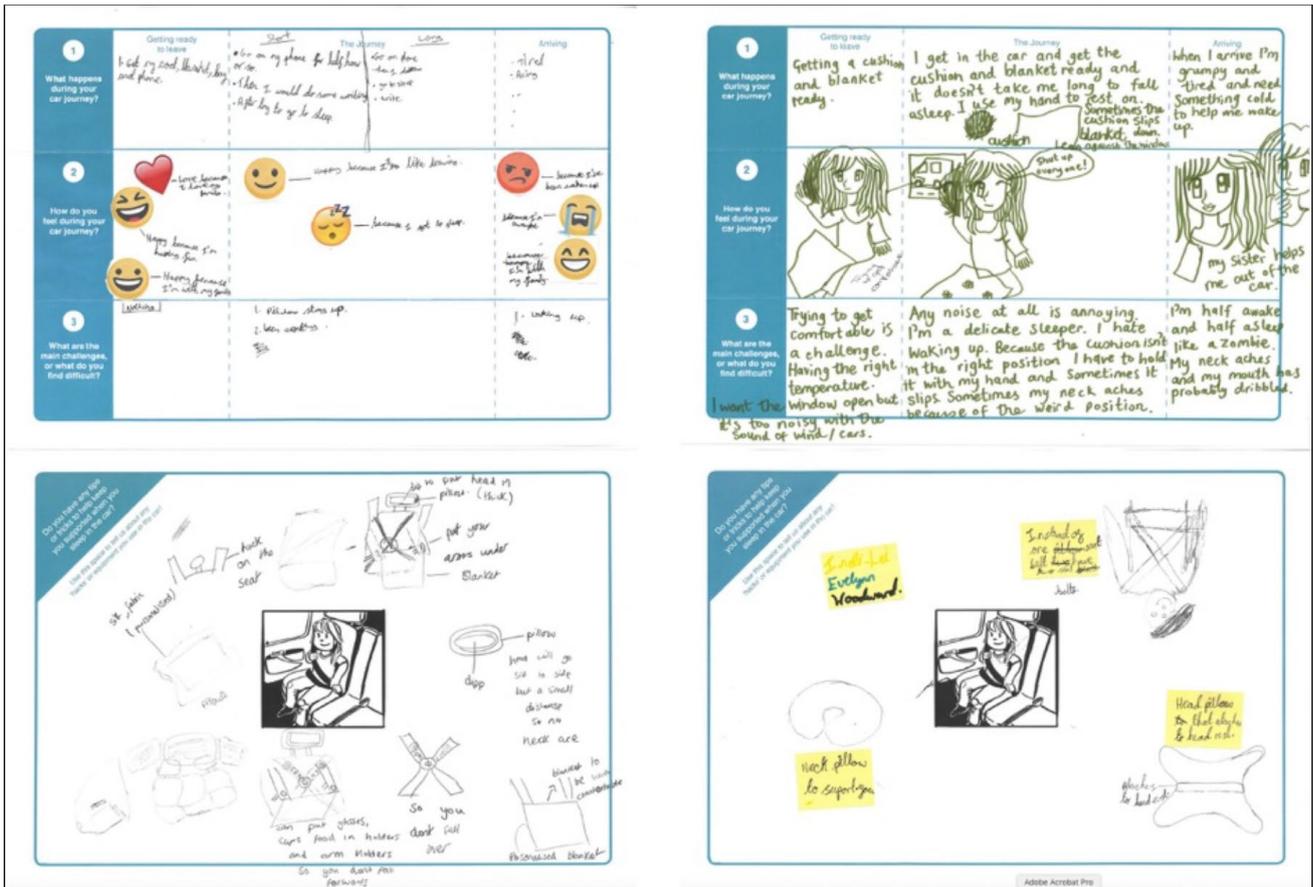


Figure 1: Examples of completed 'timeline' and 'hacks' activity sheets.

2. Workshop 2 – Develop understandings of key challenges, and test existing commercial products that aim to support sleep during travel.

This workshop formed part of the SCH narcolepsy clinic's annual 'family day,' with approximately 110 attendees (including patients, parents and families, healthcare professionals and members of the research team). As such, several activity 'stations' ran concurrently to accommodate the large numbers and unpredictability of the session:

a. A large format timeline of challenges already gathered from workshop 1 was printed and laid on the floor for families to add to or discuss with researchers (see fig. 2)

b. Several tables were set up to trial current commercial products in this area (i.e. inflatable travel pillows). Families were invited to try them on, discuss them with a researcher, add their thoughts to feedback sheets (see fig. 3) and/or edit them using a range of prototyping materials (see fig. 4).

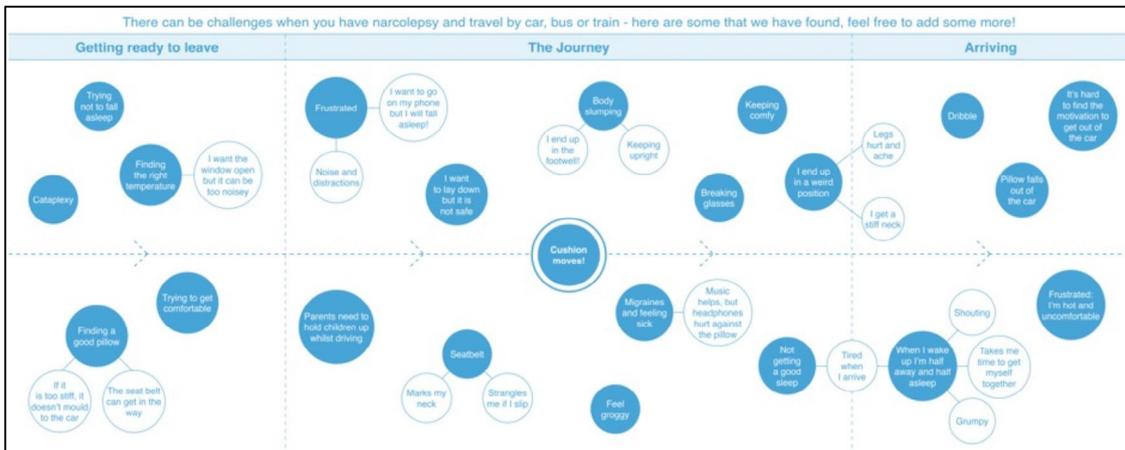


Figure 2: Car journey challenge timeline

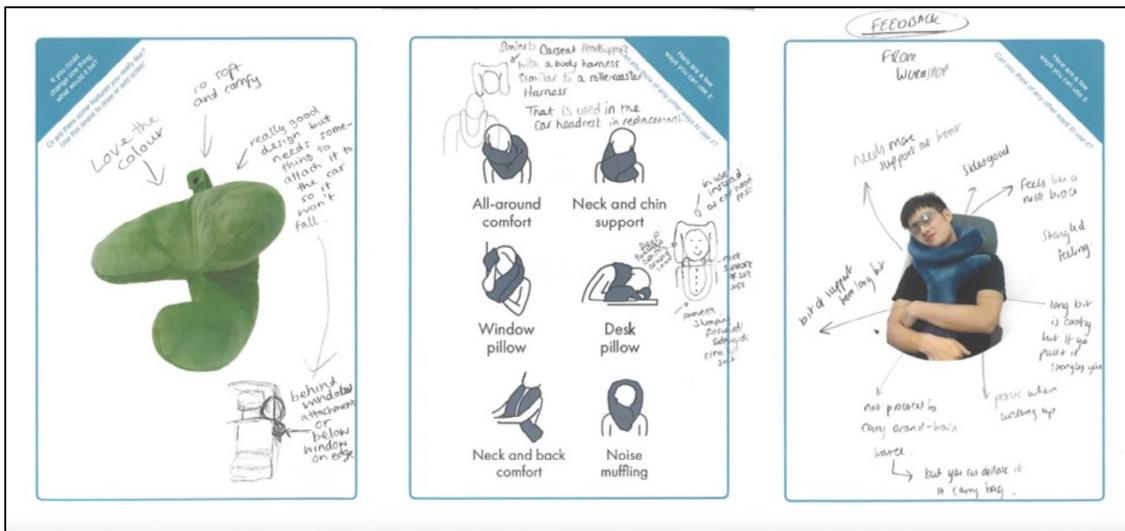


Figure 3: Feedback on existing products



Figure 4: Editing current products with prototyping materials

3. Independent design work and 'Activity Pack' – a range of sketch ideas were developed by the research team, and compiled into an activity pack for children and families to consider at home or in clinic (see fig. 5).

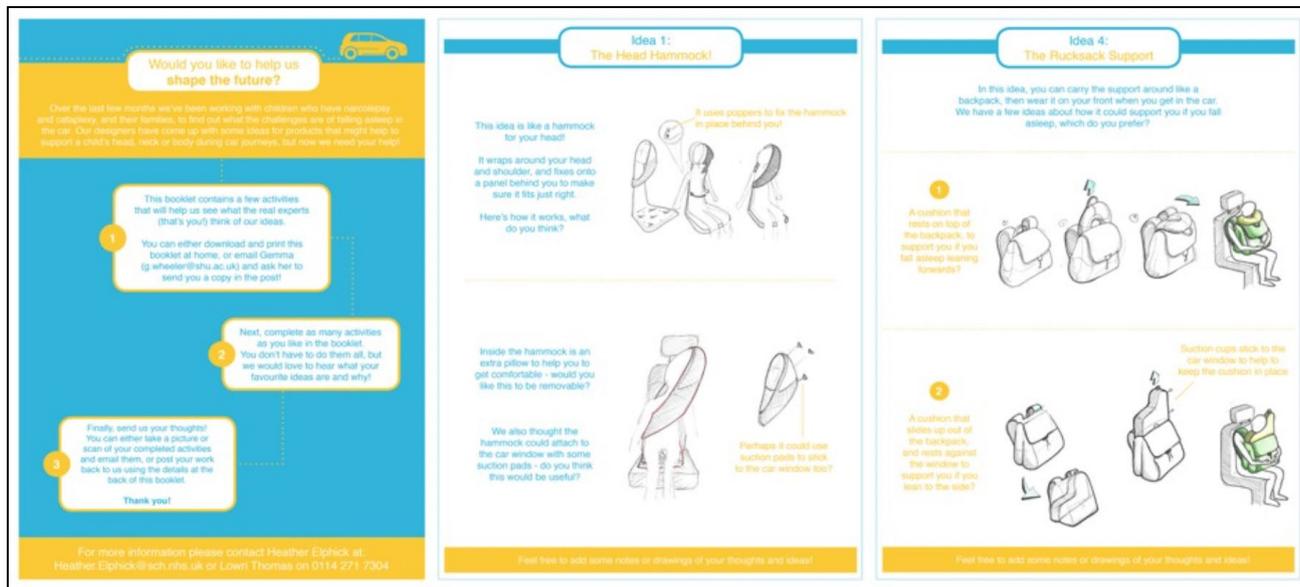


Figure 5: Example pages of the activity pack.

4. Independent design work and Workshop 3 – prototype testing.

A range of nine prototypes were built based on the sketches described above. The prototypes were designed to be fully functional (although not safety tested) and were tested in the final workshop with five children and three parents (plus clinical and design members of the project team).

As we could not be sure of the ages of children who would attend the workshop, the prototypes were modular and/or flexible to adapt to the child's height and weight, so that the concept could be tested effectively without being compromised by the fit. Several car seats were also sourced to support children's 'immersion' and create more realistic testing settings.



Figure 6: Testing final prototypes

Findings

In reality, the co-design process is iterative, and the team's understanding of the challenges continually developed through different activities and as more families contributed their experiences. For simplicity, the key insights driving the design of the potential solutions, and factors informing them, are described with separate headings below.

A need for full body support

Whilst the project originally aimed to design a head and neck support, it became clear from an early stage that a full body support for children with narcolepsy would be more useful in the car. Families explained that body slumping is a key issue, with children sometimes 'ending up in the footwell' or sustaining abrasions/breathing difficulties from the seatbelt. This is also very distressing for the parents, who voiced concerns over their child's safety if there was a car collision whilst children were in this position. They reported wanting to hold their children upright whilst driving, acknowledging that this was dangerous also.

To address this need, some families described methods they currently use to tilt the child back as much as possible. This involved sitting them in the (more adjustable) front seat or placing a pillow/rolled up towel underneath the child's legs.

Adaptability

The issue of how the support should adapt to the context and the child as they grow was raised in several activities. Most of the families involved preferred to use a simple pillow (even though this often slid down during the course of the journey), as this could adapt to different cars (i.e. can be 'squished' to fill the gaps between headrest and window) and public transport (again expanding the scope of the project).

Process of use

As the activities became more embodied (i.e. use of existing products), several questions were raised to be tested in the prototypes, including:

- Does the child wear the support as soon as they get in the car, or engage with it once they start to feel tired? This raises further questions of whether it can be put on without parental assistance.
- Does the product attach to the car (raising regulatory requirements) or to the child (raising comfort issues) or is it 'freestanding' (raising efficacy issues)?

Quality of sleep

Family involvement refined the aims of the project once more, by highlighting a need to support a good quality sleep, not just good posture, in the car. Parents (and children) readily explained that 'you take your life into your own hands when you wake [them] up' on arrival – a combination of waking up in strange positions with pain in their neck/legs, and feeling more tired due to a bad quality sleep, can result in the child feeling very bad tempered, or not being able to participate in activities on arrival.

Building on this, it became apparent that 'comfort' has many factors, some unique to this paediatric population. Families encouraged the team to use materials that are breathable (many existing products use a soft fleece material, but thermoregulation is a key issue for this group) and don't make noise (i.e. 'rustling' or 'crinkling').

Stigma

Car journeys can, for some children with narcolepsy, be yet another way of feeling 'different'. Some children described frustration that they couldn't use the journey for screen time (like their siblings), that they felt embarrassed when they slid into strange positions or drooled in their sleep, and that they didn't want a product that singled them out as 'different'. As such,

this solution had an opportunity to make the journey time more useful (i.e. getting a good sleep to make activities on arrival better) and alleviate the child's concerns over stigma.

Potential solutions & early feedback

Based on the input and ideation with families, nine prototypes were produced and tested, summarised in fig. 7 below:

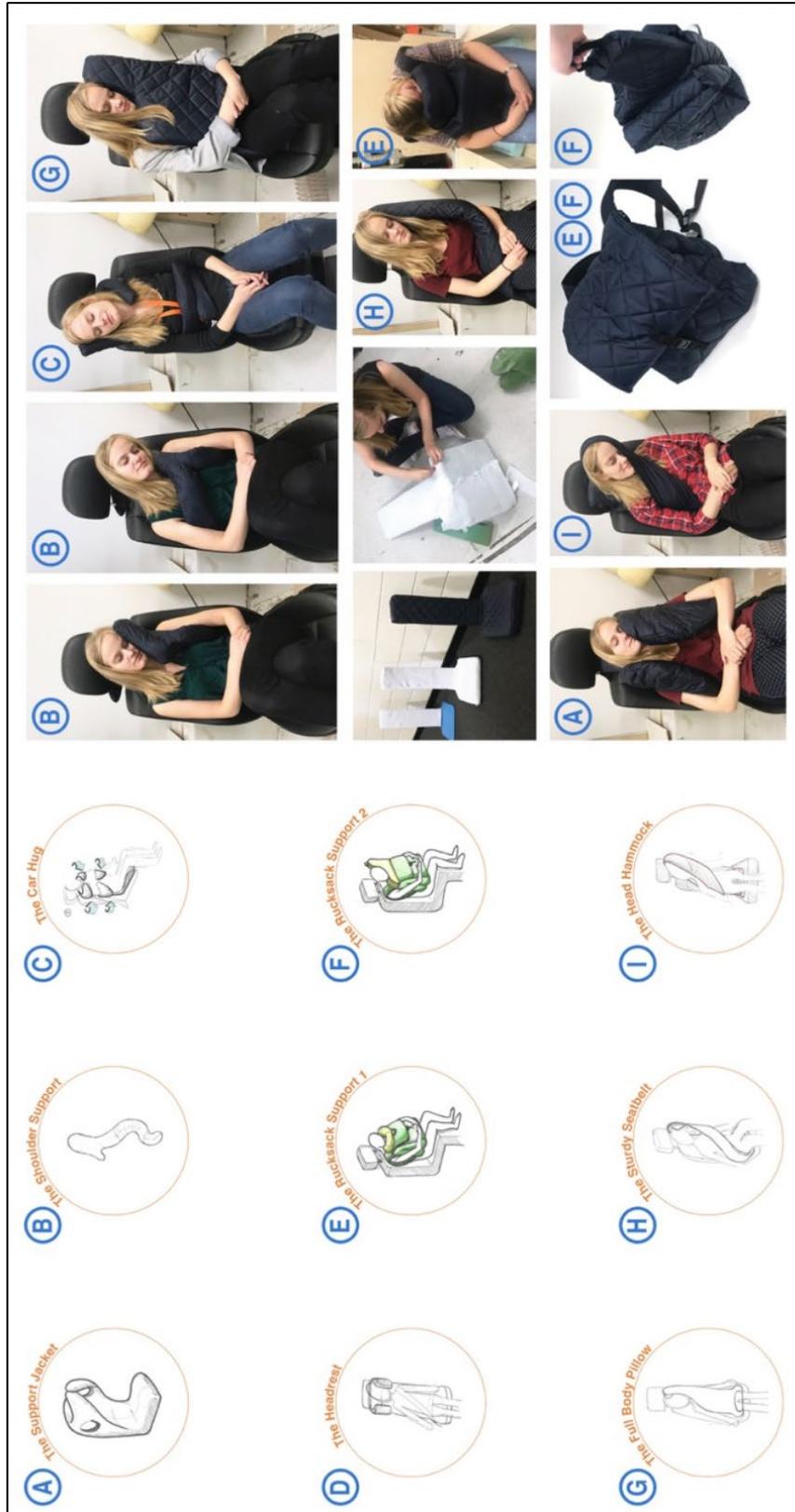


Figure 7: Potential solutions

In testing the prototypes, the team's assumptions were challenged once again. In this final workshop, children and parents were combining different prototypes to collect the features that suited them. Whilst there was no clear 'winner,' enthusiasm for the ideas was high. The most popular prototypes were those that were easier to put on/take off, and that provided lumbar as well as head/neck support.

Discussion

The fact that the majority of families currently prefer to use a simple pillow, rather than one of the many sleep supports available commercially, highlights the lack of provision for children on a broader level, and for this underserved population in particular. Whilst we have indicated some interesting potential solutions, funding is being sought for further testing, exploration and development in future work.

As demonstrated in the findings above, working closely with families throughout the project allowed the researcher's underlying (and unconscious) assumptions about the unmet need to be surfaced and challenged quickly. Providing a range of co-design activities (from paper-based reflection tools, to group card-sorting, to physical testing and prototyping activities) empowered families to access deeper levels of tacit knowledge about the challenge and communicate it effectively to be embodied in the prototypes themselves. This is important in relatively short projects such as this, and better justifies the use of public money for research in this area.

There is currently a paucity of literature concerning how to best involve children with narcolepsy in co-design. We found that some aspects of our approach are likely relatable to co-design with children in general. This includes facilitating children's input in a range of ways, for example allowing children to write, draw or use emoji stickers to express themselves (see fig. 1). It was important to make time for

activities that weren't directly related to the research aims, such as 'getting to know me' warm up games to set a playful mood. We also recommend bringing more activities than may seem necessary, for children who complete them quickly.

Other aspects of the approach aimed to specifically make children with narcolepsy feel supported and empowered. This included planning shorter (approx. 15 mins) research activities as well as break-time activities that encouraged physical movement. The environment itself should be well-ventilated, with a dedicated quiet space removed from the workshop available at all times for children who need to rest.

The most challenging facet of the co-design approach was to monitor the emotions and energy of the children. Whilst many co-design activities with children aim to foster laughter and excitement to encourage continued engagement, in this case such strong emotions can trigger an episode of cataplexy in the children (temporary loss of muscle tone). As such, close collaboration with clinicians helped to mitigate the risk of this, as well as ensuring parents were present in the workshop.

Close collaboration with the clinicians also allowed the families to 'trust' the project, develop a sense of shared ownership, and therefore collaborate well with the researchers. This is particularly important in rare paediatric conditions, around which often forms a tight-knit community of families. With this in mind, we have also found it important to build time into the workshops for these families to network and draw support from each other too.

Limitations

As with much qualitative and design research, the findings described cannot be representative of the entire population of children with narcolepsy due to the limited numbers of families involved. This is particularly true of 'lesser heard' voices who may struggle to attend such workshop

events. Recent developments in 'remote co-design' following the Covid-19 pandemic may seek to address such issues in the future.

Conclusion

This project provided a much-needed time and space to further explore a real need for an underserved paediatric population collaboratively with families. As detailed above, the input from children and families has repeatedly challenged the assumptions of the research team, allowing us to reach the crux of the issue much more quickly whilst also empowering/upskilling the patient participants involved.

Acknowledgements

This project was made possible by funding from the Medical Research Council, and the generosity of time and experience from the families involved.

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‘THE LONG NOW’: MIXED REALITY EXPERIENCES OF HUMAN AND ENVIRONMENTAL HEALTH

Matthew Wizinsky¹, Adetokunbo Ayoade²

¹University of Cincinnati, Ohio, USA

²Ayoade Design, University of Cincinnati, Ohio, USA

Abstract

Historically, public parks and urban infrastructures have generated sites of public well-being. Meanwhile, evolving media have transformed populations into subjects of public health messaging. Given the emerging realities of climate change, how might public data and public space converge to create new forms of discourse and participation on issues of human and environmental health? ‘The Long Now’ was an applied design research project that synthesized public data and public space into a mixed reality experience on health in a changing climate. An outdoor installation was produced for public exhibition and engagement. The installation was comprised of two experiences, one physical and one digital. A ‘parklet’ integrated with full spectrum lighting, as used to combat Seasonal Affect Disorder, and underground heating elements was designed to offset the decrease in nourishing sunlight in fall and extend the growing season of grasses used by the public for gathering. The digital experience was comprised of local, regional, and global data on changing environmental conditions in different temporal phases, presented as an Augmented Reality (AR) experience tied to the physical site. Research was conducted in two phases. Exploratory

technical research included iterative exploration of different approaches for interactive data visualizations made possible by AR. Evaluative research with tour guides, local residents, and youth programming docents from a local library revealed insights on the accessibility, legibility, and impact of the project with public audiences—including local residents and visitors. Results from the research were codified to reveal novel opportunities—including current and near-term limitations—for the use of Augmented Reality to synthesize public data and public space into exploratory, informative, and discursive mixed reality experiences to engage public audiences in site specific topics of health related to both the human body and a changing physical environment.

Keywords: climate change, public health, interaction design, exhibition, augmented reality

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DESIGN FOR A HEALTHY FOOD GAME FOR CHINESE ELDERLY PEOPLE USING SENSORY ETHNOGRAPHIC RESEARCH

Barbara S. K. Wong

Xi'an Jiaotong-Liverpool University, CN

Abstract

This paper was a student project about promoting healthy food and diet for elderly people in China. Elderly people have a higher risk of chronic diseases such as diabetes and hypertension and they have difficulty knowing and complying with healthy diet. The students adopted a sensory ethnographic research method and service design approach to conduct research about the food cultures and lifestyles of Suzhou city of the elderly people. The research methods used a combination of tools and methods including field trips, interviews, observations, customer journey maps, and empathy map. They went to a few communities in old town of Suzhou and interviewed more than 30 participants, as well as participated themselves in the activities with the elderly people to gain empathy with them. Video recording was used during the research for gaining insights of everyday living experiences of the elderly people. Through intensive research and gaining deeper insights, the students found that the elderly people have difficulties knowing what healthy things to eat and they also lacked of exercise and entertainment. The design objective was to provide an innovative design intervention and meaningful experience to promote healthy diet. They developed a Mahjong card game, a typical Chinese game that was familiar with the Chinese elderly people. The game included the knowledge of several most common Chinese food so that the elderly people can learn the knowledge through playing the card game. The game was initially tested with 10 elderly people

in the community and it was well-accepted. However, the elderly needed to take some time to learn the healthy food so it was suggested to play the game in a regular basis. An on-going research has been conducted in an elderly home in Hong Kong to see the effectiveness of the game in longer term. Finally, some limitations will be discussed in the paper.

Keywords: behaviour change, design intervention, healthy food and diet, gamification, sensory ethnography, user experience.

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CO-DESIGNING FUTURE TECHNOLOGIES FOR FORENSIC MENTAL HEALTH CARE: A CASE STUDY IN A TBS CLINIC

Dan Xu, Andrea Nesta, Francisco Palavecino, Gideon Asamoah, Line Sandborgh and Gijs Huisman

Digital Society School, Amsterdam University of Applied Sciences, NL

Abstract

Forensic mental health care refers to the treatment of violent offenders who suffer from severe mental disorders. In general, forensic mental healthcare services face challenges such as bureaucracy, high costs, risk avoidance and ethical considerations of detaining the patients. ICT (Information Communication Technology) innovations in forensic mental healthcare services are usually slow and lack involvement from the bottom-up. In this paper, we report on our experience of exploring technological innovation opportunities within a forensic mental healthcare clinic together with caregivers and other stakeholders. We started by sensitizing ourselves to the caregivers' daily activities and emotions with cultural probes and interviews. We hosted a co-design workshop with caregivers to speculate on future technologies that could benefit their daily work activities. Several fictional prototypes and scenarios based on previously

gathered insights were created to provoke conversations and considerations about unexpected consequences with the caregivers. All field notes and transcripts were analyzed qualitatively. Our findings suggest that current ICT innovations have the potentials to overcome existing barriers in forensic mental health care services. However, human contact is essential for the treatment so ICTs should support blended care instead of replacing caregivers. Both the agency of caregivers and patients should be considered when designing ICTs for them. Care should be taken in designing the physical forms of new ICTs to avoid disrupting trust. All participants responded positively to being involved in the creative process. Last, we reflect on some limitations of our study.

Keywords: human centred design, participatory research, design approaches, forensic mental health care



Introduction

Forensic mental health care treats violent offenders who suffer from severe mental disorders, often with extensive comorbidity, including substance abuse, neurodevelopmental disorders, and personality disorders (Mullen 2000). In order to provide appropriate care and protect the public from potential harm, the patients are often detained in secure and highly restrictive settings. As part of the public sector, incidents, actions and policy changes in forensic mental health care services frequently come into the spotlight of media coverage and are sensitive to public opinions. As a result, changes can be slow and reluctant within these services considering the unexpected responses and consequences they may have on a large scale.

Using ICTs in mental health care can reduce costs while providing convenient and accessible support. E-health applications (i.e., applications to improve and support health, well-being, and quality of care) are considered a cost-effective approach to personalize the treatment, and digitized information can provide a quantitative overview to support the diagnose and assessment (Kip et al. 2018). However, the restrictive and secured environment of forensic mental health care makes it difficult to access the users and context, as a result, researches into opportunities and considerations when designing technologies for forensic mental health care are scarce (Verbaan and Bowers 2018).

In this paper, we report on a case study within a forensic mental health care clinic in the Netherlands, in which we applied participatory design methods to involve participants in reflection on the current situation and speculate on possible ICT innovations. Based on our findings, we summarized general design opportunities and considerations regarding ICTs in forensic mental health care.

Background

In the Netherlands the courts can impose a combination verdict on offenders with severe mental disorders: a prison sentence and a penal hospital order, which is called the 'TBS' system (*Ter Beschikking Stelling*, meaning 'at the disposal of the government') (De Boer & Gerrits 2007). The TBS patient will be introduced to their treatment programme after serving their sentences, which is a combination of medication, psychological, and other therapies. As the patients' psychotic conditions stabilize, they can leave the care facility periodically with restrictions to practice social skills. A multidisciplinary clinical team, usually consisting of psychologists, sociotherapists, educational and vocational teachers, and creative teachers, work together on a daily basis with the patient. This study was conducted at one of the TBS clinics.

The custodial institutions agency (Dutch: *Dienst Justitiële Inrichtingen*; henceforth DJI) is in charge of the TBS care. It is generally difficult to implement any innovations in TBS clinics due to factors such as insufficient budget planning, safety concerns, and risks in negative media coverage. Currently, the TBS clinic in this study has implemented electronic patient file systems and several innovation projects: VR (virtual reality) for exposure therapy, a social robot, virtual tours of the clinic, and computer vision systems to detect risky behaviours. In these innovation projects there has been no structural involvement of caregivers and other stakeholders.

Meanwhile, methods such as design cards, probes, and co-design sessions can be used in participatory process to generate user knowledge and explore new design opportunities. In the context of the prison system, others have hosted participatory workshops involving incarcerated women in the making of re-entry training VR video (Teng, Hodge, & Gordon 2019). Here, instead of designing a specific product

or service, we focused on exploring ICT innovation opportunities and considerations for forensic mental health care.

Methods and Findings

We applied several design methods to engage caregivers from the clinic. All participants are native Dutch speakers. The interviews and discussions were conducted in English. Audio was recorded for all sessions and recordings were transcribed. Approval was obtained from DJI representatives and the clinic's management. All participants have signed consent forms for this study.

Interviews and Cultural Probes

To have an overview of the daily activities, current technology use, caregivers' motivations, emotions at work, and desires, we conducted semi-structured interviews with six caregivers: an educational teacher (P_{edu}), a vocational teacher (P_{voc}), a social therapist (P_{social1}) and two social workers (P_{social2}, P_{social3}), and a psychologist (P_{psy1}). The interviews were guided by preconceived questions and a timeline template marked with 'tasks', 'tools used', 'emotions', and 'dreams' (see Figure 1).

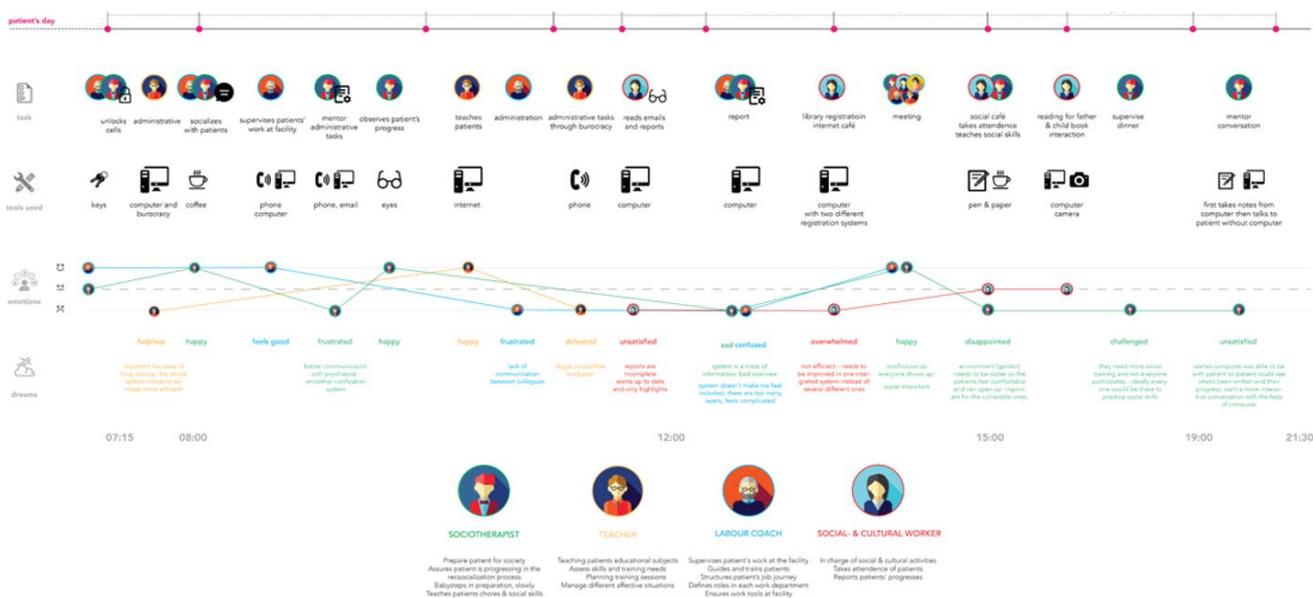


Figure 1: The synthesised timeline of caregivers daily activities with the interview data

Due to our limited access to the clinic we designed and deployed a cultural probe kit for caregivers to log their activities. It consists of a journal booklet, a deck of sketch cards and maps of the clinic (see Figure 2). P_{voc}, P_{social1}, P_{social2}, P_{psy1}, an information manager (P_{inf}), a drama-therapist (P_{drama1}) and an intern for drama therapy (P_{drama2}) who later participated in the study, were invited to use the kit for ten days.



Figure 2: Cultural probe kit

Findings

We synthesized the data about daily activities on one timeline template (see Figure 1). In general, the caregivers' daily activities include carrying out treatment programmes, filing daily reports, administrative tasks, and a multidisciplinary meeting with other caregivers. Basic digital tools like computers are frequently used. However, digital devices are strictly regulated within the clinic, especially in areas patients have access to.

In total, five of the seven cultural probes were returned. Among them, more descriptive and easy tasks in the journals were most often completed, the sketch cards the least. The returned probes have rather low response rate. Below are some of our main findings from the interviews and the probes.

Caregiving requires in-person interaction with patients and close collaboration within the clinical team. Participants appeared highly motivated in their jobs with sympathy and empathy towards patients. For instance, P_{voc} noted,

'If you ask someone on the street about TBS, [mimicking] they are so scared! They [patients] are going to kill you, they are going to rape you. If you read some patients' experiences, when they are one year old, it starts, abused, they have to steal for their parents. So, such a sad situation for a lot of patients staying here.'

Some participants noted the multidisciplinary meeting as a highlight of their work. They consider it important to fine-tune the treatment plan and an opportunity to learn from each other. Aligned with this, most of the responses from the cultural probes with positive emotions are related to activities with patients and colleagues, while reported frustrations center on patients not making progress and lack of support from colleagues.

During the interviews, main frustrations participants experience at work resulted from inefficient technological systems. P_{social2} described the electric patient file system as 'a whole mess', similarly, P_{social1} noted,

'Sometimes the patient will ask me "why are you always with the computer?" If the computer works more efficiently, that would be great, because that [social time with the patient] is the core of the business of the social workers, not the computer.'

The bureaucracy from the organizations can be frustrating too. As P_{voc} noted,

'This is a government institute. [Laughing] If we want something, if I want to order something, I have to make a document, my supervisor has to sign it, then I send it by mail to the care facilitator, they send it to the shared service centre, that is the centre part of the whole government. It may have waiting times of 13 weeks.'

While speaking of the recent two innovation projects in the clinic (VR exposure therapy and a social robot), P_{voc} reacted positively,

'A lot of patients are lonely and they forget something, their day and night rhythm, it is lost, they want to sleep, they are out of energy. With a robot, it wakes you up. It is a second week [of deployment], the patient is very positive, because it is his "buddy"'

Co-design Workshop

To explore caregivers' mindsets towards future technology, we hosted a co-design workshop with six participants from the clinic: two psychologists (P_{psy2} , P_{psy3}), P_{voc} , P_{inf} , P_{drama1} , P_{drama2} . We contextualized the workshop by asking participants to envision the tools they will be using in five years. To assess the participants' knowledge about new technologies, we created a 'technology awareness grid' poster with several innovation examples from similar context (i.e. VR, AI assistant, social robot, multisensory environment and identification and tracking implants).

The caregivers indicated on the grids how familiar they are with the examples. After filling in the 'technology awareness grid', the participants were instructed to design technologies for the clinic in the future, in pairs of two. Participants were given prototyping materials such as pen, paper, LEGO pieces, and markers. The whole session lasted about two hours.

Findings

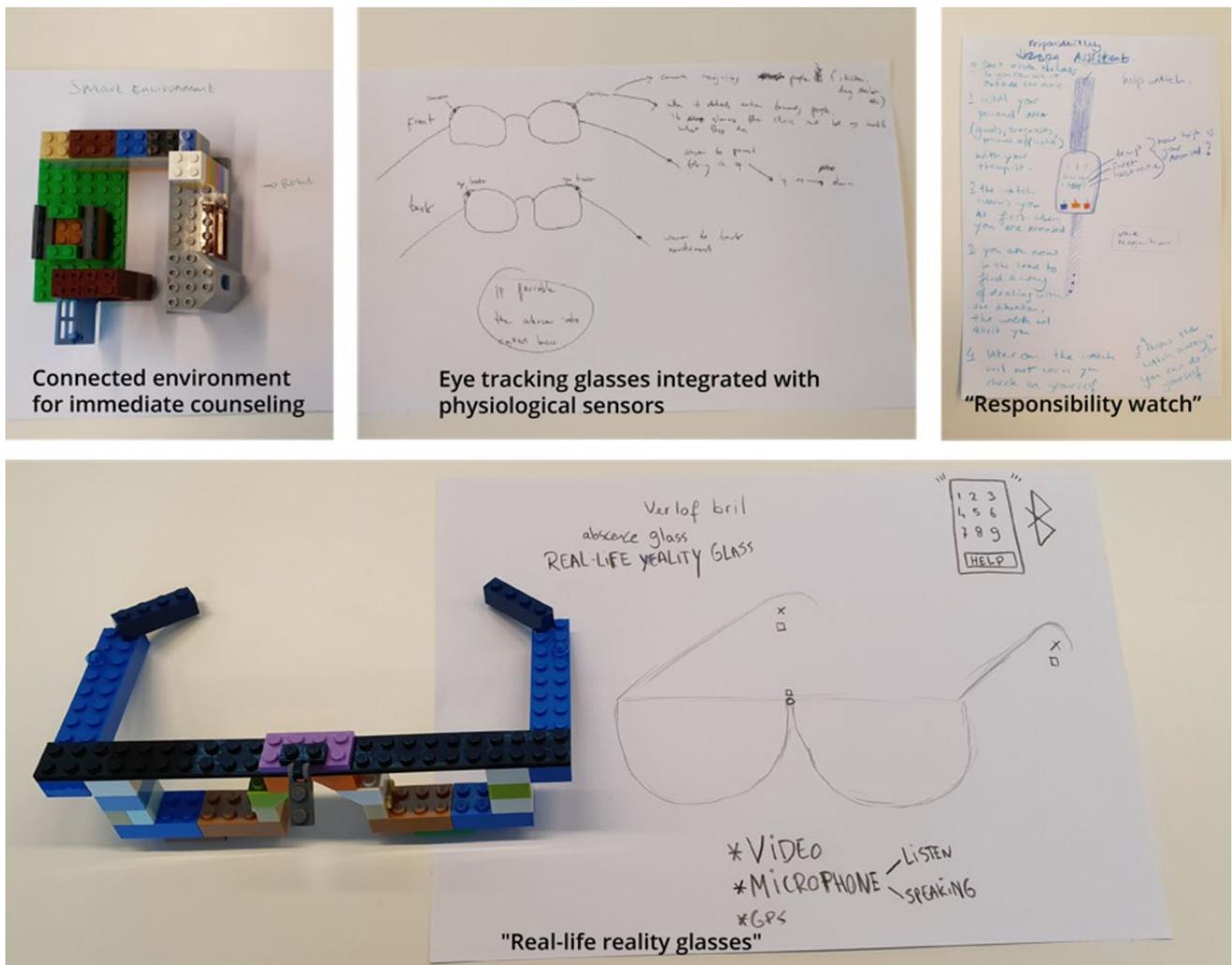


Figure 3: Co-design workshop results

All participants reacted positively to the 'technology awareness grid', and they had heard of or were familiar with all the provided examples. This indicates that participants were relatively well-informed about technological developments. The co-design workshop resulted in four prototypes:

Table 1. Results from co-design workshop

Prototype	Description
Eye tracking glasses integrated with physiological sensors (P _{psy2} & P _{psy3})	A camera is embedded in front of the glasses, combined with an eye-tracker and object recognition systems to track what the patient sees. The sensors synchronously register the emotional level of the patient. The clinical team will receive a warning instantly upon risky situations. The patient cannot take off the glass without permission from the psychologist.
Connected environment for immediate counselling (P _{psy2} & P _{psy3})	An environment equipped with constant connection to the clinical team. Once a patient experiences impulses of aggressive behaviours or relapse into addictions, they can seek support immediately through the digital connections with caregivers, instead of passively waiting for caregivers to come.
Responsibility watch (P _{voc} & P _{inf})	The psychologist sets up the watch with the patient based on the diagnoses, treatment goals, and personal difficulties. The watch monitors the patient's emotions and contexts. It provides warning and advice once risks are detected. The level of support gradually reduces as the patient rehabilitates, the ultimate goal is for the patient to live independently without additional support.
Real-life reality glasses (P _{drama1} & P _{drama2})	These glasses are designed specifically for patients going on leave to the outside world. It is equipped with camera, microphone and a GPS system to monitor the patient. All information is streamed to the clinical team. The clinical team and the patient can communicate seamlessly over embedded mobile connection. After the patient returns, all data can be used for reflection and evaluation.

Interacting with Fictional Prototype

To probe unexpected consequences of future technology use in the clinic, we created a low fidelity prototype to stir up related reactions and conversations. Inspired by the ideas from the co-design workshop, we designed the 'non-filter glasses'. It is a pair of augmented reality glasses that reveals real-time physiological information about others in view. The prototype was constructed with a cardboard

headset and the information was provided on transparent papers (see Figure 4). We introduced the 'non-filter glasses' and asked participants to imagine it to be introduced to the clinic tomorrow. P_{social1}, P_{social2}, P_{psy} and P_{inf} participated in this session. We constructed some provocative scenarios with the 'non-filter glasses', for instance, a patient is sexually aroused, or the X-ray vision was switched on by accident during meetings.



Figure 4: Non-filter glasses

Findings

All participants reported a sense of information overload. It should allow them to customize what information to show about whom and when. Caregiving involves different activities and goals, P_{psy} pointed out that,

‘In a normal therapeutic situation, it is not my job to know what the other feels, my job is to help the other to feel by him- or her-self’.

They noted that this prototype reduced their roles to only analyzing data while ignoring the social nature of their work. P_{social1} was concerned that this technology would disrupt social interactions with patients:

‘The contact is out of balance ... I believe if I am going to sit in front of him with these glasses on, it is not going to give me a relation I need to have with the patient to do my work, to trust. He also needs to trust me to reveal what is in his head. There is no such thing as trust if you would use this [‘non-filter glasses’]. It means I do not trust what he is telling me.’

The discussion surfaced the ethical concerns of the participants about this type of monitoring technology and the need of informed consent from the patient. When asked whether such sensing data can help with their practice, P_{psy} responded:

‘I think it can help us, algorithms, all kinds. Not as truth, but it gives extra information. Like we now use instruments, risk instruments in combination with the clinical sides.’

Discussions

Our interview results suggest that more efficient documentation and communication systems are highly desired within the clinic. The work of social therapists and workers rely on in-person interaction with patients to practice basic social skills, thus spending too much time on documentation, they cannot focus on the core of their work making the resocialization process less efficient. P_{voc} reported that it is a time-consuming and frustrating for any request to be processed. ICT applications can digitize information and bridge communication gaps within the clinic and

with other related institutes to reduce the time spend on administration, caregivers can focus on improving the treatment and interactions with the patients.

We observed two opportunities for digital interventions in the co-design workshop. First, the monitoring of patients' physiological states can be used to detect risky situations and provide more insights into when patients are outside of the clinic. Having access to the outside world is thought beneficial to patients' psychological development and resocialization. However, patient going on leave bears potential risks to the patients and the public, as P_{voc} addressed in the interview about negative public attitude towards TBS patients. Remote monitoring devices and wireless communication that can provide constant overview of patients' status and activities were considered as a solution to this challenge. Having more control over patients' outside of the clinic through remote monitoring devices could address some of the concerns.

Second, all four prototypes allowed patients to actively seek support and participate in their treatment. Encouraging patients to make decisions and take actions for themselves requires reflection on their emotions and consequences of their behaviours, which can help them to develop independence and a better sense of self. Including more digital tools in direct interaction with patients can help them to keep up with the changes in society which contributes to the resocialization. Others pointed out that new technology in forensic mental health care can increase patients' motivation for treatment (Kip et al. 2018), which is suggested by P_{voc} that the patient is 'buddying' with the social robot.

The results of our study also raise considerations for responsible innovation. Monitoring devices can provide quantitative insights about patients' physiological states and behaviour. In our study, participants suggested that the users should be able

to customize the configuration of these. Considering the activities in the clinic, such as diagnosis, different therapies, risk assessments, the information that would be useful on some occasions may hinder other occasions. Moreover, data insights should be validated with human knowledge. When it comes to providing quantitative measures, such as statistical classifications of sensor data, the results can carry biases in the training data sets or assumptions embedded in the computational model. To reduce mistakes and biases, the system should prompt the human user to make the final decision. After all, as the psychologist pointed out that the algorithmic results should be treated 'not as truth'.

The participants also showed negative responses to 'non-filter glasses' in that it ignores the subtlety of social interactions. The therapist remarked that the glasses may disrupt their face-to-face communication with patients. The salient physical device and the imbalance in power structure (only one party has access to the digital information) hinders the mutual trust building that sets the foundation for meaningful social connections.

Limitations

There are some limitations in our study. First, all participants joined our study on a voluntary basis. Thus, their views and attitudes expressed here may not represent all voices from the staff members. Second, we did not manage to include patients in the process. Any external activities with the patients have to be evaluated and carried out with extra care due to safety concerns and negative repercussions for the treatment. Patients views may differ markedly from those of the caregivers. Last, it should be noted that all participants were Dutch native speakers who were asked to express in English, due to our international research team. This may reduce the level of nuance in their expressions.

Conclusions

Considering that HCI research in forensic mental health care is rare, we proposed some general design opportunities and considerations based on our findings. We conclude that digital technologies have the potential to overcome some barriers in these settings and can contribute to a more inclusive and safer society. However, we should remain critical about these potential 'solutions' and incorporate multiple views during the design process, to avoid technology-driven solutions that ignore the complex interplay between technology and the socio-political factors. We hope our work can serve as an onset for more in-depth and inclusive future studies.

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CHALLENGING STIGMA BY EMBODYING SMART FUNCTIONALITIES AND FASHION IN ASSISTIVE CLOTHING CO-DESIGNED WITH OLDER ADULTS

Danying Yang and Louise Moody

Centre for Arts, Memory and Communities, Coventry University, Coventry, UK

Abstract

Despite awareness of the impact of ageing, age-related stereotypes are still embedded and reinforced in our culture. The MATUROLIFE project aims to develop assistive technology (AT) to support independent ageing and well-being with a particular focus on addressing the stigma often associated with use of an assistive device. As well as the focus on innovation and technological development, the project provides learning opportunities for fashion design students, providing exposure to new materials and the application of user-centred design for older adults.

This paper will outline how smart textile solutions have been co-designed with older adults across nine European countries. Semi-structured interviews and co-creation workshops were undertaken to prioritise user needs, establish priorities, and inform the design and development of assistive clothing.

As well as guiding the design work, the user research has informed higher education experiences. The paper will outline how fashion design students have taken part in workshop activities to develop designs that embed smart technology whilst prioritising the needs of older end-users.

The resulting designs demonstrate that innovation in smart technology coupled with a sensitive design approach can result in clothing that is assistive whilst addressing the psychological and social impact of ageing as well as the associated stigma of using AT. Project-based and research-informed teaching offers a new generation of designers collaborative design and innovation capabilities that should enable them to design for different ages.

Keywords: smart clothing, stigma, assistive technology, co-design, fashion education

Introduction

The way that society understands and regards ageing, for example negative attitudes, and ageist stereotypes, can affect how a population experiences healthy ageing (WHO 2015). Self-perceptions of ageing among older adults and age stereotypes have been found to negatively affect health, longevity, and cognitive performance (Wurm and Benyamini 2014; Ayalon and Tesch-Römer 2018). Assistive Technology (AT) is developed with the aim of providing quality of life, increased independence and healthy ageing. Unfortunately, AT has in some cases failed to achieve the intended benefits due to the impact on individual self-perception and the stigma experienced through use.

Stigma and AT usage

Arguably, age related decline in physical and cognitive abilities is viewed negatively in today's youth-driven culture (Chasteen and Cary 2015). Age-related stigma includes self-ageism, self-stigmatization and misperceptions as 'I'm too old to change' (Ayalon and Tesch-Römer 2018), as well as being treated by others as 'a group that cannot keep up with new technologies' (Jakubowska, Kłosiewicz, and Mękariski 2015). Research has shown the impact of stigma for example with people refusing assistive interventions or showing reluctance to seek technological support (Meisner 2012; Peek et al. 2014). Despite the growing development of new AT products and services, there are high abandonment rates among older adults. The products are often regarded as not being attractive or desirable (Lee 2014; Chen and Chan 2013; Yusif, Soar, and Hafeez-Baig 2016). Peek et al. (2016) highlight that perceptions and use of technology are embedded in the personal, social, and physical context with acceptance affected by stigma as well as perceived need, cost, usability, aesthetics and effective functionality.

There is an increasing focus on addressing negative ageing stereotypes through the use of creative methodologies which involve older people as co-creators in the design process (Holliday, Magee, and Walker-Clarke 2015). There has also been consideration of how education about ageing can be used to reduce ageism (Lytle and Levy 2019). For example, exposing young people to older adults in order to change perceptions (Malinen and Johnston 2013), and teaching co-design methods to redefine and de-stigmatize the image of ageing (Taffe, Pedell, and Wilkinson 2018). These two approaches have informed research and research-informed teaching related to the MATUROLIFE project (Moody et al. 2019).

Fashion design for and with older adults

In general, fashion is strongly youth oriented towards an idealized world opposed to the 'greyness' associated with age (Twigg 2013). Older adults have traditionally been excluded from fashion studies with a preoccupation with youth and high style (Twigg 2013; Townsend, Sadkowska, and Sissons 2017). Although the market has not traditionally focused on the older generation, older adults have the same desire to look and feel good and represent their cultural identity. There is limited research but growing awareness that focuses specifically on older adults and fashion. Recent research has involved co-creation with older male and female groups and explored how despite the interest in fashion there is a lack in engagement of certain groups (Sadkowska 2020; Townsend, Sadkowska, and Boxall 2019).

The limited focus on the needs of older adults in fashion has also affected the embedding and uptake of clothing-based technology to support healthy ageing (Lewis, Medvedev, and Seponski 2011). Technological innovation offers significant potential with increasing smart and wearable functionality whilst maintaining

clothing styles and aesthetics (Guler, Gannon, and Sicchio 2016; E4FT 2018).

Aim and objectives

The 3-year EU Horizon 2020 funded MATUROLIFE project seeks to embed older adults fashion preferences and aesthetic design requirements in the development of AT solutions. The AT makes use of innovative metallisation of textiles (Moody and Cobley 2020) to enable the development of smart solutions that subtly support independent ageing without stigmatising the user / wearer. The project involves 20 partners from a range of disciplines and nine European countries. The elements of the research project described here relate to the following objectives:

1. To explore and address perceptions of AT and any associated stigma and identify design requirements for clothing-based assistive product.
2. To co-design clothing based AT solutions that support the well-being and independence of older adults whilst meeting their fashion and aesthetic needs.
3. To educate future fashion designers in the ethos and ambition of the project, and to encourage fashion design for older adults that addresses identified needs.

Methods

The design elements of the MATUROLIFE project have been informed by interviews to gain a better understanding of age-related stigma and user / wearer needs. Co-design has then been used to engage older adults (Callari et al. 2019) in the development process and ensure factors that might increase stigma are addressed. As well as informing the wider consortium and the development of AT prototypes, the outcomes have provided curriculum content for taught workshop sessions with fashion design students. The research was approved

through the Coventry University Faculty of Arts and Humanities ethical review process.

Semi-structured interviews

Thirty-seven older adults aged 65 and above from partner countries (France, Italy, Poland, Spain, Turkey, and United Kingdom) took part in semi-structured interviews. The interviews explored participants' health concerns, factors affecting independence and well-being, their interest in and use of ATs as well as fashion preferences, cultural decision-makings and trends in relation to clothing. The interviews explored participants' requirements and needs and sought to reflect older adults' real-life experiences whilst providing insights to inform subsequent co-design activities.

Co-design activities

A series of co-design workshops (10 in total) were undertaken that focused on the design of smart clothing, footwear and furniture, see (Yang, Moody, and Cobley 2019) for more details. Fifty-seven older adults from six partner countries took part in co-creation activities related to clothing, working together with fashion designers, clothing manufacturers, human factors specialists, psychologists, and material experts.

Four initial exploratory workshops (in Spain, Italy, Belgium, and United Kingdom) focused on health, wellbeing and independence-related priorities that could be addressed by means of smart textile solutions. Concept ideas were explored in groups with the aim to embed smart textiles and provide assistive functionality to address the identified priorities. Two focused workshops (in Slovenian and France) further explored clothing solutions. Key well-being issues were prioritized, and functionalities were considered. Activities were undertaken to identify the characteristics, materials and styles the participants preferred and to consider how these preferences could be embedded within garments to meet their

needs and requirements. The emerging designs were then further developed by the multi-disciplinary design and technical teams (Yang, Moody, and Cobleby 2019).

Results and Reflections

The research steps outlined have sought to explore ideas around stigma and fashion requirements, design new technology with the aim of reducing stigma, and encourage a new generation of fashion designers to be aware of age-based stigma when designing.

Acceptance and stigma

In our interviews and exploratory workshops, a number of participants raised concerns about the stigma associated with ageing. They felt even if the old generation is fitter and more active, societal views and changes have not caught up.

'Before there was more respect for everything. Now everything has changed. Communications and technology go better, but human values have been lost.' [ES_Interview]

There was an indication that poor AT design was reducing their access to and use of technology, which in turn may add to age-related stigma. Despite advances in technology, the accessibility and acceptability of available solutions hinders their use of assistive and /or smart technologies.

'People said, well, you could use it (assistive product) by voice. I know I can but my voice changes and I got allergies in my voice. How does it work if your voice changes? So to me it's wasting time.' [UK_Interview]

'No, it (smart technology) will come but for now I don't understand it. I will change my phone. I am scared not to be able to use it.' [FR_Workshop]

Participants also argued that companies and marketing have not explicitly worked around

the capabilities, desires and preferences of older adults, and this needs to be further developed.

'There are a lot of older adults who can't and don't get it (technology). It is difficult for the older generation. For the youngest it will not be a problem.' [UK_Interview]

'For now I don't feel like I need it (assistive/smart technology) but if someone will make me discover and teach me I might be interested.' [FR_Interview]

In terms of their views on clothing design, the importance of style and aesthetics was clear through some of the experiential highlights given.

'Something I like and suits me', 'Happy to try different styles', 'Smart trousers and smart party top'... [UK_Interviews]

'I like young fashion, not things for old people', 'There are things I like but I won't buy because I think I am too old for it', 'There are reflections towards the old and towards the fat ones too. It's about prejudice...' [FR_Interviews]

'This is due to the way of dressing, because now people dress much more modern, even if they are older', 'Sometimes I think about inventing something, for instance, a jeans tracksuit to do sports in a more fashionable aspect'... [ES_Workshop]

Meeting needs through co-design

The interviews and workshops enabled prioritisation of health, wellbeing and independence priorities that could be addressed through smart technology and highlighted some design preferences for emerging garments.

Some examples of prioritised health needs identified during the sessions included, 'I easily get too hot and / or too cold as I age', 'I easily get dehydrated which can lead to falls and confusion', 'Help me

feel safe at home and around', etc. In the focused clothing development workshops, participants expressed a shared interest in developing assistive clothing that would help with their temperature and monitor their heart rate. In France, helping check hydration levels and managing medication were considered useful, whilst the participants in Slovenia saw a need for garments to monitor vital signs (i.e. blood pressure) and signal for help if they had fallen.

Working together in multi-disciplinary design teams, the participants co-created concepts that for example embedded heating / cooling elements within the fabric to deal with challenges of thermal comfort, and that enabled monitoring of hydration levels. An example concept to emerge from the workshops is shown below in Figure 1.

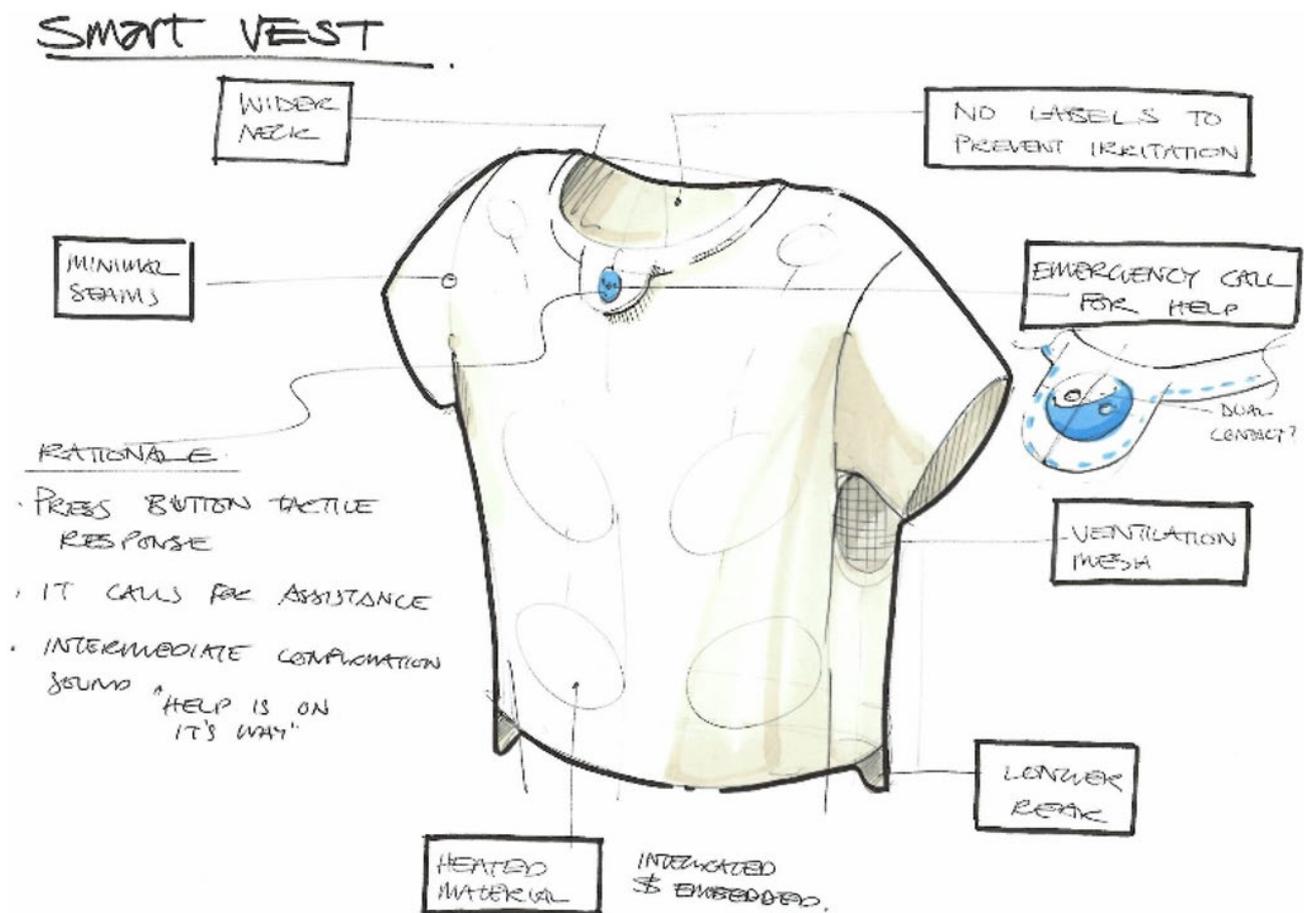


Figure 1 A 'Smart' concept idea for assistive clothing

Although comfort and functionality were key concerns, style and fabric preferences were forthcoming as one participant commented, 'When you are elegant you stay young'.

'Attractive but practical, easy-fitting but not something standing out as old people clothing.' [SI_Workshop]

'I like the feeling of cotton. Most clothes you find now are polyester, bad quality.' [FR_Workshop]

Participants reviewed available smart clothing and commented, 'These products do not look for every day, but only if you have a severe problem', 'It could be made to look less intrusive.' [UK_Workshop, Figure2].



Figure 2 Forming design priorities during a co-creation session

The review of standard and smart clothing enabled identification of styles and materials that older adults would avoid, and design features that could induce a sense of stigma. Some examples of the requirements given are highlighted in Table 1.

Table 1 Examples of design criteria for smart clothing

Design criteria
<ul style="list-style-type: none"> • Light and comfortable to wear • Be of an elegant style • Be suitable for multiple body shapes • Not be too tight or restrictive (consider stretchy fabric or elastic) • Be wearable in different seasons (consider thermal/breathable fabric, adding extra layers, removable sleeves) • Include hidden side pockets that can be closed (e.g. a zip) • Use plain (not patterned) conservative colours such as grey, navy, black and brown which can be combined with more colourful accessories or under garments. • Not impede everyday activities e.g. walking, going to the shops, meeting with friends, spending time at home. • Of good quality which is long lasting • Be easy to wash and maintain • Quick drying / easy iron

Informing the next generation of designers

To encourage students as well as the MATUROLIFE team to design with a focus on older adults, a series of taught activities were developed. These activities sought to consider the use of innovative textiles as well as reflect an understanding of fashion for the older generation.

Twenty-five students in the second year of an undergraduate degree in Fashion at Coventry University participated in the workshops. They received taught sessions in smart textiles and in designing with, and for older adults. The students were encouraged to consider - 'What are E-textiles, wearable technologies, and smart clothing?', 'What do older adults want from fashion?', 'What is co-design?', 'Why do we design with older adults rather than for them?' They were also exposed to co-creation and user-driven innovation processes and appreciated the difference between co-design methods and the traditional design process they had experienced up to that point. Whilst not directly partaking in co-creation with older adults, they were able to see how such activities are structured and facilitated. They began to explore the value of gaining understanding of the needs and preferences of the older adults as customers and co-creators, expressing a desire for active participation in similar processes in the future.

In practical workshop activities, the students had the opportunity to experience innovative ways to embed wearable electronics into fabrics (example shown in Figure 3) and to integrate 'soft' circuits within garments (example shown in Figure 4). The hands-on activities enabled them to discover the restrictions and difficulties in contrast with conventional fashion technology, and then the further challenge of designing clothing for an older audience.



Figure 3 Sewing a simple circuit on fabric



Figure 4 Applying the circuit on clothing

An example of a smart assistive clothing concept that was developed is shown in Figure 5 and 6. Despite the complexity of the design scenario, the students confronted the challenges to create elegant solutions with AT for older adults whilst displaying collaborative teamwork.

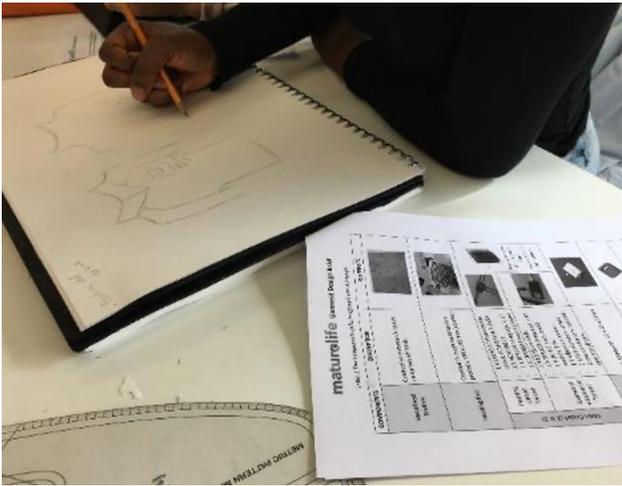


Figure 5 Particular practice with MATUROLIFE design brief

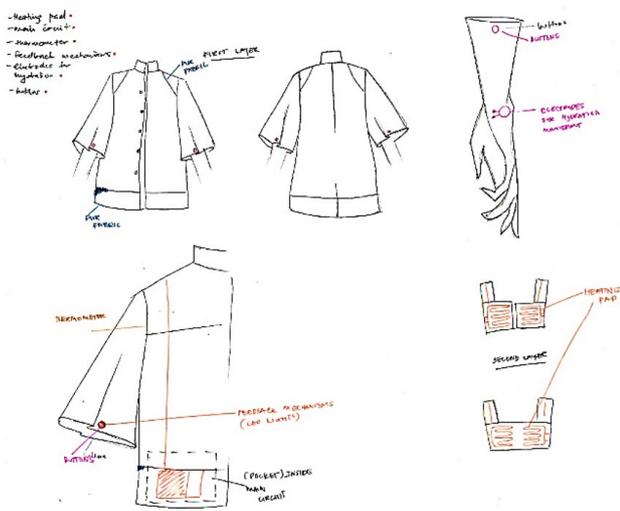


Figure 6 Assistive clothing concept design for older adults

Discussion

The MATUROLIFE project seeks to work closely with older adults to co-create novel assistive solutions that capitalise on smart textile innovations but ensure that they are driven by needs, wants and preferences rather than technological capability. The project is driven by the need to support wellbeing and independence amongst adults as they age, whilst recognising that much of the AT that has been developed with this aim has failed to have the desired impact. Smart materials, and the capacity to embed electronic functionality within textiles provides an opportunity to develop discrete AT that does not create stigma and is then accepted and used effectively.

This paper has shared some of the views of older adults in respect to technology and specifically AT. These substantiate previous research indicating the impact of poorly designed AT on acceptance, use and potential stigma. To ensure desirable and well-designed technology, older adults have to be given power to investigate and influence the design and development of the product for themselves. Through co-creation activities, we have sought to enable this. Concepts have been developed that give consideration to both user-prioritised needs and design requirements whilst capitalising on the capacity of smart textiles. Design elements associated with stigma have been identified to ensure they do not feature in the MATUROLIFE AT solutions as they develop.

The involvement of older adults, designers, researchers and a variety of stakeholders in the co-creation workshops brought together different points of view and enabled a shared understanding of user perspectives, design constraints, and technology capabilities to generate new ideas with improved satisfaction (Steen, Manschot, and Koning 2011; Holliday, Awang, and Ward 2018). This will be ensured through iterative testing, as the design are developed and prototyped.

As well as influencing the project's approach to design, this ethos of learning from each other through co-creation has been extended to the future generation of fashion designer. We have shared findings from the co-creation experience and outcomes, as well as providing access to new material innovations. The learning experience has integrated up-to-date technology with co-design methods and demonstrated this through application to a societally important domain. It is argued that the future generation of fashion designers need more opportunities to design for and with older adults. Research-inspired teaching that combines elements of ageing, participatory methods alongside smart textiles innovation may be a means

to engage new debates amongst students that challenge traditional notions of the populations to design for older adults and address negative stereotypes. Furthermore, building capacity to address real-life problems through fashion design may support future industry expectations and requirements (Taffe, Pedell, and Wilkinson 2018).

Age-related stigma can be addressed from a number of angles; by working together, by the involvement of older adults themselves, through the design of future technology and through education. Reducing stigma in the design of effective AT is crucial in enabling us all to live and age well (Swaffer 2014).

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DESIGNING WELLBEING: THE ROLE OF DESIGN IN DEVELOPING OPEN-MINDEDNESS IN MENTAL HEALTH

Jesvin Puay-Hwa Yeo¹ and Chua-Tee Teo²

¹Nanyang Technological University, School of Art, Design and Media, SG

²Nanyang Technological University, National Institute of Education, SG

Abstract

According to the World Health Organization, mental disorders are among the leading causes of disability-adjusted life years worldwide. Approximately one in four adults has experienced mental disorders at some point during his or her lifetime. Due to the misconceptions of the illness and its invisible psychological nature, people experiencing mental disorders may not seek help. While psychologists investigate the cause and effect of mental illness to provide treatments, graphic designers may contribute to improving the present mental health situation through a call for open-mindedness. Using the Strategies of Inquiry design research approach developed by Richard Buchanan (2007) that explores the human experience, a role-playing technique was engaged with twelve undergraduate students to explore mental disorders and search for unifying ideas in the design process. Then, creative action, practical thinking, and function, form and materials were investigated to understand how graphic design can encourage: (i) users with mental disorders

to become more open-minded towards support services, (ii) society to be more empathetic and accepting of people with mental illness for who they are, and (iii) designers to approach healthcare design with open-mindedness. The initial findings of the project indicated that design has a potential role in the call for open-mindedness in the area of mental health and wellbeing, as graphic design can effectively communicate complex information and issues in meaningful ways. Nevertheless, the absence of actual patients or service users as participants in the study requires a cautious interpretation of results. On this basis, further research is recommended to understand critical factors that could strengthen the association between creativity, design process, mental health patients and service users, as well as the distribution and evolution of design objects.

Keywords: well-being design, design research, visual communication design, strategies of inquiry, mental health

Introduction

According to the World Health Organization, mental disorders are one of the leading causes of disability-adjusted life years worldwide, and one in four people has experienced mental disorders at some point during his or her lifetime. There is a long history with regard to prejudice towards patients with mental illnesses and this attitude has continued into today's society. There is a bias associated with patients of mental diseases as they are perceived as sick, incapable, and even dangerous (Subramaniam et al. 2017). Due to these misconceptions of the illness and its invisible mental nature, people experiencing mental disorders may choose not to seek help from health professionals. While psychologists investigate the cause and effect of mental illness to provide treatments for psychiatric patients, how can we, as graphic designers, contribute to improving the present situation of mental health, and how the use of designs can call for open-mindedness towards people with mental illnesses.

Visual communication design has long been used by graphic designers to address social issues. Recent campaigns and projects include: 'We Listen Campaign for Samaritans' by the MullenLowe Group and 'This book will make you stronger' by Mind Journal have successfully targeted the problems of mental health and wellbeing. Building on these experiences, this project draws on the results of twelve student projects to explore the previously unexplored theme of open-mindedness through design. By investigating the participants' design process and various graphic design outputs, this study seeks to understand how graphic design can encourage: (i) users with mental disorders to become more open-minded towards support services, (ii) society to be more empathetic and accepting of people with mental illness for who they are, and (iii) designers to approach healthcare design with open-mindedness. However, a

limitation should be noted. This is a project with undergraduate students and thus no patients or service users were included in the research.

Research Design

The research framework

This study employed Strategies of Inquiry (Buchanan 2007), a design research approach that seeks to explore the design capacity of the human-made world in the service of human beings. Essentially, it focuses on searching for knowledge and understanding of a specific phenomenon, with the ultimate goal of performing principled actions that are derived from the knowledge. This project engaged three procedural steps: dialectic, inquiry and design science. The first step (dialectic) is the process of data collection, which takes the form of role-playing to search for unifying ideas of mental disorders. Following the data collection step, the perception of mental disorders is explored through two aspects of inquiry as the second step: Rhetorical Inquiry examines the creative action and practical thinking of the participants, while Productive Science considers the function, form, and materials of the design objects. In the last step (design science), underlying meanings are investigated to provide an understanding of the complexities of the design process and the workings of design in the area of mental health.

Sampling

Twelve design-art students from the School of Art, Design and Media at Nanyang Technological University were enrolled as participants to explore creative ways and designs for people with mental health conditions. These third-year students were selected through the purposive sampling technique (Emmel 2013), as this project calls for participants who have knowledge and experience of visual communication design in order to meet the research objective.

Procedures: dialectic

A role-playing technique (Saunders 2016) was undertaken to enable participants to begin by answering this question: What does mental illness mean to a mental health patient, to a medical expert, and to a family member? Firstly, the participants formed a group of three to conduct research on a specific mental health disorder, such as anxiety disorders, mood disorders and depression, stress-related disorders, and disruptive behavioural disorders. Each participant was assigned a role (a patient, a medical expert, or a family member) and was responsible for researching the symptoms associated with the mental illness pertaining to their role. This exercise aimed to obtain different responses from various ways of speaking, listening, and acting, and acting was understood less as performing and more as a way of thinking. Participants were prompted to engage with the data and communicate research findings from the perspective of the role that they played.

Procedures: inquiry

In the second step, the participants' experience of understanding mental disorders was analysed through two aspects of inquiry. First, rhetorical inquiry focuses on the participants' creative and inventive ability and how their thinking contributed to the process of social change. Second, productive science examines how the students made decisions on the function, form, and materials of the design applications. Through this process, numerous sketches—from thumbnails to roughs to comprehensives—were created to develop and illustrate their design ideas. The rationale behind each idea was explained, and refinement and improvement were made consistently before the final critique session. As this project took place in an educational setting, the focus was more on the process of designing, developing, and prototyping, rather than distributing and evolving the design products in society

Procedures: Design Science

In the last step, underlying meanings were investigated to provide an understanding of the design process and the function of design in the area of mental health. The design outcomes and logic of decision-making will be discussed in the following section.

Findings and Discussion

This section presents the final designs of two (see G1 and G2 below) out of the four groups for more detailed discussion, including the findings resulting from the role-play, the participants' creative and inventive ability, and how their thinking contributed to the process of social change

G1: Calm-down

The design project 'Calm-down' consists of a light and sound installation, as well as a series of graphic and digital design applications (book, website, and mobile app) that aim to raise awareness among panic disorder patients and assist in lessening their anxiety. These creations are designed to release daily stress, according to the findings of the role-playing exercise which determined that panic attacks occur when one constantly feels fearful and worries to the point of being overwhelmed. The symptoms include hyperventilation, chest pain, rapid heart rates, and tremors (Taylor 2006).

After establishing the design intent, the group explored self-help interventions, such as abdominal/diaphragmatic breathing and books based on cognitive behavioural therapy principles. According to Lewis, Pearce, and Bisson (2012), self-help interventions are a useful option for people with panic disorder. The group then developed colours and graphic elements based on the calming theory. Soft blue was selected as it calms the mind and aids concentration, while pale brown was chosen as it is warm and soft, and people find it

quietly supportive (Cherry 2019). The final design outcomes, “breathe” and “Don’t panic”, were designed to provide a serene and mentally calming outlet for individuals who have panic disorders as a way to note useful information, share stories, and maintain their wellness through mindful breathing and writing exercises.

The light and sound installation ‘Typhoterapy’, in contrast, was designed to express confusion, unruliness, and hysterical emotions, as it aims to reduce the

stigma against people with a mental health condition through an immersive experience that seeks to build empathy and educate the public. It also allows the public to experience the uncertain and volatile nature of a panic attack. Three motion graphic animations that mimicked three different intensities of chaos that a panic disorder patient can face were created and activated by ultrasonic distance sensors when an audience entered the space.



Figure 1: “Don’t panic” book design, “breathe” App design, and “Typhoterapy” installation concept

Limitations observed from the design process of the group showed that there was a lack of challenging components in the decision-making process. In fact, the group tended to settle on the apparent design outputs and did not explore further possibilities once the decision was made.

G2: Tenderealm

‘Tenderealm’ was built upon the idea of people with post-traumatic stress disorder (PTSD) feeling calm after being treated with tenderness and in a safe place with therapists. The group learned that PTSD is a mental health condition that is triggered by either the experience or witness of a terrifying event, and that it was an ongoing emotional and social development (Lewis et al. 2019). Besides having flashbacks and severe anxiety, one of the common symptoms includes a loss of interest in life and daily activities (National Institute of

Mental Health 2019). Consequently, the group aspired to encourage people with PTSD to go outdoors more often, as even activities like window shopping or tide watching can benefit them.

Based on the project intent, the group posted questions such as ‘How can we help to create a comfort zone to make going out less daunting for PTSD people?’ and “What can be changed to make public places more welcoming and easier to navigate for people with PTSD? Moreover, Gestalt therapy, a treatment of choice for PTSD as it helps patients focus on the present and become more aware of their current thoughts and surroundings, was explored as an underlying theory to stimulate creativity. After a few rounds of discussion, the group decided on a wayfinding idea and a mental and physical health app to encourage people with PTSD to become more active.

The final design outcomes used convivial colours such as warm yellow, healthy green, and organic graphics to express humanity and encouragement. The wayfinding concept, “ALT”, aims to create a joyful and easy wayfinding experience by encouraging users to take breaks and pause in the flurry of navigation. ‘Phases’ was designed to

invite individuals to immerse themselves in the tranquility of Mother Nature and to pause and self-reflect. The app seeks to promote wellbeing through connecting with like-minded friends and embarking on nature immersion activities such as stargazing and tide watching.

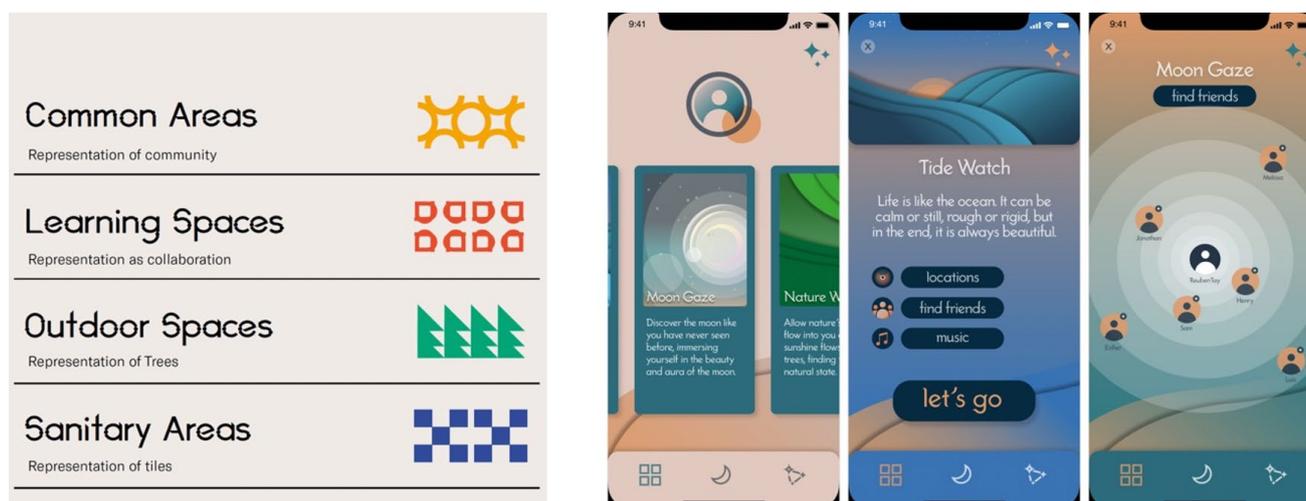


Figure 2: ‘ALT’ Wayfinding concept and ‘Phases’ App design

The limitations of the design process of this group included confinement to the standard design and branding system, as the student participants hesitated to take risks or step into uncharted fields of inquiry and designing.

The role of design in calling for open-mindedness

This paper has outlined two design projects that positively supported and impacted wellbeing. These projects explored the varied and essential relationships between graphic design and mental health. They also demonstrated how design strategies and visual languages were engaged to support, inform, and encourage people living with a mental or psychological condition. The other two projects not discussed here were related to helping people with behavioural disorders and obsessive-compulsive disorder. Through investigating the design process, we can understand how designers digest a given mental health situation

through role-playing, discover what they can do to facilitate mental health, and then strive to realise their design ideas through creative exploration and decision-making that support the development of mental wellbeing. While seeking sustainable design solutions for the mental health situations, there were inevitable limitations for each design group. These might be overcome with reflections and debriefing as the graphic designers gain more experiences.

Owing to the challenging situation of the COVID-19 pandemic, the original installation ideas that were to be built for and tested with the public were converted into conceptual designs and the final design outcomes became graphic mock-ups without user testing. Therefore, the following findings were derived mainly from the analyses of the student-participants’ design processes and intents of their designs. The initial results have reasonably demonstrated the value that graphic design can bring to the area of mental health and

wellbeing. Consequently, graphic design has the potential to encourage open-mindedness in these three aspects:

1. To provide a channel of open-mindedness towards support services
Through the targeted wayfinding design and mobile apps, people living with mental disorders can become more open-minded and receptive towards support services because it is easy to understand design and visual languages. These design solutions are created to offer experiences and environments that can help to reduce the chances of losing one's way and to ease anxiety in times of crisis.
2. To open an empathetic window on people with a mental condition
The installation project, 'Typotherapy', seek to offer the public an opportunity to experience the 'actual' feelings and conditions of people with mental disorders. It aims to raise awareness and urge society to be more empathetic and understanding of the perspectives and needs of people with mental illnesses.
3. To embrace open-mindedness in designing
For design students, this project has provided a platform for them to take up a challenge that touches lives and moves beyond the mere acquisition of knowledge to the consideration of societal issues. Students are therefore being encouraged to be more aware of their contextual environment, to be receptive of different ideas and attitudes, and to show concern for the common good through communicating a cause, and collaborating with others.

Thus, design has a potential role in calling for open-mindedness in the area of mental health and wellbeing. In fact, graphic design can effectively communicate complex information and issues in meaningful ways, in this case, the feelings and attitudes of people living with mental illness.

Conclusion

This paper has explored the role of design as a pathway to support current issues of mental health, which is one of the most urgent topics facing humanity today. The Strategies of Inquiry approach has offered insights to the core question: How can design call for open-mindedness? Through the collection of data based on three different perspectives of mental health, integration with the beliefs of the design students, and the use of methods of analysis and creative thinking, exciting ideas have been produced to overcome differences in understanding people with mental health problems, while emphasising and promoting the social and cultural context of design. Whereas psychologists investigate the cause and effect of mental illness to provide treatments, young graphic designers, in this case, have shown the potential of using graphic design to support mental wellbeing.

Because the participants were all undergraduate students, it is acceptable to characterise their design process as less sophisticated or less well developed. Thus, limitations such as lack of in-depth consideration and user testing during the design process might have hindered the attainment of sustainable design solutions to problems. The process of decision-making could be complicated and at times overwhelming to the student participants who could spend inordinately long periods deliberating on decisions. Educators could provide guidance and techniques to ease the process. Future researchers can conduct a similar study with full-fledged designers in order to better understand the associations among creativity, design process, and mental health patients and service users, as well as the process of distributing and evolving creative products in society.

Acknowledgements

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GROUNDING PRACTICES: HOW RESEARCHERS GROUND THEIR WORK IN CREATE-HEALTH COLLABORATIONS FOR DESIGNING E-HEALTH SOLUTIONS

Marieke Zielhuis^{1,2}, Christa van Gessel¹, Remko van der Lugt¹, Berit Godfroij¹ and Daan Andriessen¹

¹University of Applied Sciences Utrecht, NL

²Delft University of Technology, NL

Abstract

Research through Design projects in the health domain often involve collaborations of design and healthcare researchers. All partners have their own ideas and expectations with regard to what they consider valid ways to support their work. The evidence-based approach that dominates healthcare research differs from the ways that are common in design research, in which more iterative approaches are applied with focus on developing solutions to fit to the users and their context.

The question that we address is twofold: a) How do differences in grounding approaches manifest themselves in projects where design and healthcare researchers collaborate? And b) How do project teams deal with these differences?

We analyzed the grounding practices within 10 Dutch research projects that address the development of e-health applications to support people as they grow older. All projects are collaborations of design and healthcare researchers and practice partners. We applied a multiple case study research approach in two series of interviews, with a cross-case interpretation after the first series of interviews to direct the second series. Differences in grounding approaches in the projects manifest themselves on four themes, each representing a spectrum: time, structure, control and position. These differences provided challenges, but were also used to strengthen the project.

Keywords: research through design; design research; grounding; multidisciplinary teams; e-health



Grounding practices in research

Throughout a project, researchers have to substantiate their choices and findings. In this paper, we refer to this as 'grounding'. Findings may be the end results of a study or the final designed product. But findings can also be in-between building blocks, inferences, insights, design decisions on a micro scale. Grounding happens throughout, even as early as in the grant-writing and preparation of a project. Goldkuhl and Cronholm (2010) distinguish three types of grounding. Grounding in practice refers to the connection with actual real-life data, grounding in theory to the dealing with previous research, and internal grounding to internal lines of argumentation.

When design and healthcare researchers collaborate, different grounding approaches meet. This might lead to challenges. The dominant approach in health is evidence-based practice or evidence-based medicine (e.g. Portney and Watkins 2000; Burns, Rohrich and Chung 2015), in which different types of evidence are hierarchical ranked. Meta-analyses, systematic reviews, and randomized controlled trials are considered strong, case-control studies are considered weak. Rooted in epidemiology, this approach has also become prevalent to evaluate non-pharmacological interventions. In recent years, the monopolist position of randomized control trials within evidence-based medicine has been criticized (e.g. Howick, Glasziou and Aronson 2009). Also, the importance of considering the individual situation and needs has been emphasized (e.g. Council for Public Health and Society 2017).

Design can be seen as an inquiry into three domains of knowing that come with three ways of reasoning (Nelson and Stolterman 2003). Jonas (2006) describes these as: the true (the natural world, how it is today) the ideal (the world of value-based exploration, how it could be) and the real (the world of acting and making, how it is tomorrow). Along these ways, design research has its

own grounding approaches. Grounding in practice is sought by using grounded theory approaches, in which theory development is continuously 'grounded' – connected with the actual real-life data (e.g. Glaser and Strauss 1967). Internal grounding is sought by providing process structure, for instance, by a structured weighing of design alternatives, or by the systematic application of personas when selecting options to bring in the voice of the different users and their needs.

How do research partners from these different backgrounds deal with grounding when they collaborate? Blandford et al. (2018) listed some differences between the design (HCI) and health domain. With regard to grounding, they found a difference in the way researchers establish a state of the art: a systematic literature review (health) versus a more opportunistic overview of relevant literature (design). They also see a difference between summative evaluation which is focused on effect studies (health) and formative evaluation which is focused on user experience and usefulness.

In this paper, we address the following research questions:

- a) How do differences in grounding approaches manifest themselves in projects where design and healthcare researchers collaborate?
- b) How do project teams deal with these differences?

Method of this study

We analyzed 10 Dutch research projects in progress within a program aimed at funding fundamental research on which to base the development or improvement and implementation of e-health applications. These applications are intended to support the day-to-day functioning of people as they grow older and have to deal with dementia, loneliness or overweight. Each project addresses one of these three themes. Consortia are collaborations of design and health researchers and practice partners.

To investigate how differences in grounding approaches manifest themselves in these projects, we applied a multiple case study research approach in two series of interviews with the main researchers. The interviews were recorded and transcribed.

A cross-case interpretation after the first series of interviews directed the second series towards the theme 'grounding'. We conducted 6 short card sort sessions in which we asked small groups of researchers from the 10 projects to sort the research methods as described in the project proposals, while thinking aloud. We recorded the conversations. After an open coding round, we organized the identified grounding approaches in a collective 'on the wall' interpretation session (Sanders and Stappers 2012) (figure 1). The results were condensed into a visual landscape (figure 2) of four grounding themes: time, structure, control and position. The first and second author coded the transcripts of the second series of interviews on these four themes, to investigate how researchers deal with these themes and what challenges they encountered.

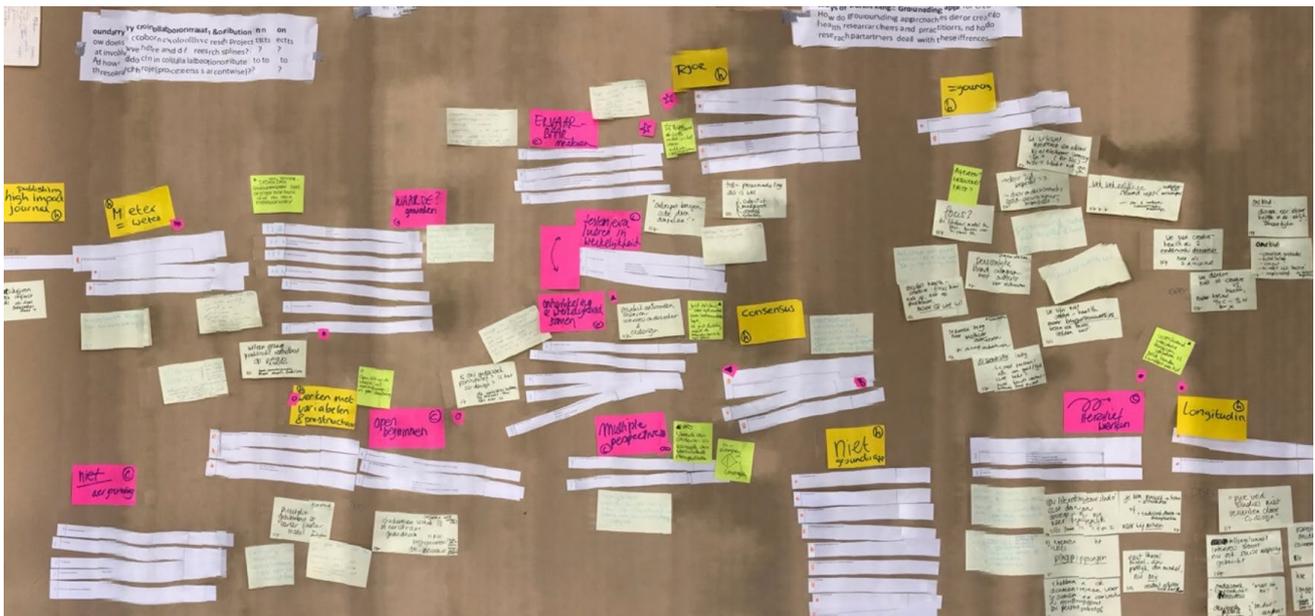


Figure 1: Organizing the grounding approaches in the 10 research projects

Time

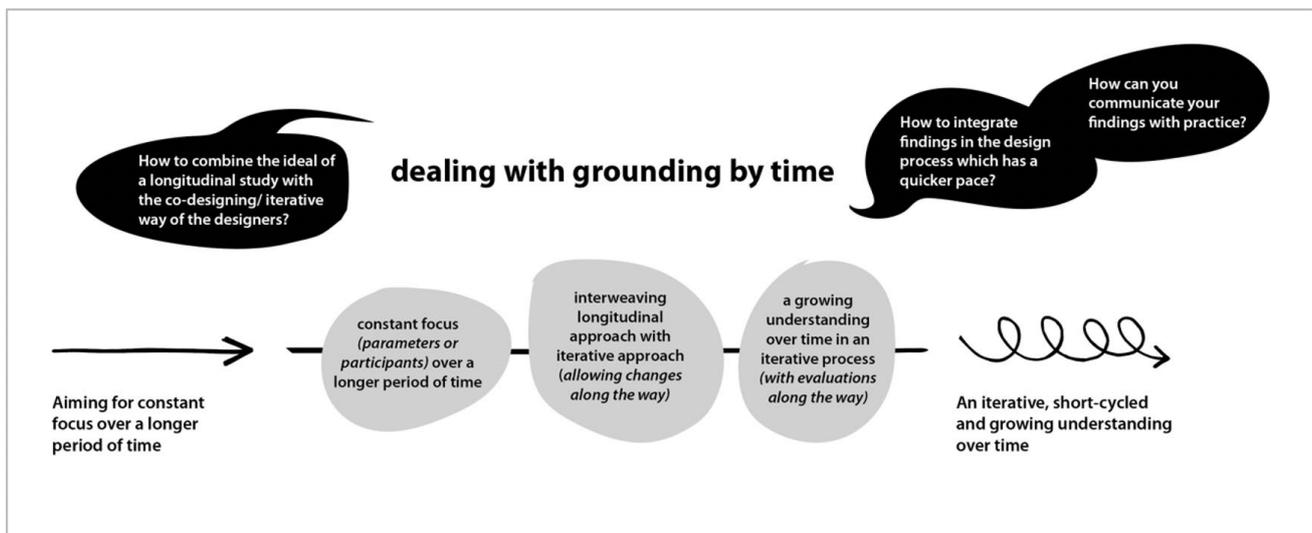


Figure 3: The spectrum of approaches and challenges of dealing with grounding by time

One end of this spectrum represents an approach of aiming for constant focus over a longer period of time, the other end represents an iterative, short-cycled and growing understanding over time. We found various challenges within this spectrum, for instance: how to combine the ideal of a longitudinal study with the co-designing and iterative way of the designers. Such a mix will be difficult to publish in health discourse, as it contrasts with the principles of the field. One of the researchers (P5) describes this as follows:

'At first, I did not want the participants of the field study to be influenced by the design activities. The journals that I aim for do not accept that.'

A difference in pace between analysis and design also posed challenges. As data analysis tends to take a lot of time, results will lag behind. How to integrate findings in the design process which has a quicker pace? And how can you communicate your findings with practice? One project (P6) describes that while waiting until an academic paper is finally published, the interest from practice partners already dwindles.

Projects that aim for a constant focus over a longer period of time find this focus in specific parameters (e.g. P2) or following a limited number of participants (e.g. P6). By choosing to value the applicability of the study over success in high-rated journals, one of the projects (P5) is able to allow for insights from the iterative design research to find their way in the longitudinal study. Finally, some projects (e.g. P8) find that smaller, low-key evaluations during the iterative process provided sufficient grounding.

Structure

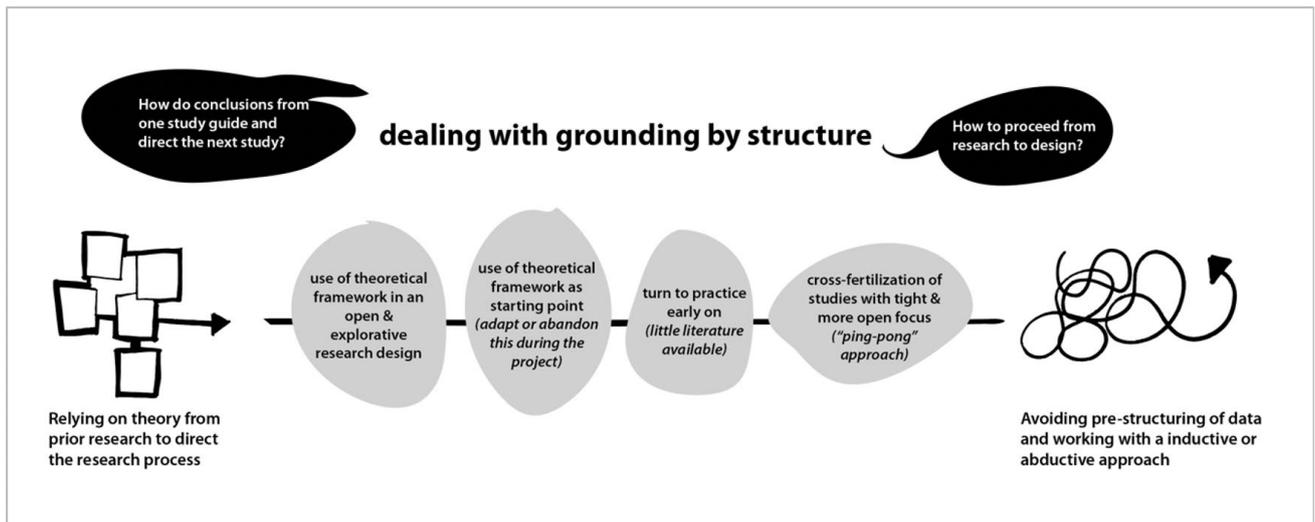


Figure 4: The spectrum of approaches and challenges of dealing with grounding by structure

One end of this spectrum represents an approach of relying on theory from prior research to direct the research process, the other end represents avoiding pre-structuring of data and working with an inductive or even abductive approach (Dorst 2011). Dealing with structure occurs at various moments during a project, for instance in drawing conclusions from one study to direct the next study, in proceeding from research to design, or in choosing for an open or structured interview approach. These choices provide several challenges. For instance, an extensive literature review slows the project down. At the other hand, an open approach without a clear plan for the ethics committee can cause delay as it can present difficulties to recruit participants and, as one interviewee (P7) describes:

'We could have included this group of participants, if we would have been able to provide a clear plan in time.'

Some projects use a theoretical framework in an open and explorative research design. Aspects of the framework are explored by a range of prototypes and research artefacts (e.g. P8, P9). Some use a theoretical framework as a starting point, but adapt or even abandon this in light of new insights in the projects. When there is little literature available to build on, projects turn to practice early on in the projects, e.g. by using focus groups (e.g. P1, P4). One project (P5) describes a 'ping-pong' approach in which the focus of a co-design study is provided by the previous interview survey. This allows for a cross-fertilization of studies with a tight and more open focus.

Control

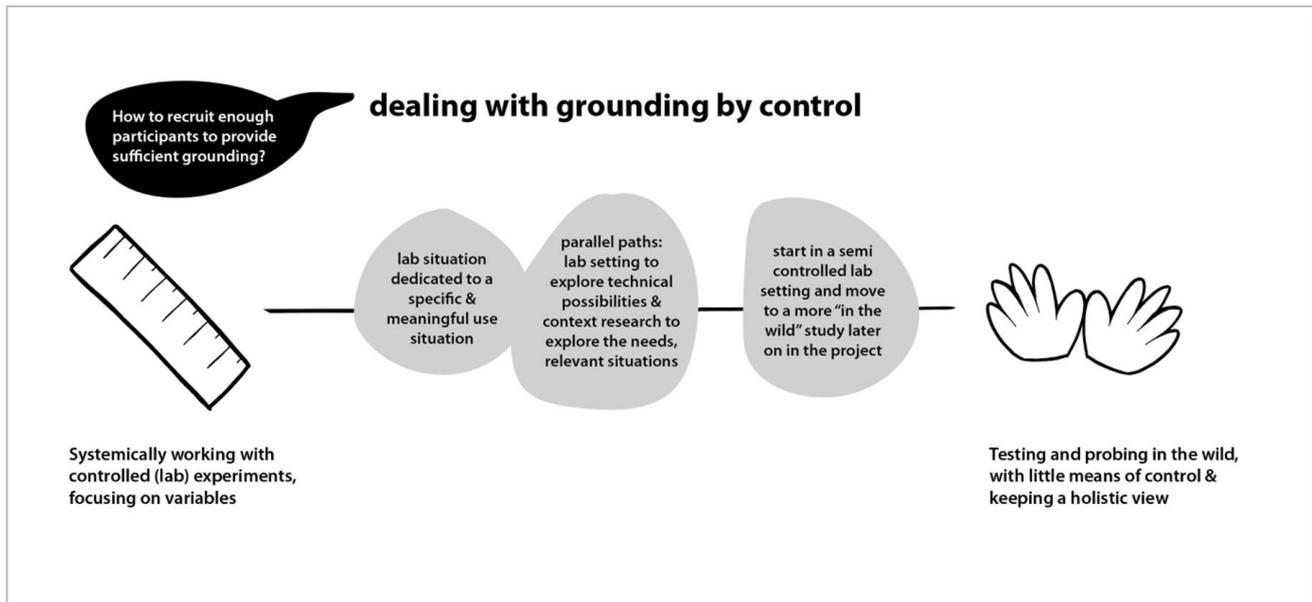


Figure 5: The spectrum of approaches and challenges of dealing with grounding by control

One end of this spectrum represents an approach of systemically working with controlled (lab) experiments with a focus on variables. The other end represents an approach of testing and probing 'in the wild' with little means of control, while keeping a holistic view. Both the lab or 'in the wild' situations can provide challenges, for instance in recruiting enough participants to provide sufficient grounding. Coming to a lab can be too strenuous for elderly people (P3). However, 'in the wild', it is difficult to know up front if enough people will engage with your prototype. One of the projects (P8) describes how they are dependent on the participation of care professionals to secure the inclusion of elderly people in day care or homecare. However, care professionals often have little time.

Many of our projects aim for a 'in the wild' study at the end in the project, such as in care facilities or at people's homes. One of the projects (P2) works towards that by parallel paths (work packages) with on the one hand a lab setting to explore the technical possibilities, and on the other hand context research to explore the needs and the relevant situations. Testing 'in the wild' proved unfeasible within

the timeframe of this project, so they aim instead for setting up a final realistic lab situation dedicated to a specific and meaningful use situation. Other projects start in a semi controlled lab setting and move to a more 'in the wild' study later on in the project. One of the projects describes a process of design explorations to study elements of their theoretical framework, using experiential prototypes in a lab version of a home (P10). The aim is to bring a final prototype to a real 'in the wild' situation such as a home and study how it is used or experienced by several participants over time. In one project (P9) this is described as 'letting the prototype live'. Evaluation of these 'in the wild' studies is often a qualitative evaluation, as one of the projects (P4) describes:

'We will focus on the experiences of people using the prototype, and on the persuasiveness.'

Position

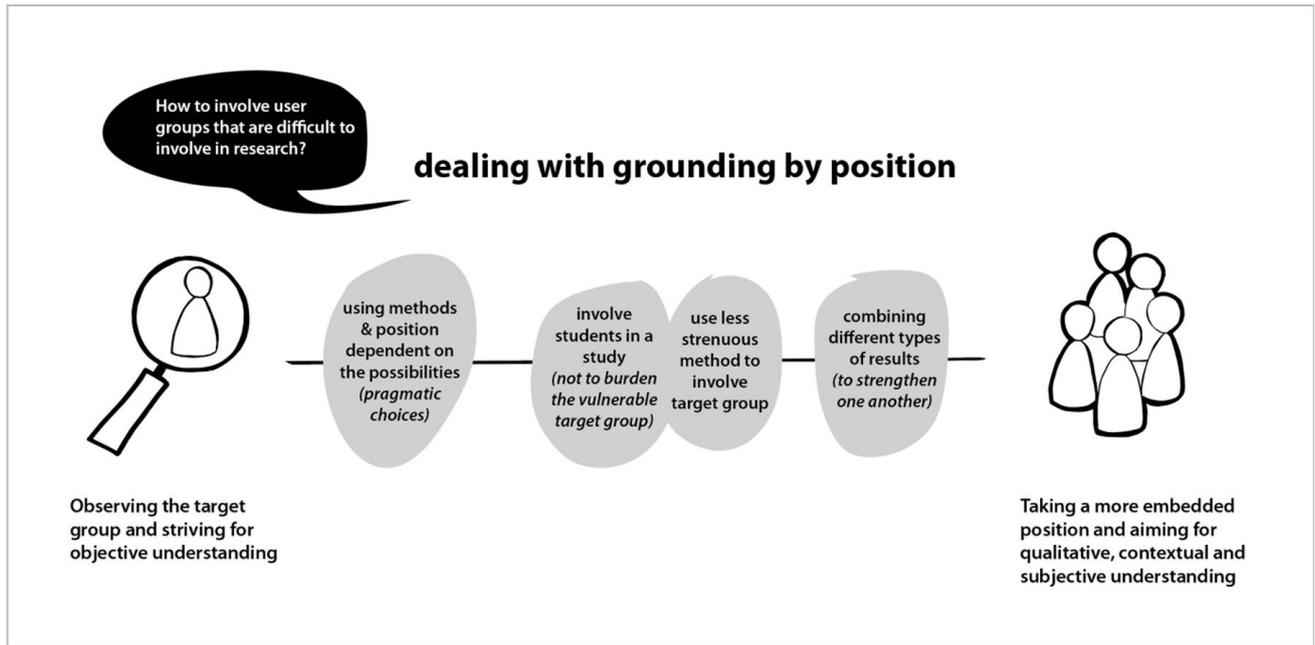


Figure 6: The spectrum of approaches and challenges of dealing with grounding by position

One end of this spectrum represents an approach of observing the target group and striving for objective understanding. The other end represents an embedded position while aiming for qualitative, contextual and subjective understanding. Both positions provide challenges, especially when working with user groups that are difficult to involve in research. The 10 projects need to involve people with dementia or low socio-economic status. Questionnaires and surveys can be used to involve stakeholders such as caregivers, but are found to be difficult to handle for some people in the vulnerable target group (P3). Finding a good constellation to include the views from multiple stakeholders can be challenging, as one project (P2) describes:

‘A person with dementia and the informal carer are reluctant to voice their views in the presence of the other.’

Certain techniques to get a view of the subjective context, such as diaries, are also difficult in working with this group. Sometimes projects are able to involve their user groups by using experiential prototypes, e.g. when involving people with dementia by using sounds (P6).

Many projects aim to combine approaches from both positions to deal with these challenges. They make pragmatic choices, using methods and position dependent on the possibilities. One of the projects (P3) chooses to involve students as participants in one study, and use another (less strenuous) method to involve the vulnerable target group. The different types of results are combined to fill the voids and strengthen one another. The ping-pong approach (P5) that was described in ‘structure’ allowed the researchers to let both a survey study and an explorative co-design study contribute to joint personas.

Conclusion and discussion

We investigated the grounding approaches in 10 research projects where design and health researchers collaborate. We found no clear demarcation of health- and design researchers in the collaborations, as many actors embody a mix of healthcare or design approaches as a result of their experience and education. Differences in grounding approaches manifested themselves on four themes, each representing a spectrum: time, structure, control and position. We found

that differences within these spectra did not just provide challenges, but were also used to strengthen a project by grounding from multiple angles (e.g. both in theory and in practice).

Our results suggest the importance of mutual understanding between actors from different disciplines for a fruitful meeting of grounding practices (see also Andriessen et al. this conference). Some grounding challenges indicate different views among partners with regard to the contribution of their project. Apart from contributing to science, the 10 projects aim to contribute to creative practice and healthcare practice. Different views occur not only between disciplines, but also between research

and practice partners. For instance, the interviews show different views on the role of prototypes. Practice partners tend to view them in the light of eventual implementation, but some researchers see them as research artefacts for eliciting responses by the target group (see also Wensveen and Matthews 2015). How do researchers deal with these different views and goals in their ways of grounding?

To conclude, we hand the suggestion that researchers in create - health collaborations discuss their views on the four grounding themes early on in their projects, in order to develop mutual understanding and respect. A playful suggestion for a tool is provided by figure 7.

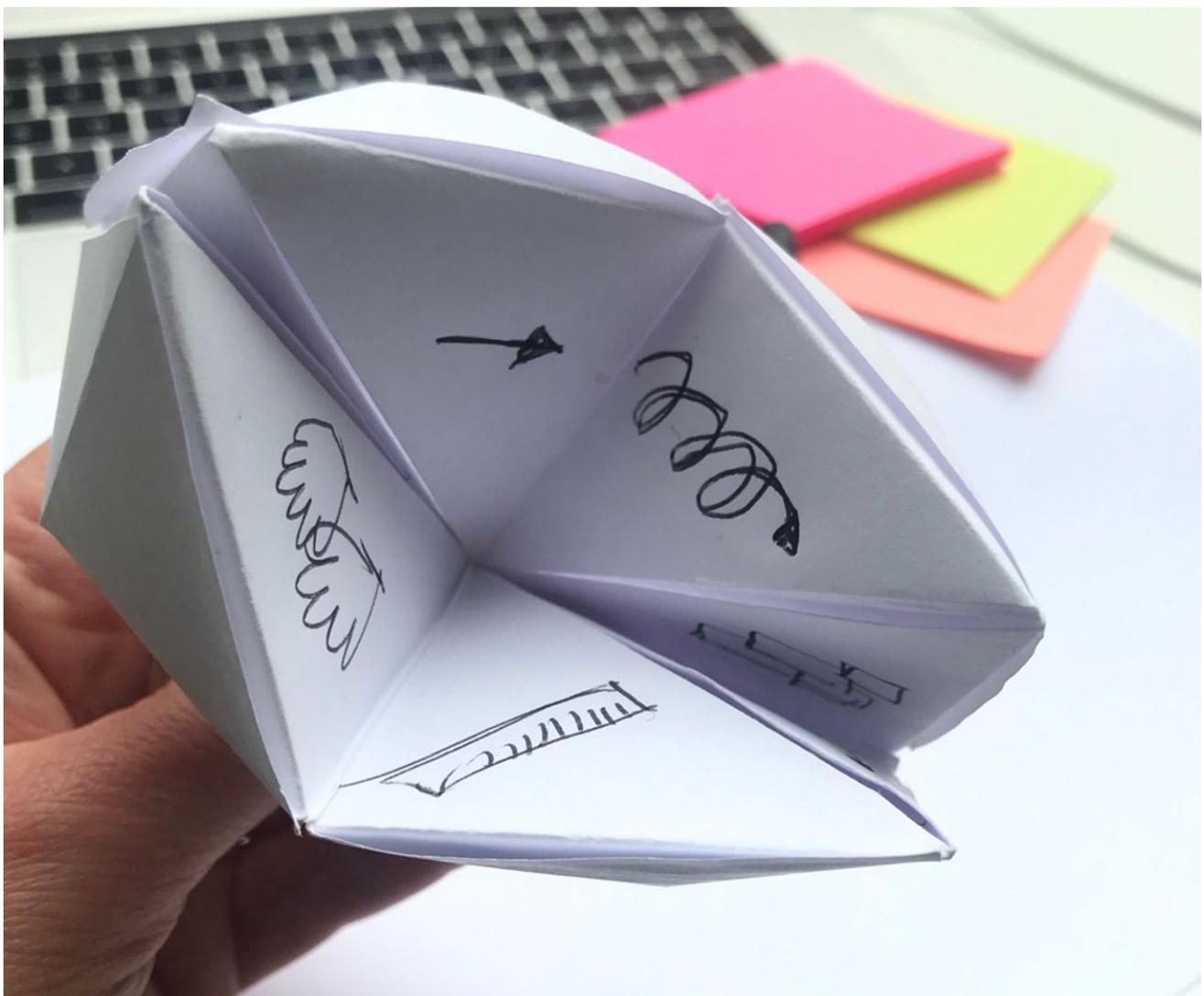


Figure 7: Do-it-yourself suggestion to consider the four aspects of grounding and the corresponding challenges

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¹<https://www.zonmw.nl/nl/over-zonmw/ehealth-en-ict-in-de-zorg/programmas/programma-detail/create-health/>

