



Proceedings of the 6th International Conference on Design4Health,
Amsterdam, 2020

Editors: Kirsty Christer, Claire Craig & Paul Chamberlain

Volume 1



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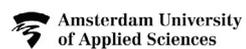
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Volume 1

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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)
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- 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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COLLABORATING IN COMPLEXITY: STRATEGIES FOR INTERDISCIPLINARY COLLABORATION IN DESIGN RESEARCH

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Abstract

The ever-increasing specialization of scientific research, combined with the complex challenges that health in society is facing calls for more interdisciplinary design research. However, healthcare and creative researchers come from different worlds that do not automatically align and intensive collaboration between different disciplines is often not without obstacles. We analyzed 10 projects that are in the process of interdisciplinary research on solutions for living with dementia, obesity or loneliness. The question we address is: Which

strategies do health and creative professionals use to work together in design research? We found that an array of strategies is used to foster collaboration as recommended in literature. However, the strategies to foster interdisciplinary collaboration in research recommended in literature do not easily fit the unpredictability of design research projects and the complexity that comes from doing research in health practice.

Keywords: interdisciplinary research; healthcare; creative sector; design research



Introduction

The ever-increasing specialization of scientific research combined with the complex challenges that health in society is facing calls for more interdisciplinary design research (Koch 2010; Witteman and Stahl 2013). However, healthcare and creative researchers come from different worlds that do not automatically align and intensive collaboration between different disciplines is often not without obstacles (Gavens et al. 2018; Kumar 2012; Smith 2007; Thompson 2009).

We analyzed interdisciplinary collaboration within 10 research projects that were granted by the Dutch funding agency ZonMw, within the programme 'Create Health – E-health knowledge base for a healthy and active old age'. This is aimed at funding research on which to base the development or improvement and implementation of e-health applications intended to support people suffering from dementia (five projects), obesity (three projects), or loneliness (two projects). All 10 projects are executed by a consortium that includes design and health researchers as well as health and design practitioners. At the time of writing the projects are halfway through their three-year period and participants have found ways to collaborate. Based on an analysis of documents and two rounds of interviews we answer the question *Which strategies do health and creative professionals use to work together in design research?* With the term 'professionals' we refer to both researchers and practitioners.

Strategies for interdisciplinary research

Key characteristics of interdisciplinary research are the presence of at least two disciplines, a shared delineation of the research questions, and the involvement of the disciplines throughout the research process (Nair et al. 2008). Barriers and strategies for interdisciplinary collaboration in research projects can be

found throughout both health and design literature (Aagaard-Hansen and Ouma 2002; Gavens et al. 2018; Hord 1981; Topaloğlu and Er 2017; Curry et al. 2012; Stember 1991; Nair et al. 2008; Turner et al. 2015; van der Bijl-Brouwer and Dorst 2017; Sleeswijk-Visser 2013; Blandford 2018; M. S. Kleinsmann 2006; Meroni 2008; Kleinsmann and Valkenburg 2008). We provide an overview of the most notable of these to create a framework to analyze the data. We use the BASIC-model by Gavens et al. (2018) to organize barriers and strategies into five types: **B**lueprint, **A**ttitude, **S**taffing, **I**nteraction and **C**ore Science.

Under the heading **Blueprint** fall strategies that have to do with planning and outlining the project in order to overcome confusion about goals, output, division of labour and means for coordination. This includes allocating time and resources to explicate expectations, goals, and methodologies, to let every discipline have its own home group so that project's results do not get downgraded to the lowest common denominator, and to recognize that not all questions within a project require an interdisciplinary approach. During the project it is also important to adjust the project's output to the stakeholders, to value the collective interests and goals and to keep the organizational structure flexible to be able to adapt to emerging challenges.

Attitude refers to the mind-set of participants regarding their own discipline and the discipline of others. Strategies may be employed to overcome a lack of trust and mutual respect and a perceived inequality between the disciplines: it is important to be reflexive of the strengths and limitations of their own discipline, to maintain a sense of equality, and to value each discipline for its own merits. Furthermore, it is important to explicate why each team member is partaking in the interdisciplinary project. Mutual respect and trust are further fostered by promoting openness and candour so that pluralistic

views can exist within a team and different viewpoints can be meaningfully exchanged.

Staffing strategies are aimed at avoiding imbalanced teams with a lack of shared understanding. Each discipline should be well represented with enough senior researchers. In addition, maintaining certain continuity within the staffing is important to prevent knowledge loss. A well-balanced team also includes so-called boundary crossers: people who speak the language of both disciplines and who explicitly support integration between the disciplines (Akkerman and Bakker 2011).

Interaction includes strategies to avoid miscommunication and overcome geographical distances. Strategies include organizing enough face-to-face meetings and employing the right communicational means to share data. Furthermore, it is paramount to manage any emerging tensions by creating an open atmosphere in which discussion is possible about how the project is experienced.

Core Science strategies aim to tackle challenges relating to differences in concept definitions, methodology and criteria for evidence. One such strategy is to use early meetings to develop disciplinary understanding and to agree on core concepts. Also important is to provide space to discuss how evidence is constituted in the different disciplines. This requires that participants speak each other's language well enough to be able to communicate. However, it is also important to let each discipline have its own group language.

Methods

Based on principles of organizational ethnography (Ybema et al. 2009) we longitudinally (18 months) collected data within the 10 projects. For each project, we collected the project proposal, two yearly progress reports, and project specific documents and conducted two interviews using probing materials (see Figure 1 for an impression).



Figure 1: Interviewing researcher with probing materials

The first two authors analyzed the data in two rounds of analysis within Atlas.ti using a coding scheme adapted from the BASIC-model. We discussed quotations to get a shared understanding in interpreting the data. In a second round we looked per code at all quotations and comments. Based on this cross-case analysis we discussed findings per theme focussing on whether strategies from literature were found in the data and on how these strategies work in the daily practice of doing design research.

Findings

This section describes the strategies to foster interdisciplinary research found in the data, organized by type.

Blueprint

Blueprint strategies in literature focus on making sure participants agree upfront on scope, timeframe and output plan. Findings show that at the start each project developed an output plan, although some in more detail than others. However, setbacks occur while executing the projects and new opportunities arise and therefore the output plan needs to change. At play here is an element of unpredictability in design research that makes it difficult to agree on the output in advance. As one respondent put it:

'[...] the advantage [of design research] is that at the start of the project there is no obligation to specify exactly what the

results will be. As a design researcher I consider that to be a big plus.'

However, this can lead to irritation with researchers from other disciplines:

'I can get irritated because as a behavioural scientist I like to know exactly what we are going to do and why. He [design researcher] says "we just have to do something".'

A further complication is that in design research the output does not only consist of scientific papers. Many of the projects also produce guidelines, toolboxes and prototypes that may only be relevant for certain partners in the consortium. As a consequence, there is a constant need to align expectations among project partners. This constant alignment is also necessary because the composition of the consortium often changes (see Staffing).

Attitude

We did not find strategies to overcome a lack of trust and mutual respect and a perceived inequality between the disciplines. We did find indications about the importance of enthusiasm for the topic and learning potential of the research as driver for cooperation:

'[...] everybody is super enthusiastic about the project and that is noticeable in the collaboration and during meetings. Everybody puts in all the time that is needed.'

In addition, respondents report that creating trust requires time. Those who have worked with the same consortium partners in previous research find this helpful. At the same time, publishing constraints may limit the willingness to do everything together in an equal way. As one respondent puts it:

'I think it will be difficult to include all of the co-design activities in the results [...] Then I would make the results paragraph of the paper too complicated and then I need to reflect on all those results.'

Staffing

Literature stresses the importance of a stable team. However the data shows that this is difficult to achieve. In all projects partners are opting out and extra partners gradually become involved. Respondents refer to those extra partners as 'informal partners' or 'external partners'. The projects need those extra partners to get access to the target group. Another problem arises when students cannot be found while they are planned for crucial tasks.

Literature also promotes a balanced team with both junior and senior researchers in each discipline. Findings show that imbalanced teams are common, with a senior and junior researcher in one discipline (often the discipline that was the main applicant of the proposal) but mainly hours for junior researchers in the other. In this situation applicants try to at least make sure that the junior researchers are good ones if they perform crucial tasks, or that the senior researcher perform those crucial tasks with student-work as an addition. Another strategy that we identified is to have a PhD-student act as a boundary crosser taking office at both institutions or to use a (PhD-)student from one discipline who is then guided by a researcher from the other discipline.

In all projects interdisciplinary collaboration is further fostered by high-level actors (for example professors in research, or policy officers in practice) who provide substantive guidance and connect to actors in a broad network for the implementation of the results. A respondent emphasized the importance of this working together at both decision and implementation level:

'It is important to make good contact on all those levels, based on what you need.'

Interaction

The data shows that miscommunications arise because it is difficult to communicate designerly ways of working to health

partners. One respondent put it that health researchers are used to plan a project in advance using strict procedures while design researchers 'are used to make something, throwing it in and seeing what happens'. To make design-oriented methods more transparent respondents suggested to indicate clearly that the process consists of iterations, to organize frequent interactive face-to-face meetings and workshops, and to use prototypes as 'boundary objects' in discussion with health care partners.

Further difficulties arise in the communication between research and practice. One example is that academic output often takes too long to produce and does not fulfil the information needs of health and design practitioners:

'The real-life timeline and the academic timeline do not run in parallel.'

Therefore, some projects add non-classical dissemination activities, e.g. press releases, , symposia and events that are organized in the flow of the project to communicate data and evolving insights with project partners.

Core science

Core science strategies are aimed at aligning different views on concept definitions, research methodology and criteria for evidence. We found a few of those strategies in the data. In one case a meeting at the beginning of the project was used to compare and discuss research methods. In this project health researchers have become so enthusiastic about the qualitative method for data analysis employed by the design researcher that they adopt it into their future research. However, respondents indicate that during the project methodological choices may shift because of the iterative nature of design research:

'It is an iterative process in which ends and means alternate. Therefore, you need to check every couple of months: Where am I? Can I go to the next phase? This is more difficult to plan than a tight evaluation study.'

The different backgrounds sometimes create tension about the way evidence is constituted (Zielhuis et al., n.d.), and customs and scientific journals may not accept certain ways of working:

'He wants to start with design activities in my field while I have been trained not to influence people. [...] And also the journals I publish in [...] are not that creative saying heh, let's use all kinds of design methods.'

At the same time respondents report the benefits of combining different disciplines in one project by creating various forms of 'mixed method' research. E.g., combining interview data with co-design sessions to create a richer picture of people with dementia.

Conclusion and discussion

Studying ten projects that are in the process of interdisciplinary research on solutions for living with dementia, obesity or loneliness shows that there is a need for constant alignment between partners of the consortium because of changing circumstances, new insights and the unpredictable nature of design research. This entails a degree of trust that requires time to build and a degree of enthusiasm to overcome hurdles. Changes in staffing are inevitable, but can partly be overcome by supervision across disciplines and making use of PhD-students as boundary crossers. Miscommunication between researchers may arise, particularly about the nature of design research, but also between researchers and practitioners. Frequent interactive face-to-face meetings, workshops, symposia and events and the use of prototypes as 'boundary objects' are used to mitigate this. Tension about the way evidence is constituted may arise. Meetings to discuss methods from the various disciplines are used to overcome this.

This study shows that the strategies to foster interdisciplinary collaboration in research recommended in literature do

not easily fit the unpredictability of design research projects and the complexity that comes from doing research in health practice. Further research is needed to determine what additional strategies can be successful to nurture interdisciplinarity in design for health.

Acknowledgements

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USING A CO-DESIGN APPROACH TO DEVELOP TECHNOLOGICAL INTERVENTIONS TO HELP CHILDREN WITH ARTHRITIS TO BE MORE ACTIVE AND INDEPENDENT

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Abstract

15,000 Children and Young People (CYP) in the UK have Juvenile Idiopathic Arthritis (JIA). 1,000-1,500 new cases are diagnosed every year. Currently there is no cure for JIA. Management interventions are available, but these are often stigmatising and children disengage. Improving self-management skills for children is particularly important as they transition to adulthood. The aim of this project was to understand different perspectives and needs of all stakeholders affected by JIA, and to develop a design response to better support them. A co-design approach was used to explore these issues and to develop the response. Phase 1 focused on using surveys, with rapid response rates highlighting the lack of current products, 1:1 interviews to establish key areas of unmet need within the different stakeholder groups, as well as storyboarding and rough prototyping. As the prototypes took shape, stakeholders continued to contribute particularly around ergonomic and tactile issues. The different priorities of each stakeholder were emphasised: the children wanted help with their joint pain whilst the healthcare professionals wanted to improve physiotherapy adherence. The parents wanted to keep better track of the condition

whilst the teachers wanted to improve communication with the child. Stakeholders initially dismissed other stakeholders' views, believing they knew best. Through these discussions, the complexity of JIA management was highlighted and therefore the importance of a multi-product approach became apparent. One of the key difficulties in managing chronic illnesses (particularly for children) is the lack of communication between different stakeholder groups but also between healthcare professionals across different disciplines. Through incorporating different stakeholders' opinions, the technologies created resulted in effective methods to not only address the problems mentioned but also to facilitate discussion around these issues throughout the design process, eliciting previously unknown needs and developing a more engaging and successful product. Further funding is being sought between university and hospital partners to continue developing the products collaboratively with children, families and clinicians.

Keywords: co-design, self-management, Juvenile Idiopathic Arthritis, paediatric healthcare

Introduction

Juvenile Idiopathic Arthritis (JIA) is one of the most common causes of physical disability in childhood (Versus Arthritis 2019) and is defined as an autoimmune disease that causes inflammation of the joints (Versus Arthritis 2019) resulting in pain and stiffness, which can make everyday activities difficult to achieve. This can affect physical and emotional wellbeing and cause delayed development, meaning children with JIA struggle to be active and independent.

Most self-management tools that assist with daily tasks are aimed at adults, so they can be difficult and stigmatising for children to use. The products that are currently available do not take into account the wider stakeholders involved and how their support, or lack of it, impacts the child's overall health.

This project's aim was therefore to address this gap in the market by using a co-design approach to understand the challenges faced by the key stakeholders involved: the child, parent/carer, healthcare professionals (HCP's) and the child's teachers. These challenges were then explored to realise a suite of self-management tools. This paper focuses on the process involved, specifically the importance of sustained multi-stakeholder involvement, and how the design-led approach facilitated their involvement and the development of an engaging and successful outcome.

Background

A major priority for health services is helping people with chronic long-term conditions, including arthritis, as highlighted in the 2030 Agenda for Sustainable Development. Arthritis can be life-limiting with emotionally and physically debilitating effects, as well as making simple tasks painful and difficult to achieve. At a macro level, it can restrict an individual's access to employment, putting increased pressure on the economy and healthcare resources. The

current COVID-19 climate further highlights the need for these patients to self-manage effectively as healthcare professionals are being diverted to help support the recovery of COVID-19 patients. This withdrawal of or limited access to key supports can have a considerable negative impact on the physical and mental wellbeing of chronic disease patients. The development of self-management tools is therefore key to helping relieve pressure on healthcare professionals and to alleviating the concerns of patients. Harnessing the wider informal support network surrounding each patient was a specific focus of this project, recognising that this support network also needs resources (tools, knowledge, information) to enable them to provide the best support.

Arthritis is generally associated with older adults. The fact that it affects children is little-known, resulting in a lack of tools to support them. Children develop by interacting with the world through play, 'allow[ing] children [to develop] their imagination, dexterity, and physical, cognitive, and emotional strength' (Ginsburg 2007). However, 'CYP with JIA live with recurrent pain and disability, limiting their ability to complete daily physical tasks and participate in school and social activities' (Tong et al. 2012). Whilst there are existing studies describing the experience of living with JIA (Cartwright, et al. 2015; Chomistek, et al. 2019; Van Gulik, et al. 2020) they tend to focus exclusively on the child's experience or only focus on the physical symptoms, neglecting both the wider life impact and insights of other stakeholders.

A co-design approach was chosen to ensure wider stakeholder views were incorporated. Co-design is defined in this context as 'the creativity of designers and people not trained in design coming together in the design development process' (Sanders & Stappers 2008). This approach is particularly useful within healthcare contexts as it helps to give equal consideration to the knowledge that each stakeholder brings.

Families can often feel as though their lived experience is ignored or that the medical opinion of their healthcare professional holds greater weight than their own. It was a conscious aim of the project to continually involve children with JIA, their families, healthcare professionals and the children's teachers equally. Their collective input directly steered the focus and prototype iterations.

Methods

Fully informed consent was obtained at the start and strict ethical procedures were followed throughout. The clinical stakeholders involved were part of Sheffield Children's Hospital (SCH) Rheumatology department, with this link aiding the recruitment of families. Further family stakeholders were recruited through online support groups, ensuring a wider population was involved. Both teachers and teachers in training were recruited to capture their experience and knowledge of new teaching practices being implemented.

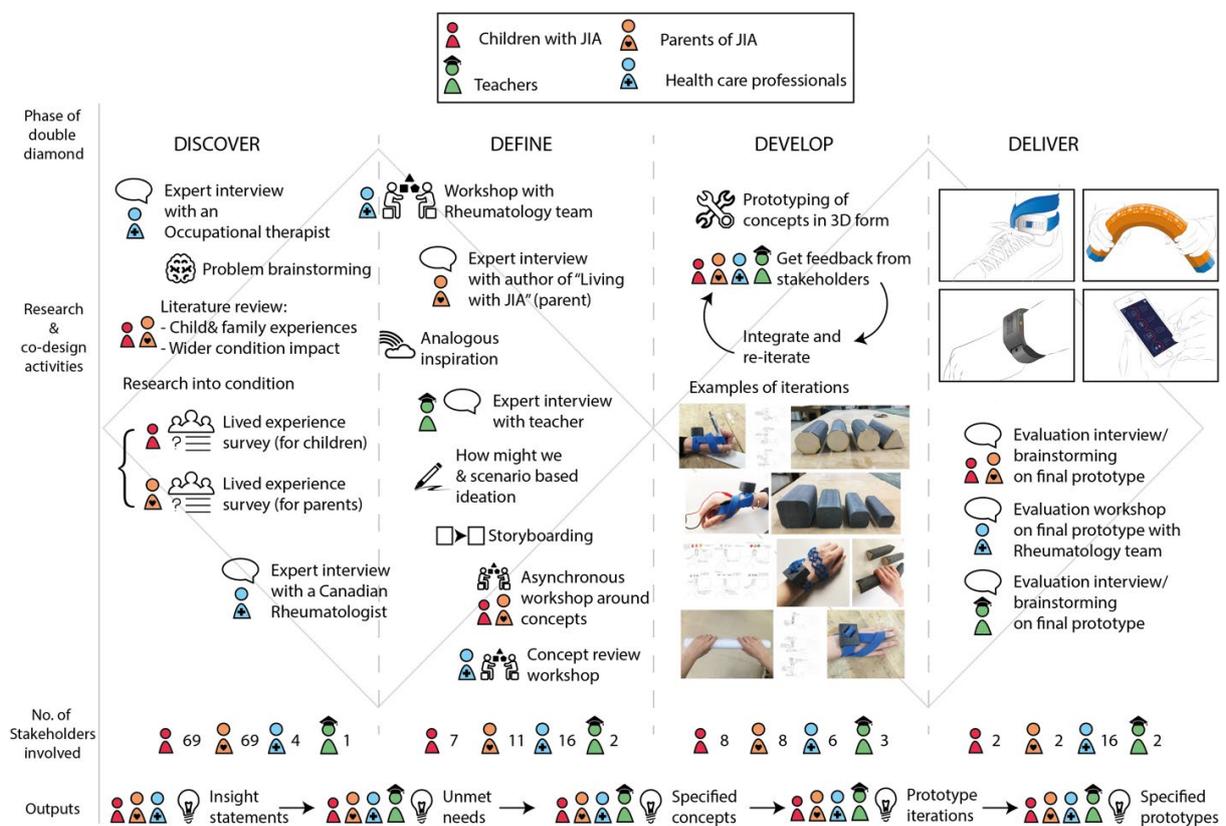


Figure 1: Method Diagram using the Double Diamond Framework (Design Council 2015)

Stakeholder input was sustained throughout, with each phase involving a mix of research activities and independent design work, described below.

DISCOVER

Aim: To discover the breadth and characteristics of unmet needs from different stakeholders. **Activities included:**

- Research into the condition and a literature review for context.
- Expert interviews with healthcare professionals to expand on the problems, in an open format to encourage discussion of current treatments, children's and healthcare professionals' issues and products they did/didn't recommend.

- Online lived experience survey to understand the problems that children and their parents face, enabling participants to answer in their own time, reducing potential pressure, resulting in richer lived experience data. This accessed international patients.

DEFINE

Aim: To define the problem(s), and develop initial concepts. Activities included:

- Independent sketch ideation by the designer as a starting point to consolidate findings from 'discover' in a format that can be used to stimulate further discussion.
- Workshop with a Rheumatology team. Ideas were presented in rough sketch form to facilitate discussion.
- Expert interview with the author of a guide to living with arthritis (parent of a child with JIA, USA), on her wider experiences and responses to initial ideas.
- Expert interview with a primary school teacher in training, focusing on strategies she used to help children who struggled physically in the learning environment.
- Consolidation of stakeholder-identified needs and prioritisation of key issues to take forward: pain management, encouraging physiotherapy, help in the classroom and condition management
- Development of concepts using design methods including: scenario-based ideation and storyboarding activities around who the ideas would benefit and how.
- Asynchronous design workshop involving children and their carers around the concepts. Creating a co-design space where families could use post-its and emoji stickers to build on comments and ideas.

- Concept review with healthcare professionals, building on insights gathered from the asynchronous workshop.

DEVELOP

Aim: To prototype the concepts based on feedback. Multiple prototype iterations took place, following the process of making prototypes, getting feedback from stakeholders, integrating and re-iterating. The prototype iterations covered the following elements such as accessibility, physical properties, digital security and aesthetics (see figure 1).

DELIVER

Aim: To test user response to final prototypes. The stakeholders were given the prototypes during these interviews, allowing them to interact with them naturally and explore what worked well and what they would improve.

Findings

Theme	Challenge/ unmet need	Priority for which stakeholder?			
		HCP's	Children with JIA	Their parents/ families	Teachers
Symptoms	Pain as a symptom				
	Obesity				
	Unique symptoms				
Impact on school	Missing school				
	Writing as a major difficulty				
Treatment	Pain from treatment				
	Current aids are stigmatising with children not engaging as they are obviously different				
	Lack of compliance with physio stretches				
Emotional impact	Feeling isolated/ different				
	Invisibility of disease leads to disbelief				
	Feeling the disease controls them				
	Emotional burden from changing symptoms				
	Feeling helpless as your child suffers				
Wider desires	Increased understanding from key stakeholders				
	Increased awareness/ reduction in trivialisation of disease				
	Desire for independence				
	More knowledge on condition				
Monitoring	Diagnosis of JIA can take a long time				
	Keeping track of symptoms				
	Need to juggle workload/ child's condition				

Figure 2: Unmet needs

Challenge/ unmet need	Quotes/ Evidence to support	Priority for which stakeholder?			
		HCP's	Children with JIA	Their parents/ families	Teachers
Pain as a symptom	"It would be great to know what it's like to not be in pain... I'm in pain all the time" (Tong et al., 2012)				
	Better pain relief daily was cited as the product that was wanted to help				
	"Something to help with pain so that I don't have to stop doing fun things because my hands or knees hurt"				
	76% of children reported pain on >60% of days despite taking medications (Schanberg, Anthony, Gil, & Maurin, 2003)				
	Distracting child from painful symptoms was highlighted as key challenging aspect				

Figure 3: Unmet needs with supporting quotes

The iterative co-design process meant that the concepts and prototypes continually changed in response to feedback. The needs accumulated through the different stakeholder activities have been collated in figure 2, with examples of the evidence supporting one of the needs, highlighted in figure 3.

The key priorities for each stakeholder, that drove the concepts, were:

For the **children** with JIA, their priority need was help with joint pain as this hindered their ability to be active and independent, making them feel different. They wanted 'something to help with pain so that [they] don't have to stop doing fun things'. While aids were considered stigmatising, children emphasised the problem of having an invisible condition as it often led to disbelief. Missing school and the lack of understanding from key stakeholders were highlighted; 'I struggle with PE and some teachers just say: 'Come on, you're fine''.

For **parents/carers**, recurring themes were how to easily keep track of the condition to help reduce lengthy diagnosis times, help to identify an upcoming flare up 'allowing a full episode to be averted' (Miller, 2013), ways to improve diagnosis as 'it was scary and frustrating knowing something wasn't right, but not having a reason' and expanding knowledge of the condition.

For **healthcare professionals**, the priority problem was lack of compliance with physiotherapy stretches, despite pain relief when done regularly. Children cited pain, lack of motivation or fatigue as deterrents to physiotherapy. Other problems included the uniqueness of JIA symptoms, 'The key problem with treatment is working out which treatment is the right treatment for each kid' (Mosher, 2019) and potential obesity through lack of exercise.

For **teachers**, the priority issue was understanding when children were in pain or needed help, closely linked with problems of disbelief and lack of awareness around

the condition. Children said teachers had accused them of feigning their pain. Children were reluctant to use current systems such as traffic light cards to indicate when help is needed, as they were embarrassed by their difference in front of their peers.

These unmet needs were developed through a prototyping process resulting in four products in a suite of self-management tools. Photographs of the prototypes have been omitted for Intellectual Property reasons. The concepts are shown in Figures 4, 5, 6 and 7 and show how stakeholder input drove every decision.

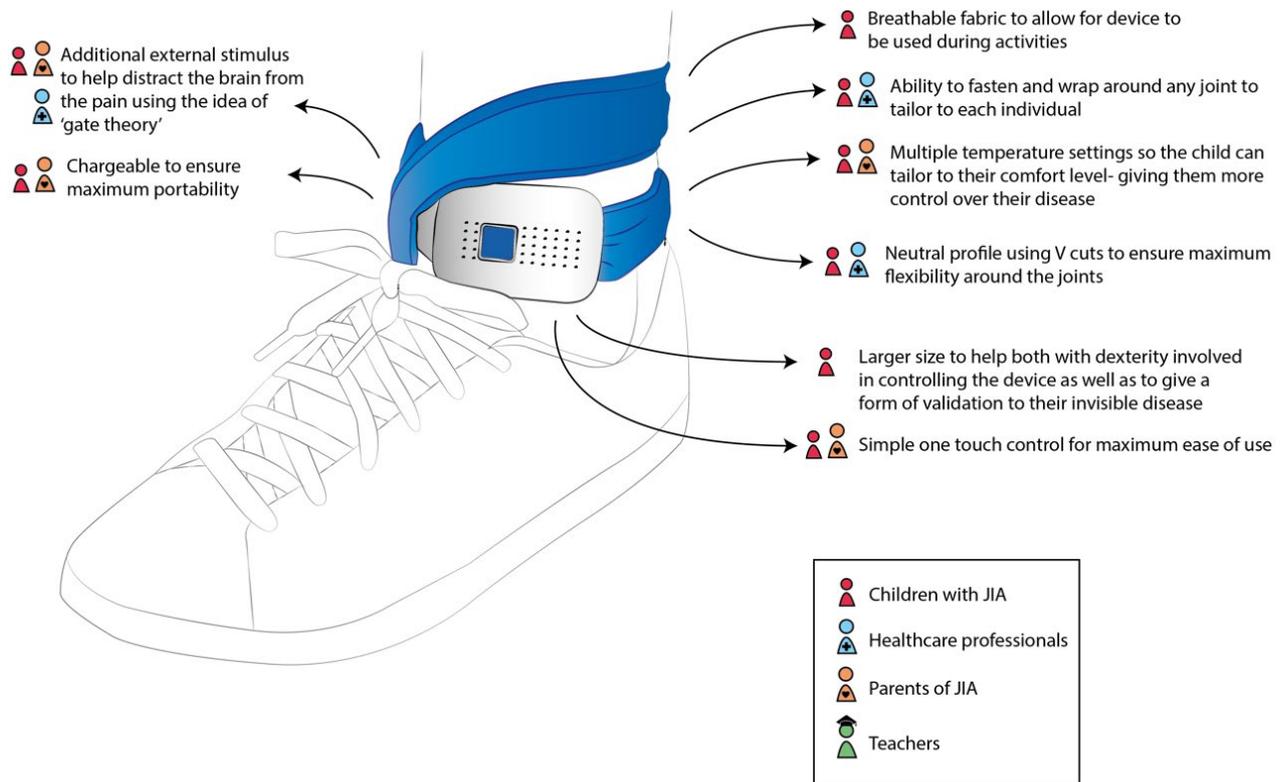


Figure 4: C1: Pain Management Tool

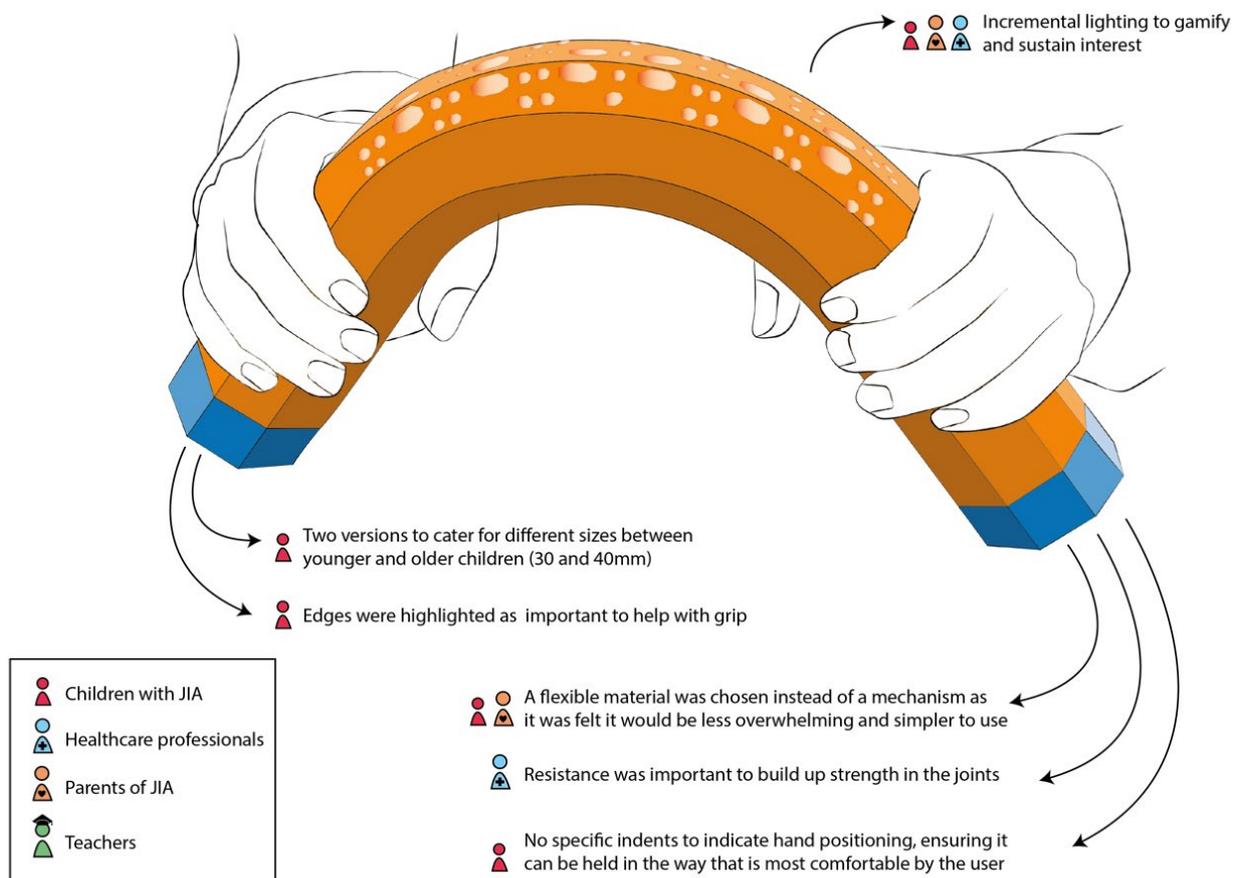


Figure 5: C2: Motivational Physio Tool

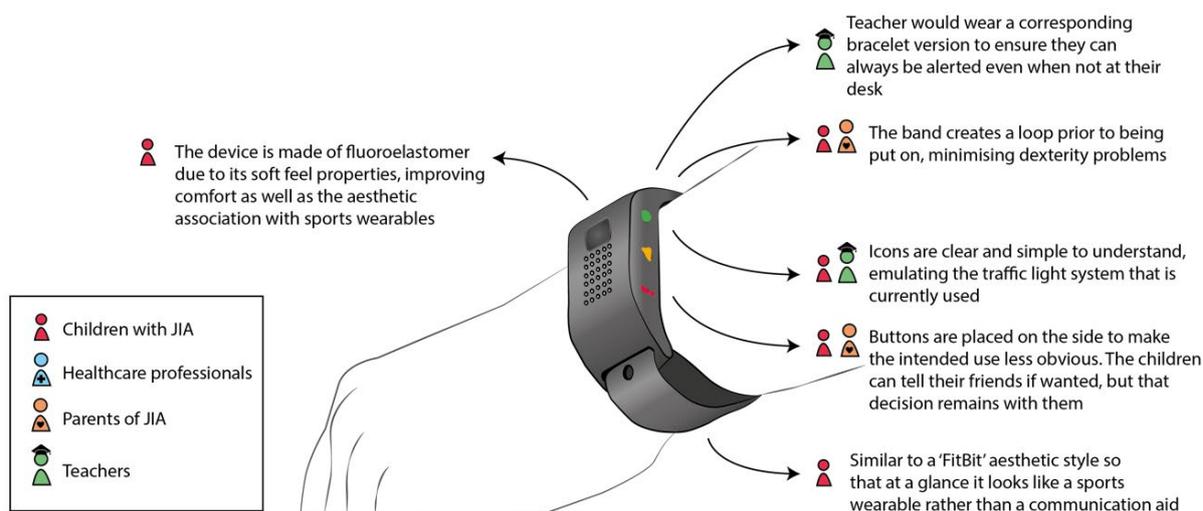


Figure 6: C3: Communication Tool

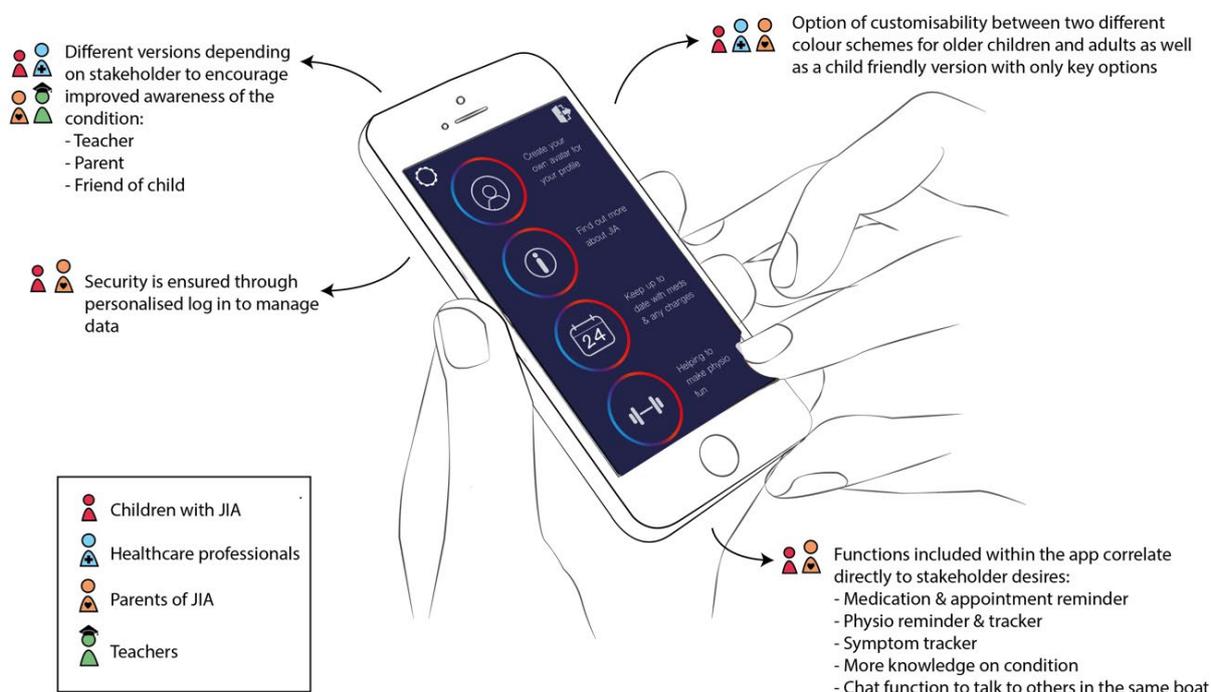


Figure 7: C4: App to manage the condition

Discussion

The wide range of unmet needs identified in Figure 2 highlights the extent to which JIA impacts a child's life including their emotional, academic and social wellbeing, which in turn impacts their condition and treatment. Current products often ignore this wider context which leads to a lack of engagement. The key issue is that previous products are often designed with only one, possibly two stakeholders in mind (the child and their carer), neglecting to take account

other critical stakeholders involved. As one parent emphasised 'your child's teacher spends more waking hours with him or her during the week than you do' (Miller, 2013), similarly the healthcare professional is heavily involved. By including these other stakeholders, challenges related to communication, awareness and disbelief, and their impact on each child with JIA could now be addressed collectively. The co-design approach enabled multiple perspectives to be taken into account, by

expanding the context of the disease and offering a cohesive response to all the issues.

The sustained multi-stakeholder input provided constructive challenge through all stages of the design development, steering the direction of the solutions. For example, during phase 1, the desire to and the importance of being active was emphasised by all stakeholders. The initial design response was therefore a product that encouraged activity, tailored to the individual's specific limitations. The co-design process then uncovered two key underlying issues: 1) from the healthcare perspective, the need for daily physiotherapy exercises to extend the range of motion and 2) from the child's perspective, a product to help with pain management, to enable them to do their physiotherapy exercises whilst also engaging in general physical activities. These insights were only achieved through the mutual trust and sustained involvement of all stakeholders.

The designer's adaptability is key for a successful co-design approach, as they must adjust the resources and design setting to enable input from different stakeholders. An example was the asynchronous workshop in phase 2. The fact that children with JIA often miss a large amount of school had been previously highlighted. As a result, the setting for this workshop was timed to coincide with clinic at SCH. This co-design space enabled multiple children and families to comment on the concepts independent of each other, thus building on each other's insights. Stakeholders usually comment simultaneously within a singular workshop, but an asynchronous approach made the best use of the participants' availability and gave them the safe space to comment freely. With regards to the tools, younger children often want activities that are fun with immediate reward whilst older children want to be treated as an equal and resist patronising elements. As a result, storyboards were used to engage

younger children whilst concept sketches were used to appeal to older children. The storyboards felt like a game but allowed younger children to understand the context, whilst the concept sketches enabled older children to expand upon their opinion, validating their lived experiences. A designed approach is what enables this flexibility, altering tools to engage the different users and offering full voice to all participants, resulting in richer outcomes.

Prototyping is key to co-design, embodying stakeholder preferences as well as designer's own expertise and judgements for continued reflection and development as shown in (Langley 2019). This iterative process was particularly useful when sizing C1, the pain management tool (see Figure. 4). The design challenge initially appeared to be balancing the constraints of the technology with the child's embarrassment of using an aid. Two crucial insights were then gained when the children interacted with foam models: arthritis is known as an invisible condition with scepticism being a common reaction; so in reality a visible, physical aid validated their condition and combated disbelief. However, users also explained the lack of engagement around current aids; these are clunky and medical-looking, and children wanted something 'cool' to show to their friends. Prototyping also challenges perspectives, as when deciding the form for C2, the motivational physiotherapy tool. Most physiotherapy aids are spherical in form, for comfort. Alternatives were prototyped including cylindrical, triangular, octagonal and dodecahedral, to challenge received wisdom, but it was assumed cylindrical would be selected. Through interacting with the prototypes, the children highlighted that profiles with edges were crucial for comfort, providing a more sustainable grip. Only through interacting with the prototypes was this ergonomic need uncovered, highlighting the importance of both prototyping and co-design, with sustained stakeholder involvement.

This project and research into other self-management tools identified a tendency for designers to align a product with one stakeholder over another or to compromise, with less than satisfactory results. In contrast, this project demonstrates the value of working with varied and sometimes contradictory perspectives to develop stronger outcomes that answer multiple needs. By addressing the main priority from each group, the stakeholders all felt validated in their contribution. This encouraged them to input on the other tools which didn't appear to answer their particular need. What began as four different tools addressing four separate priorities, became a suite of tools that had benefited from insights and decisions from every group. This co-design approach shows how the differences between people's opinions can be used to challenge potential solutions and create stronger design outcomes that take into account whole life impact.

Limitations

The findings of this project are not representative of the views of all stakeholder groups within JIA due to the limited number of healthcare professionals, families and teachers involved. In mitigation, the international response rate to online surveys within the JIA community during the project - 20 responses in 20 minutes - was indicative of a real need.

Conclusion

The co-design process of incorporating different stakeholders' opinions, and facilitating discussion around their individual issues throughout the design process, resulted in eliciting previously unknown or unexpressed needs and effective design outcomes to self-manage the condition as well as alleviating the whole life impact of JIA. The design decisions around each product thus relate directly back to the co-design involvement of all stakeholders.

This outcome of a suite of self-management tools aims to fulfil its purpose on a product level of improving activity and independence for children with JIA. It also aims to highlight on a more conceptual level, the value of stakeholder involvement, and how an initial lack of consensus should not be seen as a weakness, but as an opportunity to challenge potential solutions and thereby achieve more viable outcomes. Further funding is being sought between University and Hospital partners to continue developing the products collaboratively with children, families and clinicians.

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DESIGN FOR IMPACT: STUDYING THE ROLE OF DESIGN IN SPATIAL COGNITION OF CHILDREN WITH AUTISM

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Abstract

The discussion around the impact of the built environment was first argued in the 1960s by the work of environmental psychologists Stringers (1970) and Canter (1969), who put forward a common approach toward architecture and psychology. Their efforts raised the awareness of the design potential to affect diverse aspects of a human being. Regarding this matter, the state of mind and how an individual would perceive the built environment is the main focus of this paper. Additionally, the discussion within the field of the autism-friendly environment which Recently gained increasing prominence and encouraged us to examine how an individual with autism responds to spatial features. In accordance with Downs and Stea's (1973) opinion, the information of surrounding is obtained from an 'uncertain, changing and unpredictable source' and it's been collected 'via a series of imperfect sensory modalities'. But, when it comes to autism, this indication is arguable. Autism is a neurodevelopmental condition along with sensory difficulties that causes a distinct way of perception and processing style of the visual elements

which leads to the proposition of the 'Weak Central Coherence' theory (Frith 1989). In this paper, we tried to shed a light on this theory in the architectural context by assessing how individuals with autism interact with two different spaces, one consists of less spatial details and the other one with more locally integrated details. We asked children with High-Functioning Autism (HFA) to explore those spaces in VR and then we evaluated their post-exploration experience by asking them to configure the same space in a physical model on a smaller scale. The main enquiry was to discover whether the different spatial features would affect their spatial perception, and if it did, to understand what the impacts were. As a concluding remark, the design of a space for High-Functioning children with autism is suggested with fewer details and more globally integrated features, expressing the whole picture rather than the segregated visual elements.

Keywords: high-functioning autism, spatial cognition, spatial perception, cognitive map, space syntax, visual perception.

Introduction

The notion of 'Architectural Psychology' was exploited in the late 50s and early 60s (Pol 2007). There was a mainstream discourse about the role of environmental psychology and the way how it should guide to improve spaces in order to optimize the quality of life for users (Fleury-Bahi et al. 2017). This is how the discourse relating to the relationship between architecture and wellbeing was established and led to a range of theories focusing on architecture and health including Salutogenic design (Antonovsky 1991), Biophilic design (Fromm 1964; Wilson 1984) and Evidence-based design (Ulrich 1984). Designing a better place to support human health gradually opened up the discussion for a wider audience, the ones with special conditions. In reference to the design of educational spaces for children with autism, John Jenkins states,

'Mainstream children are probably more "able to cope" with badly designed spaces than an autistic child would be. So, the responsibility to create a "good" environment is brought into sharp relief' (as cited in Scott 2009, 41).

Usually, the design process contains several assumptions and scenarios regarding the functions of the place but when it comes to the design for individuals with cognitive or sensory impairments, so-called 'less visible' as Smith puts it, those assumptions and scenarios are way beyond the reality. Their needs are mostly overlooked. The primary role of design is to make something for the people to meet their needs and be inclusive. So, in order to shed light on this responsibility, we explicated some possibilities about having a better place for individuals with autism who statistically owns a large population. As the World Health Organization (WHO) published, It is estimated that worldwide one in 160 children has an ASD (As of November 2019, the WHO declared on its website: <https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders>).

Perception and cognition in autism spectrum disorder

Autism Spectrum Disorder (ASD) is a pervasive neurodevelopmental condition, identified by social communication challenges and repetitive behaviours, highly restricted interests and/or sensory behaviours (Lord et al. 2020). One of the subsets of the condition is 'High-Functioning Autism' (HFA) referring to individuals with average or above average intelligence with a diagnosis of Autism and relative preservation of linguistic and cognitive development (Klin and Volkmar 2003; Volkmar 1998). Another main characteristic of this population is their sensory processing difficulties, the way the nervous system receives, organizes and interprets sensory input (Diagnostic and Statistical Manual of Mental Disorders, 5th Edition by American Psychiatric Association - DSM-5).

The sensory system and cognition have an interactive dynamic. As Downs and Stea (1973) indicates, cognitive sources include direct interaction between an individual and the environment, involving a bunch of information importing from all his/her sensory modes. This system is different in autism though. Individuals with autism tend to focus on details and It has been suggested that this cognitive style may underlie the presence of stereotyped routines, repetitive interests, and behaviours, and both relate in some way to sensory abnormalities. Regarding this obsession about details, cognitive theories have emerged which link behavioural characteristics to an underlying cognitive style typified by a style of information processing known as 'Weak Central Coherence' (WCC - Frith 1989). Frith postulated that a cognitive style indicative of WCC will result in a reduction of the usual tendency to strive for coherence and integrate sensory stimuli into a 'gestalt' or 'perceptual whole' whilst the ability to focus on detail is preserved or in some instances even enhanced (Chen et al. 2009). The

findings of the latest study conducted by Burghoorn et al (2020), also are in line with this claim.

Spatial cognition and cognitive mapping process

Spatial cognition has been previously assessed by Lynch (1960, 1981) who proposed cognitive map as a method to evaluate spatial cognition in the city scale. He believed that every detail and physical characteristics of the environment have a significant influence on the spatial behaviour of the human. According to many scholars and urban specialists, Lynch's study did not cover the relational characteristics between physical elements within the total urban configuration, that's why other scholars like Kim and Penn (2004) proposed the same viewpoints as Lynch but also present an approach to link the theory of space syntax to cognitive map model, since cognitive map method and Space Syntax theory (Hillier 1984) are both involved in the field of environmental cognition (Zheng and Weimin 2010). In this paper, we also thrived to get the advantage of the Space Syntax tool to analyse the individuals' cognitive map.

Methodology

In this study we developed several tasks to explore design strategies that might provide an environment where encourages exploration and easy navigation for individuals with autism. The research group was composed of 6 pupils aged 10-11 years (all boys) who attended from a specialist school for autism located in Yazd-IRAN. The selection criteria were their clinical profile representing them as HFA (High Functional Autism) and the lack of physical disabilities which could make participants unable in conducting visual tasks and hand involved performances. During the experiment, we asked the participants to pass three tasks and then considering their recorded performances, we analysed the data by

Space Syntax 2D software tool (Univeristy of Michigan licensed 'Syntax2D' software).

Studying children with autism requires an ethical methodology that supports their rights and consider their condition. During our experiments, we had the school specialist to be sure that no harm of any kind, physical or psychological could happen to the students. We also kept each students' experimental data anonymous.

VR model design

There are two different building models with distinct plans. One of the models is designed to assess _as we call it _ the 'Local-oriented' perception pattern, the pattern that WCC theory addresses as an obsession of individuals on spectrum with details. The structure includes many details and decorative elements (Figure 1.a). The other model includes fewer details, simple and identical patterns with less distractions (Figure 1.b). We also reviewed several studies about designing for autism and considered their common suggestions like simplicity, predictability, care about transitional zone and designing low stimuli environment (Beaver 2006; Irish 2015; Mostafa 2008, 2014; Altenmüller-Lewis 2017; Humphreys 2005; Whitehurst 2006).

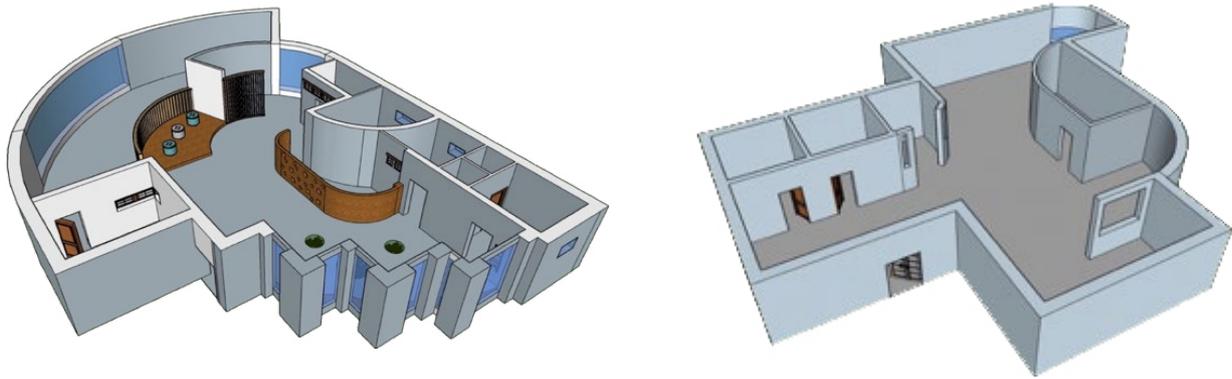


Figure 1: -left- Detail-oriented Model, -right- Global-oriented Model

Procedure

First Phase: Training and Preparation

We wanted to make sure that participants were comfortable with the HMD (Head Mounted Display) glasses and could interact with the virtual environment. During this trial task, we asked the child to look around the VE (Virtual Environment) in different direction and make use of the helmet. Looking around enabled participants to practice manoeuvring in a confined space, individually.

Second phase: VR model exploration

After feeling more confident with technology and use of the HMD, the computer had been switched to the first VE model (Local-oriented space) and participants completed a free exploration task. Firstly we wanted the individuals to navigate through VE by

a remote joystick, but they couldn't use it properly. Hence the experimenter took the control of joystick while the participant gave her commands for navigation until the individual thought he had seen the place entirely. The other model, Global-oriented space, have been presented after that the third phase (Configurational Task) was done for the first model (Local-oriented model) and then we had proceeded same for the other model as well.

Third Phase: Configurational Task: Revealing Participants' Cognitive Map

For this phase we asked participants to arrange the physical model (1/100 scale) of the explored buildings. They had unlimited time to hand out the models. The physical models were consisted of fixed boundary walls and separate interior elements (Figures 2).



Figure 2 : The physical models for configurational task

AVERAGE OF TIME SPENT BY CASES IN VR EXPLORATION TASK

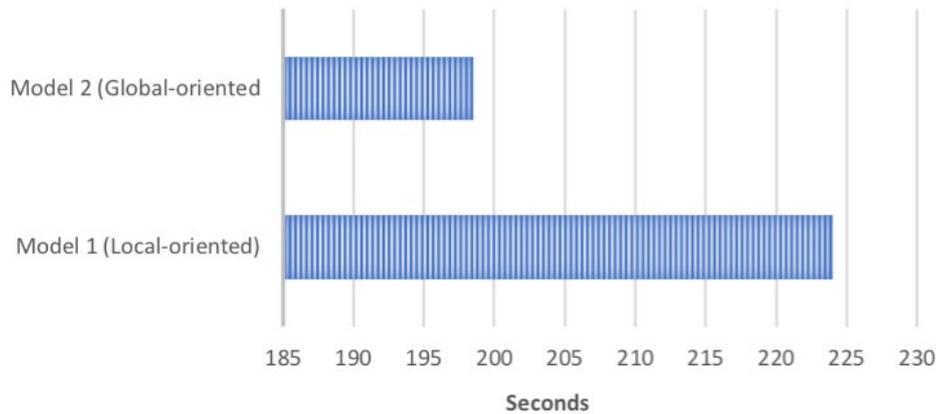


Figure 3 : Average VR exploration time

The data obtained from third task is provided us with the participants' cognitive map and how they perceived the virtual environment. We assigned a name to each of the objects and specified their spatial features such as their displacement profile (difference from the accurate position relatively). Regarding the directional perception, we compared the exact orientation of each objects configured by participants in physical models with their original direction in the VR models (Figure 4). We defined 30 degree as the threshold, meaning that the rotation more than 30 degrees determines a weak directional perception and below that is not significant enough to count as so. The results show that the participants performed better in Global-oriented model (Figure 5).

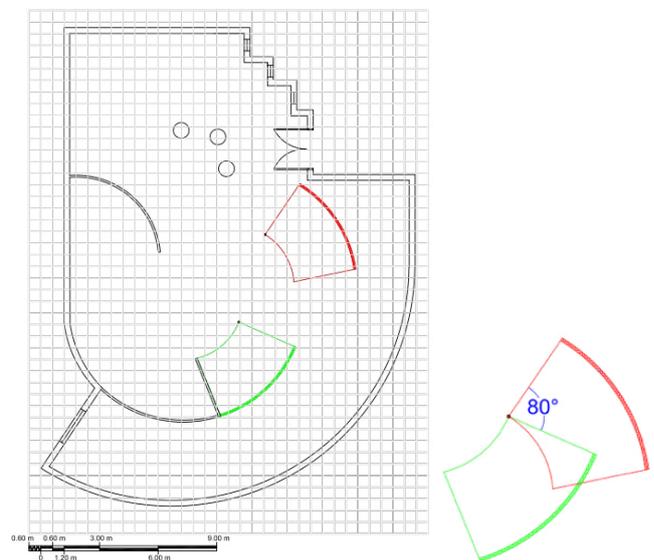


Figure 4 : An example of directional displacement measurement

MODEL 1 (LOCAL-ORIENTED) MODEL 2 (GLOBAL-ORIENTED)

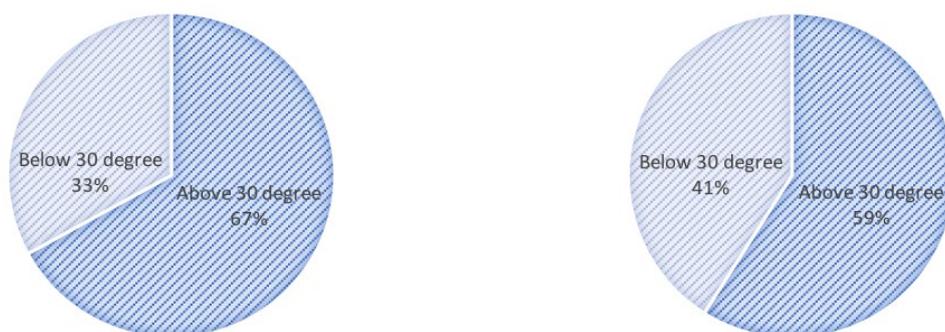


Figure 5 : The participants' directional performance

Location is another part of spatial characteristics. We compared the area of each object's accurate position with its configured position (Figure 6). The final result indicates that participants made more mistakes in terms of location in Local-oriented model.

About the syntactic analysis, firstly we calculated the average integration of each participants' configured models, then we compared their performances. As Figure 7 confirms, individuals configured more integrated space in Global-oriented model. It seems logical since this model is simpler and contains fewer objects inside.

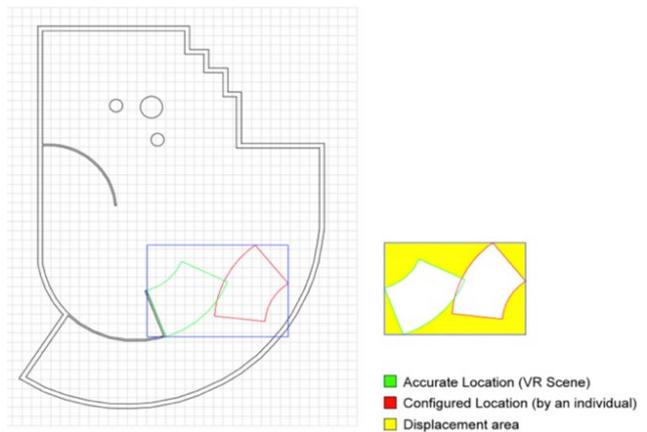


Figure 6 : An example of locational displacement measurement

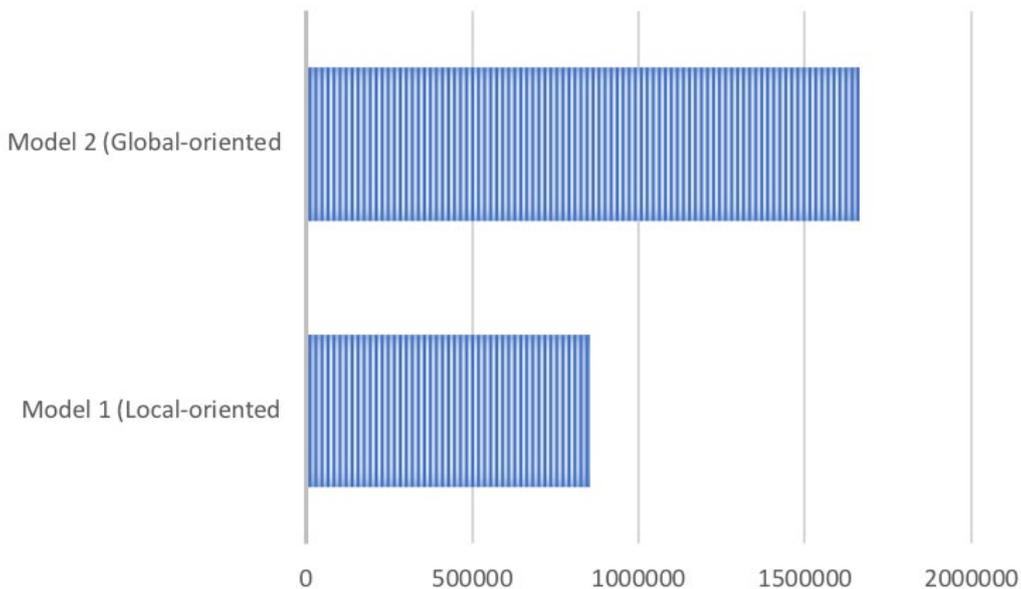


Figure 7 : The average integration

Considering the quality of integration in a space, 'Intelligibility' is arguable. In an intelligible world the correlation between local and global properties of space is perfect, so the whole can be read from the part. Hillier (1996) explains this notion using a Scattergram that shows the correlation between connectivity and integration. He

notes that the degree of intelligibility can be predicted by looking at the form of the scatter (Abdelraheem 2010). In our case the Scattergram of models (Figures 8) both have a positive slope, but in Local-oriented model, the spots are closer to the line than the Global-oriented one, hence it has been configured in a more intelligible way.

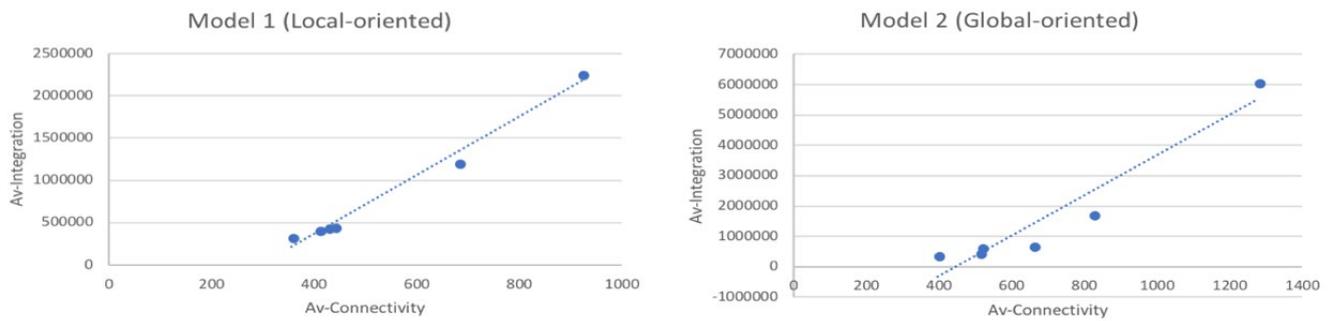


Figure 8 : Scattergram illustrating the relationship between connectivity and integration

Conclusions

In this study, we tried to assess the cognitive map of individuals with autism and how they perceived different environments. The two models, Local-oriented and Global-oriented were the main parts of this investigation. First of all, the participants' explorational behaviour is a significant outcome of the study. Kawa and Pisula (2010) in their research found that in case of individuals with autism, the spatial exploration time decreases when the visual complexity of the environment increase.

Considering their result, we expected the shorter exploration time by the individuals in Local-oriented model since it contains more details inside and in a sense, is more complex. But as a result, the participants spent more time in the complex model rather than the simple one (the area of both models were same). It is in contrast to the Kawa and Pisula (2010) study, but yet it should be mentioned that the difference between the average time of both models' exploration is not that much significant (26 seconds), but still, it has a value.

Accordingly, we may expect that individuals perceived the space better in Local-oriented model; they spent more time there and might perform better in the configurational task meaning an accurate cognitive map formation as well. But the results show something else. Although the participants spent less time to explore the Global-oriented VR model, they did quite better in the configurational task and formed a more integrated and connected plan with fewer

displacement mistakes in terms of direction and location. This is exactly the result that we expected base on the WCC theory.

Following syntactic analysis, we found the higher value of Connectivity and Integration for the configured Global-oriented model. So, based on our hypothesis, the participants formed an inappropriate and incomplete cognitive map for Local-oriented space, confirming that the spatial details and architectural elements doesn't help individuals with autism to form a better and accurate cognitive map; instead, make them more focused on different details and consequently causes to form a segregated cognitive map.

In the end, we should mention that, since in this paper we studied a small group of individuals with autism (n=10), the results are not generalizable, because even with a big population, none of the individuals with autism are same and it is not appropriate for findings to be generalised, but it would be a considerable material for the future works in the architectural discourses involved in well-being discussions.

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DESIGNING FOR AN ACTIVE LIFESTYLE: FACILITATING INTERDISCIPLINARY COLLABORATION

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Abstract

Designing wearable technology to make physical activity an integral and routine part of people's everyday life is a challenge, requiring expertise from different disciplines. COMMONS, a research prototype, is a serious game designed to facilitate interdisciplinary collaboration early in the design process. In this study, we present data obtained from four game sessions with 15 players from different disciplines. By combining objective data from the game with subjective data from a questionnaire, we gained insight into the process of interdisciplinary collaboration.

COMMONS was found to have little effect on the internal views of players. However, the game has a positive effect on active involvement and sharing opinions, also players have a substantial influence on each other when adjusting a point of view. The results seem to suggest that COMMONS facilitates the readiness for collaboration between experts from different disciplines.

Keywords: interdisciplinary collaboration, wearable technology, physical activity, serious games



Introduction

A lack of physical activity and an increase in sedentary behaviour are responsible for major health risks in our society (Kohl et al. 2012). Activity trackers and smartwatches can support individuals in incorporating physical activity in their daily routines. However, the effect of these wearables on sustained physical activity remains minimal (Gal et al. 2018). In most consumer-based wearables a customized approach is not available, and these wearables are often no longer used within six months after purchase (Epstein et al. 2016; J. Clawson et al. 2015). To have a significant impact, the wearable technology must address individual, social, and environmental factors. To this end, interdisciplinary collaboration is crucial because interdisciplinary research and development can promote knowledge, insight, and understanding from multiple perspectives (Kostoff 2006). However, this kind of collaboration is not self-evident and requires focused research (Blandford et al. 2018). Members of interdisciplinary teams often have different research methods and different definitions of key terms. In addition, they may have internal views in which they fully or partially disregard other disciplines, leading to sub-optimal outcomes (Blandford et al. 2018; Thompson 2009).

In a previous study (Arts, Kromkamp, and Vos 2019), we found that the use of serious games is an option for facilitating interdisciplinary collaboration early in the design process. Both games and interdisciplinary collaboration involve rules and strategies, and both require consultation and adjustment of participant positions. As a result, we developed a research prototype, named COMMONS. In this study we used COMMONS: (1) to gain insight in interdisciplinary collaboration in designing wearable technology for physical activity and (2) to facilitate this design process.

Method

COMMONS is a research prototype with components for logging data, such as individual voting behaviour, voting composition, and card positioning. Data are collected by means of voting boxes, RFID cards and readers, and a microcontroller. The game starts with four players being assigned to a team to develop wearable technology focused on a fictional persona which is characterized by a context, goals, motivation, and obstacles to physical activity. To develop effective wearable technology, in which all determinants are addressed, the input of different disciplines is needed. Therefore, the players must have different backgrounds, such as in the behavioural sciences, movement sciences, industrial design, engineering, or user experience design. The game is played with a set of 52 features (cards) divided into four categories: hardware (12), software (11), user design experience (9), and behavioural change techniques (20). Players vote on these features with the persona in mind. The features can be accepted or rejected. However, if there is no consent a discussion round follows. Consent means that a decision has been taken when none of the players present argue or predominantly object to taking the decision. Only when there is agreement is there a decision. When a feature is accepted, players must agree on a ranked position (one to five) of the card on the board. If a discussion round is initiated, the overriding objections must be cleared, and the players discuss their opinions. The final solution consists of the five features that the players determine are necessary for the design.

At various moments, the players must resolve a 'Kairos' card, which is designed to disrupt the game and cause unpredictability. The disruption and unpredictability change the state of the game and requires the players to adapt to the situation. The only way players can handle these cards is by working together. A game session ends after 90 minutes, or when all 52 cards are played. Figure 1 depicts COMMONS.



Figure 1. COMMONS, including four voting boxes, the board with ranked positions, a set of features, Kairos cards, and the persona (Arts, Kromkamp, and Vos 2019).

For this study, COMMONS was played four times with a total of 15 different players (three games with four players and one game with three players). Of all players, 67% were male, and the average age was 34 years old ($\pm 8,7$). The participants had different backgrounds. Six participants had a background in exercise and lifestyle coaching. Six other participants had a behavioural sciences degree, six had a degree in human movement sciences, four had an industrial design degree, two had a degree in user experience design, two had a degree in information communications technology, and one had an engineering degree.

After the game ends, the players were asked to complete a questionnaire. Next to their personal background characteristics (gender, age and expertise), players were asked to rank their opinions on 27 items on a five-point Likert scale, ranging from one (strongly disagree) to five (strongly agree). These items relate to two major themes in interdisciplinary collaboration: (1) shifting

the individual mental model (ten items) and (2) interdisciplinary work (17 items). With regard to the mental model, Mathieu et al. (2000) indicated that mental models serve the three crucial goals of helping people to describe, explain, and predict events in their environment. These internal views are formed by the norms, values, assumptions, beliefs, and expectations of the individuals (Clawson 2002). In terms of interdisciplinary work, it is assumed that different disciplines must cooperate to solve a problem. Influencing each other determines the content. The emergent insights transcend the boundaries of the individual professions (Kostoff 2006).

Results

Game data

The results showed a diversity of accepted features, voting behaviours, compositions, and vote changes. A significant amount of data was collected. We compiled the data that involved the (1) voting compositions,

features, and their unpredictability, (2) resolution within the teams, and (3) vote changes. When the game was played with four players, with three choices per round (accept, reject, consent), there were 15

possible voting compositions per round. Figure 1 shows the total number of the different voting compositions for all four game sessions. In total, 177 rounds were played during the four games.

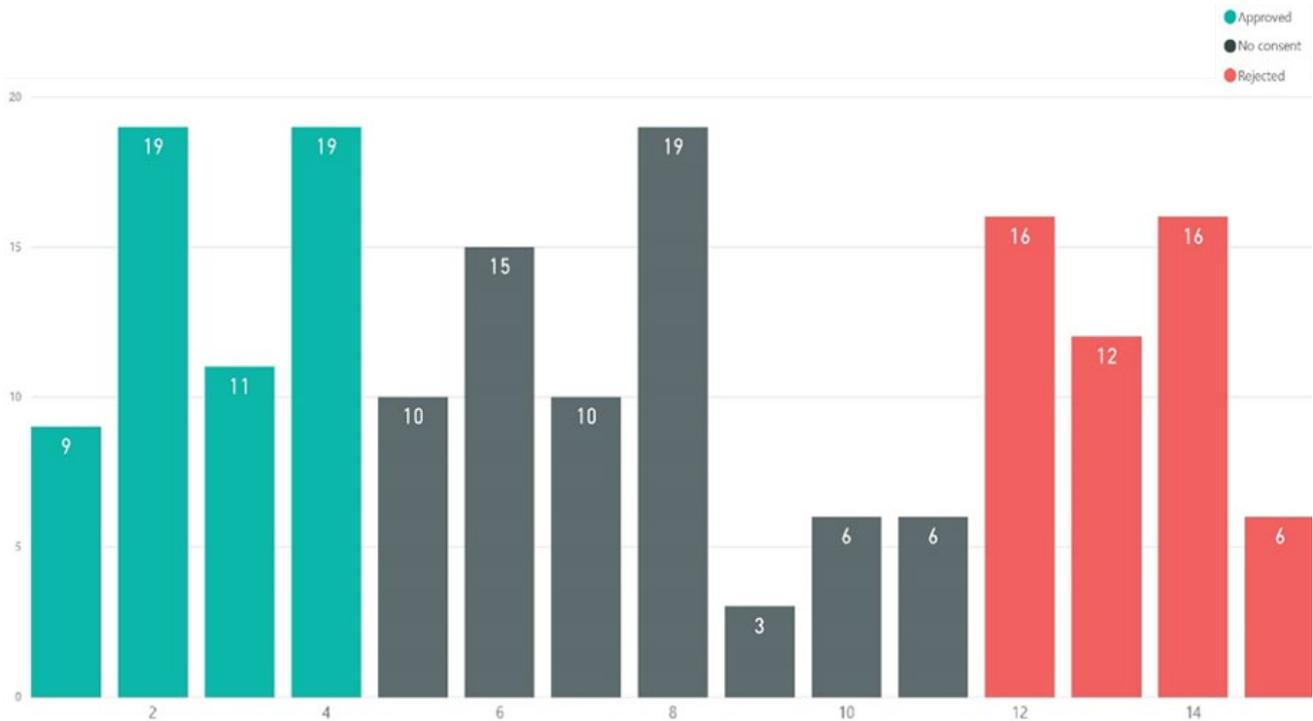


Figure 1. Occurrence (Y-axis) of each voting composition (X-axis) during the first vote (prior to discussion) coloured with respect to the result.

Composition 1-4 (green) means the feature was accepted, 5-11 (grey) denotes no consent (leading to discussion), and 12-15 (red) means rejected. In total, 58 features (33%) were directly accepted, 50 features (28%) were rejected, and 69 features (39%) led to discussion. Of the 177 rounds that were played, 108 rounds resulted in an immediate consent (all players accepted or rejected the feature). As mentioned earlier, 69 rounds ended in a discussion (39%), of which 53 were resolved to consent after the discussion (77%). Only 16 features (23%) did not produce a consent (a discussion remained). Thus, there was a total of 161 resolved rounds (91%).

discussion. After discussion, only 16 features showed that no consent could be reached. In playing the game, these features are placed in the discussion box (no match) to sustain the game flow instead of continuing the discussion. Figure 3 shows the category distributions of these unresolved features.

The amount of discussion within a specific category was diverse. Figure 2 shows that the category behaviour change technique (BCT) led to the most discussion, whereas the hardware category led to the least

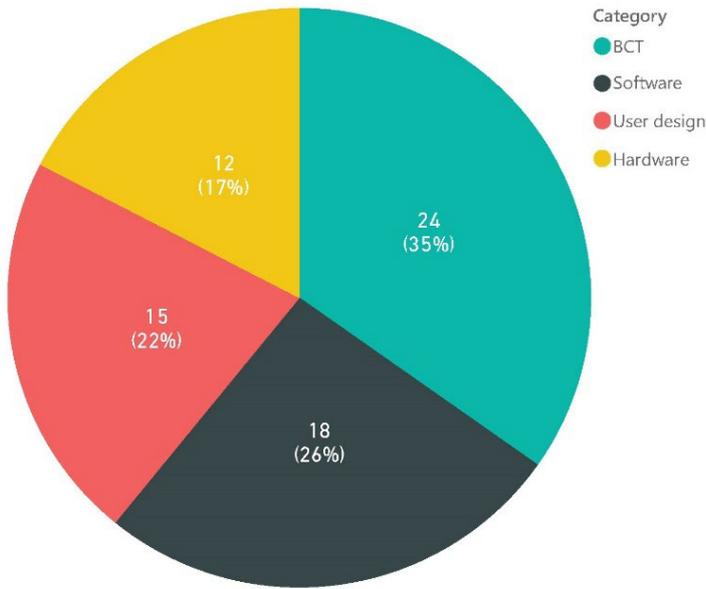


Figure 2. Number of times a feature within a category lead to discussion

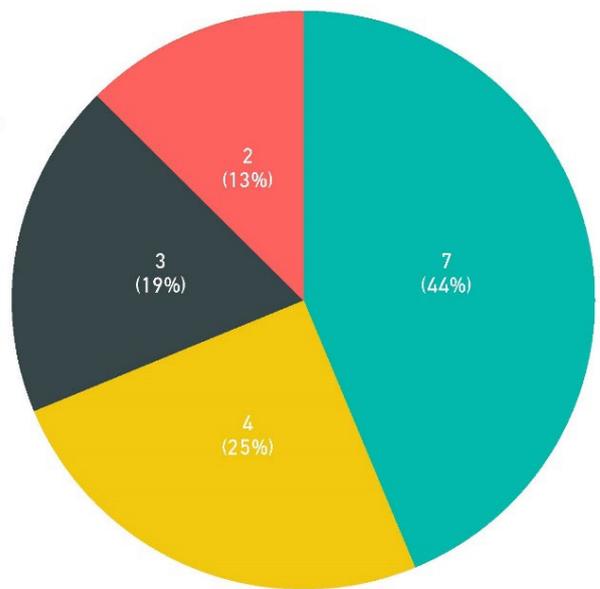
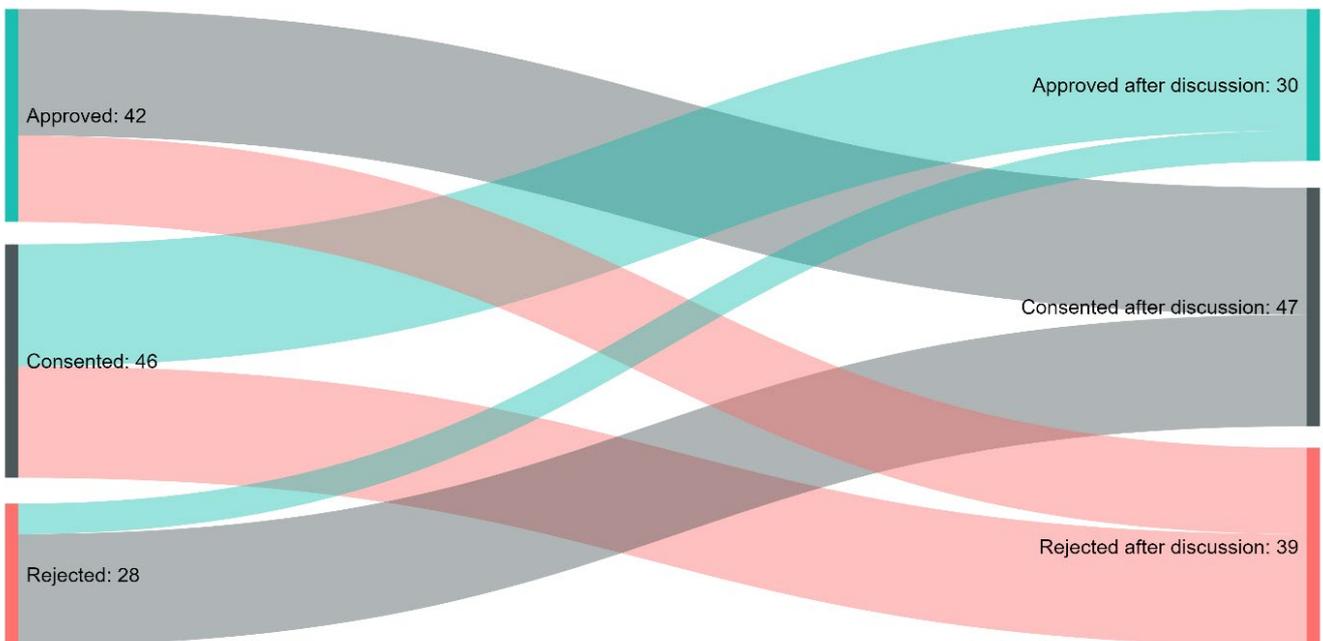


Figure 3: Categories where no consent was reached

A total of 116 individual votes were changed after the discussion. Of them, 93 votes (80%) were changed from rejected or accepted to consent, or vice versa. In addition, 23 votes (20%) were changed from rejected to accepted (six times), or from accepted to rejected (16 times).

Graph 4 shows how vote-changing players changed their vote after a discussion. This graph only includes player votes that changed after a discussion; it thus excludes votes that remained the same.



Graph 4. Player vote changes after discussion (N=116). The width of the streams is weighted by the number of votes.

Table 1. Percentage of participants (N=15) who disagree or agree with the statement or are neutral.

Statement	Disagree	Neutral	Agree
<i>Mental model</i>			
I have gained insight into the arguments of other players	0,0%	0,0%	100,0%
I understand why other players consider other features important	0,0%	0,0%	100,0%
I look at the presented features from a different angle	6,7%	6,7%	86,7%
We better tailor the features to the user (profile)	13,3%	6,7%	80,0%
I've adjusted the importance of certain features	6,7%	20,0%	73,3%
It is clear why my expertise is needed	13,3%	20,0%	66,7%
I got more knowledge of the presented features	20,0%	26,7%	53,3%
I have often adapted to the opinion of the group	46,7%	26,7%	26,7%
I adjusted my vision on wearable technology	46,7%	33,3%	20,0%
I have adjusted images of other areas of expertise	46,7%	33,3%	20,0%
<i>Teamwork</i>			
I could freely express my opinion	0,0%	0,0%	100,0%
I could share my point of view	0,0%	0,0%	100,0%
I was actively involved in the process	0,0%	0,0%	100,0%
We listened to each other's point of view	0,0%	0,0%	100,0%
I had fun	0,0%	6,7%	93,3%
We could brainstorm pleasantly	6,7%	0,0%	93,3%
We have worked well together	0,0%	6,7%	93,3%
We let each other finish sentences	0,0%	13,3%	86,7%
I have more understanding for other people's views	0,0%	26,7%	73,3%
I got to know other areas of expertise and disciplines	13,3%	20,0%	66,7%
I can empathize better with someone else's vision	0,0%	33,3%	66,7%
We have come up with a joint solution	26,7%	6,7%	66,7%
As a team we have a clear direction	13,3%	26,7%	60,0%
We have clarified concepts and definitions	26,7%	20,0%	53,3%
We have created a common language	20,0%	26,7%	53,3%
We as a team have improved our adaptation skills	6,7%	40,0%	53,3%
We have clear idea of what is important in the design process	33,3%	13,3%	53,3%

Players were asked for the main reason for adjusting their vote. The question was multiple choice and players were allowed to give multiple answers. Of the players, 33% indicated that the 'choices of the other players' played a role in adjusting their vote. The following items had a greater influence: 'a new insight into the feature application'

(67%), 'a better understanding of the feature' (73%), and 'knowledge of other players' (73%). The following responses were not listed as a reason to adjust their choice: 'I did not want to vote differently from the group majority' or 'I wanted to remain connected to one of the other players'.

Discussion and Conclusion

In this study we used a research prototype, COMMONS, to gain insight in interdisciplinary collaboration in designing wearable technology for physical activity and to facilitate this process. Insights into interdisciplinary collaboration

Blandford et al. (2018) contended that the differences in cultures, practices, and assumptions among disciplines are subtle but pervasive. The mental model results of our study support this contention. Of the players, 50% indicated that nothing changed in 'their view of wearable technology' or 'view of other areas of expertise'. However, a large portion of participants indicated that their changing view was based on 'new insight', 'an improved understanding', or 'the knowledge of fellow experts'. In the short term, COMMONS may thus change views; however, in the long term, with respect to assumptions, cultures, or beliefs, this effect may be smaller.

The game results provided us with insights on the voting compositions and features, as well as their unpredictability. Almost all voting compositions occurred during the respective game rounds. The overall results of each vote round formed an almost three-way split among 'approved', 'rejected', and 'no consent'. We conclude that, regardless of the team composition, no consent—and thus the occurrence of follow-up discussion—was inevitable and also unpredictable in terms of when this would occur and for what topic. This finding aligns with the conclusion that, if no action is taken, there will be a sub-optimal outcome (Blandford et al. 2018; Thompson 2009). However, it was clear that COMMONS was beneficial in helping teams engage in these discussions.

Regarding changing the vote/position, it is concluded that most of the changes proceed from consent to accepted/ rejected or vice versa (80%). It is thus unlikely that a 'yes' will become a 'no' or vice versa.

Limitations and future work

This study had some limitations, including the small number of game sessions played. Given the specificity of the theme (wearable technology in relation to physical activity), it was not easy to find specialists. Participants were obtained from throughout The Netherlands with very diverse backgrounds. Moreover, all participants indicated that they had multiple areas of expertise. Thus, they were already accustomed to extending their perspective and obtaining a broad view. Consequently, the results may have been more positive than when the game is played with individuals who are accustomed to working only within their own discipline. Future work should demonstrate how COMMONS works in interdisciplinary teams developing wearable technology for physical activity.

Conclusion

In conclusion, by means of our game COMMONS, we not only gain insight into interdisciplinary collaboration, but also identify a method to support and promote such collaboration.

Acknowledgements

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CO-DESIGN STRATEGIES FOR MERGING EVIDENCE-BASED AND EXPERIENCE-BASED INPUT IN A HEALTHCARE CONTEXT

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Abstract

We present a co-design case study in which we worked with cancer patients and oncology nurses to co-design an eHealth intervention focused on training self-compassion. Reflecting on our case study we show how in co-design both evidence-based and experience-based input figure in the process, especially in complex design contexts such as eHealth design. The question is how to act when such input seems to suggest conflicting design requirements. On the one hand, designers may be inclined to favour requirements based on scientific evidence, in order to increase scientific validity of the final intervention. On the other hand, a human-centred perspective suggests to favour the lived experiences of users, in order to increase the likelihood of technology adoption and sustained use. Successful integration of both types of requirements would lead to synergetic design that is based upon the assets of both sources of input. In this study, building on known theories in design, we offer four concrete and practical ways to accommodate both

top-down and bottom-up input in co-designing eHealth. The strategies are: selecting (prioritizing one type of input over the other), combining (satisfying both types of requirements by giving the user freedom of choice), integrating (designing a new, coherent functionality that satisfies both types of requirements at once) and reframing (revisit basic assumptions and redefine the design challenge in such a way that the apparent conflict dissolves altogether). We give examples of each strategy drawing on our case study. These practical strategies add to the health designer's toolbox, contributing to effective co-design with patients and healthcare professionals, that goes beyond mere product evaluation and respects both evidence-based and experience-based input. Further research could investigate the utility of these strategies in other healthcare-oriented design contexts.

Keywords: co-design, eHealth, oncology, evidence-based, experience-based



OMNIVISI EARABLE: CONTINUOUS AND NON-INVASIVE MONITORING OF VITAL SIGNS

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Abstract

In the Maastad Hospital Department of Surgery in Rotterdam, two types of patients undergo an abdominal surgery: 1) mobile obese patients 2) patients with cancer. These types of patients need personal contact and guidance, especially patients with cancer. However, nurses are overwhelmed with work and utilize a great amount of their time to measure the vital signs of patients three times a day. These vital signs are: heart rate, blood oxygen level, respiration rate, tympanic temperature and blood pressure. The current method of measuring the vital signs is highly inefficient and vulnerable for human error. Additionally, there is a lack of an alarming system that can notify nurses when patients' health condition deteriorates. There are existing wearable devices in the market but those are not able to measure all aforementioned vital signs. Additionally, these devices do not fulfil the needs and wishes of the user group. The aim of this study is to design a wearable device that is able to continuously and noninvasively measure vital signs of the patients, considering

the level of comfort for patients and level of user-friendliness for the nursing staff. Different research and design methods are applied to gain insight in the context of use, users, stakeholders, human factors, technology and organization. These insights are synthesized in different concepts. From these concepts the most innovative and suitable solution the so-called 'Omnivisi Earable' concept is selected. Omnivisi Earable is the product ecosystem proposal of this study. It is a compact and wireless wearable that is able to continuously and non-invasively measure a patient's vital signs. Due to lack of wires and extra modules, it can be easily attached on the patient's body. The organic form of the Earable provides high comfort for patients. The time saved to manually measure patients' vital signs will be used for personal contact and guidance of the patient.

Keywords: health data, human factors, continuous monitoring, human centred design, wearable, vital signs, participatory design, medical device, e-health.

Introduction

Department of Surgery Gastroenterology (GE)

The Maastad Hospital is a teaching hospital which is based in Rotterdam South. It has 600 beds and every year more than 450,000 patients receive a medical treatment. Department of Surgery Gastroenterology (GE) is one of the departments at the Maastad Hospital. In broad lines, every department has 32 available beds that are divided into 16 individual rooms and four wards. In this particular department, patients recover after they undergo abdominal surgeries. These surgeries can be divided in two: 1) General

abdominal surgeries, including bariatric surgery; 2) Oncology related surgeries. The provided care for this group of patients is considered complex, especially patients with cancer, since they need continuous monitoring of their health condition, more personal contact and support. However, nurses are overwhelmed with work. An in-depth study showed that nurses spend 2.5 hours per day on measuring patients' vital signs to assess their health condition in the department (Aydin 2019). In current practice, different medical devices and methods are used to monitor three times a day the following vital signs: heart rate, blood oxygen level, respiration rate, blood pressure and tympanic temperature (Figure 1).

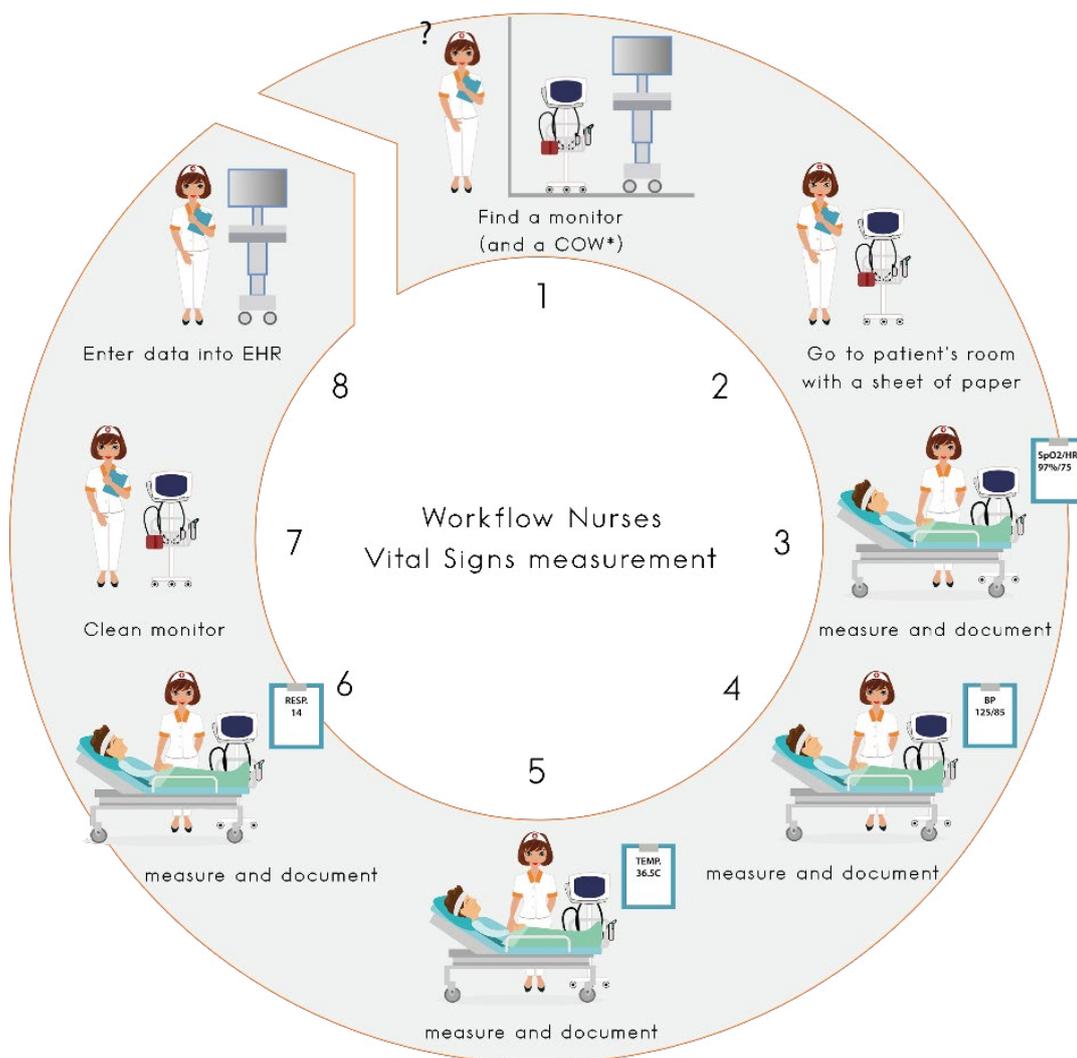


Figure 1: Workflow of nurses

With the use of Modified Early Warning Score (MEWS), a clinical scoring system, physiological changes can be documented and medical staff can act upon it if necessary. This scoring system shows relevant information about the health condition of patients. However, due to the limited amount of measurements per day, it is possible that medical staff do not detect patient deterioration in time. This is especially the case at night when the majority of patients are not measured. Additionally, there is a lack of an alarm system that can notify nurses when a patient's health condition deteriorates. Hence the current method is highly inefficient and also vulnerable to human error. Digitizing the current measuring method with a wearable system with integrated biosensors is a possible solution.

Aim of the project

For this project, the Basic Design Cycle model (Roozenburg & Eekels 1995) was used in combination with the Participatory Design methodology (Dorst 2006). The project's main objective was to design a wearable device that has the following characteristics: 1) It should measure all aforementioned vital signs in a continuous and non-invasive way; 2) It should provide high comfort for patients; 3) It should provide a high level of user-friendliness for nurses, meaning that their performed actions are minimal. Digitizing the current method has several advantages. It will increase nurses' work-efficiency and save time that can be utilized for patient contact and guidance. Additionally, nurses can intervene at an early stage when small changes in patients' health condition are detected. By doing so, it can prevent a patient's health from worsening and also prevent transfer to intensive care unit (ICU), reanimation or even mortality. Admission to the ICU is also more expensive compared to the other departments in the hospital. Lastly, it could decrease the high and demanding workload of nurses.

Research methods

Analysis

Several research methods were utilized to collect information during the design process. A benchmark study was performed to evaluate current wearable devices and systems for medical applications in the market, and to determine the shortcomings of these products.

A field study was conducted in order to collect data from users and its context. Patients, nurses and specialists were interviewed to analyse their needs and wishes regarding the wearable device.

Shadowing was performed in order to observe nurses' work process when they are measuring the vital signs of their patients. During this observation method, the pain points of both patients and nurses were collected. In addition, a literature study was carried out regarding the used technology and methods of measuring the vital signs in a continuous and non-invasive way. Although the benchmark study already provided some information about the technology and used methods, it was not sufficient to fully understand the science behind it. In clinical settings, heart rate and blood oxygen level are measured with the finger pulse oximeter sensor with photoplethysmography (PPG). This particular sensor can be placed anywhere on the human body where the artery is close to the surface. These areas are known as pulse points, however, other areas on the body are also possible, such as the finger, auricle and earlobe. Respiration rate can also be measured with a PPG sensor in three different ways by analysing the respiratory-induced variations in amplitude, intensity and frequency.

The standard for accurately measuring the blood pressure is using cuff-based systems. However, these systems cannot continuously measure in an unobtrusive manner. Additionally, it is difficult to integrate these in a universal vital sign

monitoring system. As alternative methods pulse transit time (PTT) and pulse wave velocity (PWV) are proposed and discussed. Both can serve as an indirect measurement of pulse pressure. PWV has several advantages over PTT. For instance, PWV only uses two PPG sensors that must be placed between two predefined locations (Velzen et al. 2017), while for PTT more equipment is required.

In order to continuously measure the body temperature, it was decided to focus on tympanic- and axillary temperature. The level of invasiveness for the other methods, such as rectal or oral temperature, were too invasive and impractical for patients.

Additionally, skin temperature is not reliable for continuous monitoring due to external factors that can affect the measurements. Possible areas to place the PPG sensors were scored based on predefined criteria, such as reliability of measurements, comfort for patients and level of hygiene.

Based on the benchmark study, it was concluded that current wearable devices for medical applications cannot measure all five vital signs that are needed for a complete MEWS. Additionally, most of these wearables are not user-friendly, due to high amount of actions that must be performed by the user group to use the wearable device (Figure 2).



Figure 2: User-friendly vs Completeness diagram of current wearable devices for medical use

Wearables were designed to increase work-efficiency and facilitate a more efficient use of nurses' time. However, it can cost nurses significantly more time to install and maintain when using these wearable devices.

Several requirements for the wearable device were created based on the insights from the conducted interviews with patients, nurses, client and experts (Aydin 2019). All these insights were synthesized in different concepts.

Results

Conceptualization

Based on the insights from the analysis phase, six different concepts were generated that are in line with the design vision. All concepts were evaluated with the Harris Profile and Weighted Objectives method (Daalhuizen et al. 2014). These concepts were also discussed with patients,

nurses and experts (Aydin 2019). In a conversation with clinical physician (S. Niehof, personal communication, November 21, 2018), it was concluded that PPG sensors are limited to measure areas with excessive fat. Considering the fact that part of the patients suffers from obesity, some areas, including the arm, would not provide reliable measurements. Therefore, Earable v2 concept was selected for further development (Figure 3).

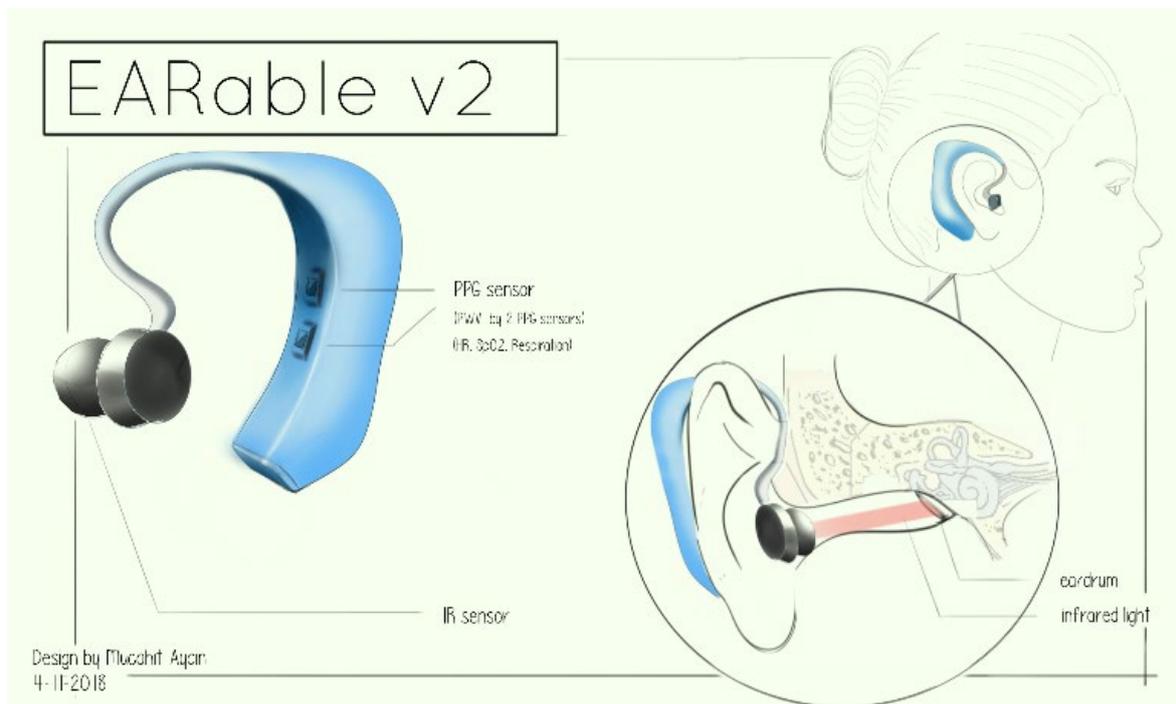


Figure 3: Earable v2 concept

Compared to the other five concepts, Earable v2 would provide more reliable measurements of patients' vital signs and a higher level of user-friendliness for nurses. This concept does not require any extra modules or wires. Due to this, it can easily be attached on patients' body by nurses and it will not limit the movement of patients. This concept uses an infrared sensor and two photoplethysmography (PPG) sensors to monitor all aforementioned vital signs. The infrared sensor monitors the tympanic temperature. The two PPG sensors serve to monitor the heart rate, the blood oxygen level and respiration rate. From the difference between the sensor signals, the blood pressure variation can be obtained by using PWV.

Prototyping: Ergonomics and Electronics

In order to accomplish a high level of comfort, and to obtain strong reliable signals from the ear, proper contact between the wearable and the external ear is essential. However, the relevant data regarding the curvature behind the ear was not available and it was not possible to directly scan the back of the external ear with the handheld 3D scanner Artec Space Spider (3D scanner of metrological accuracy, Artec 3D, Luxembourg). Therefore, we created hand-made ear models using polymorph (Figure 4).



Figure 4: Hand-made polymorph ear models

This material can be formed and reformed after being heated. After scanning all models, the 3D data were processed with the software program R3DS Wrap to create an average model in 3D (Russian 3D Scanner, Russia). In order to test the level of comfort with potential users, the average 3D model was 3D printed in Polylactide (PLA) with the Ultimaker 2 (single extrusion 3D printer, Ultimaker, the Netherlands). The selected participants for the user-test were healthy and were acquaintances or fellow students. They were asked to wear the 3D printed model as long as possible, while they were performing their daily activities, such as working, studying, walking or lying. In total 10 participants (aged between 24 and 54 years old) were involved in the test.

On average, the 3D printed ear model was worn for five hours. The participants scored the comfort level on average with a 3 (1=not comfortable at all, 5= very comfortable). Only three participants felt discomfort after two to three hours. Their experience was the 3D printed model became 'heavier' over time. The other seven participants did not experience any discomfort while sitting. However, they did experience some annoyance when walking. This was due to the slightly moving 3D printed model. The insights gained from the user-test were used to improve the 3D model.

In order to show that the concept could work, a proof of concept was created with available electronics and the data was real-time visualized on the laptop (Figure 5).

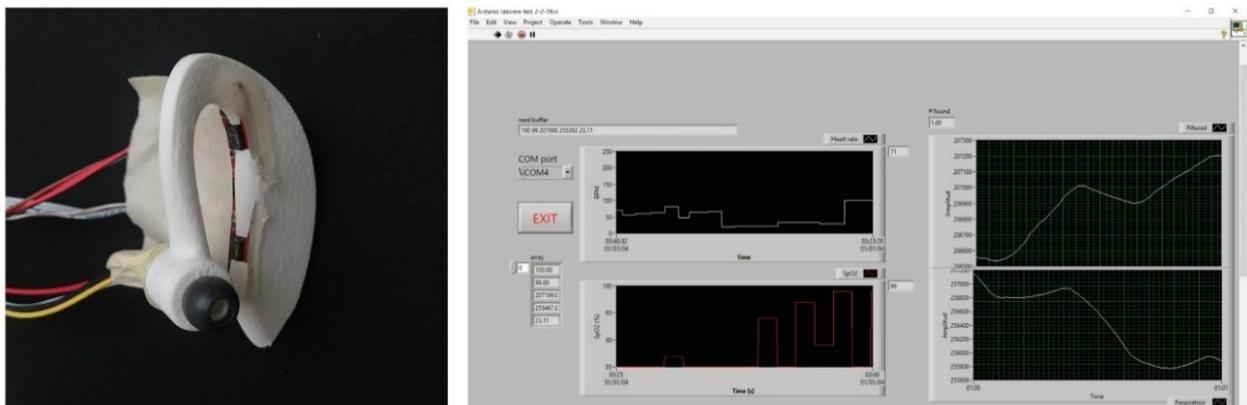


Figure 5: Left: Proof of Concept. Right: Visualizing real-time data with Labview

The proof of concept was created by using a 3D printed model, two pulse oximeter sensors MAX30105 from Sparkfun and a temperature sensor MLX90614 from Melexis. Arduino, an open-source prototyping platform, was used to obtain relevant data from the sensors. Labview, a software design and development platform, was used to process the signals in real-time and to eliminate false measurements. By combining both software platforms,

it was possible to visualize the following data in real-time: heart rate, blood oxygen level, tympanic temperature, respiration rate, indirect blood pressure measurement (PWV), IR signals from both sensors and MEWS score based on heart rate.

Final Design

After an iterative process of prototyping, a final design was proposed: Omnivisi Earable (Figure 6).

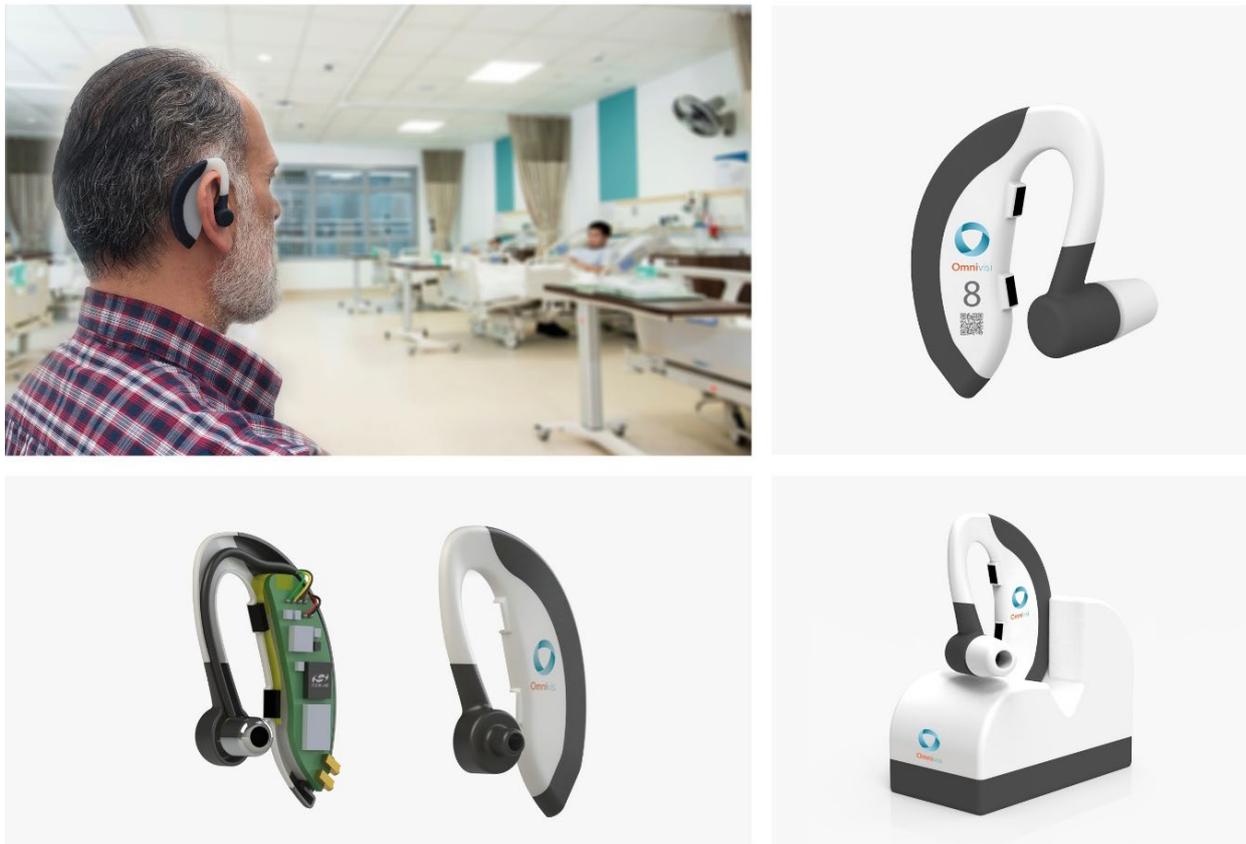


Figure 6: Omnivisi Earable device

This wearable device is part of a bigger product ecosystem that consists of the following components: 1) A Bridge that can wirelessly transfer data to the server; 2) The server and back-up server; 3) An application that is used on a medically certified mobile device and a personal computer. The lack of wires and extra modules make this wearable user-friendly and it enables patients to freely move within the hospital. The integrated 3-axis accelerometer can count the steps of patients. By doing so,

nurses have better insight into the recovery process of their patients and nurses can even encourage them to walk more often. Nurses can check patients' vital signs on a mobile device and analyse the data further on a personal computer. When the vital signs exceed its boundaries determined by the clinical scoring system MEWS, nurses are immediately notified about their patients and can intervene at an early stage (Figure 7).

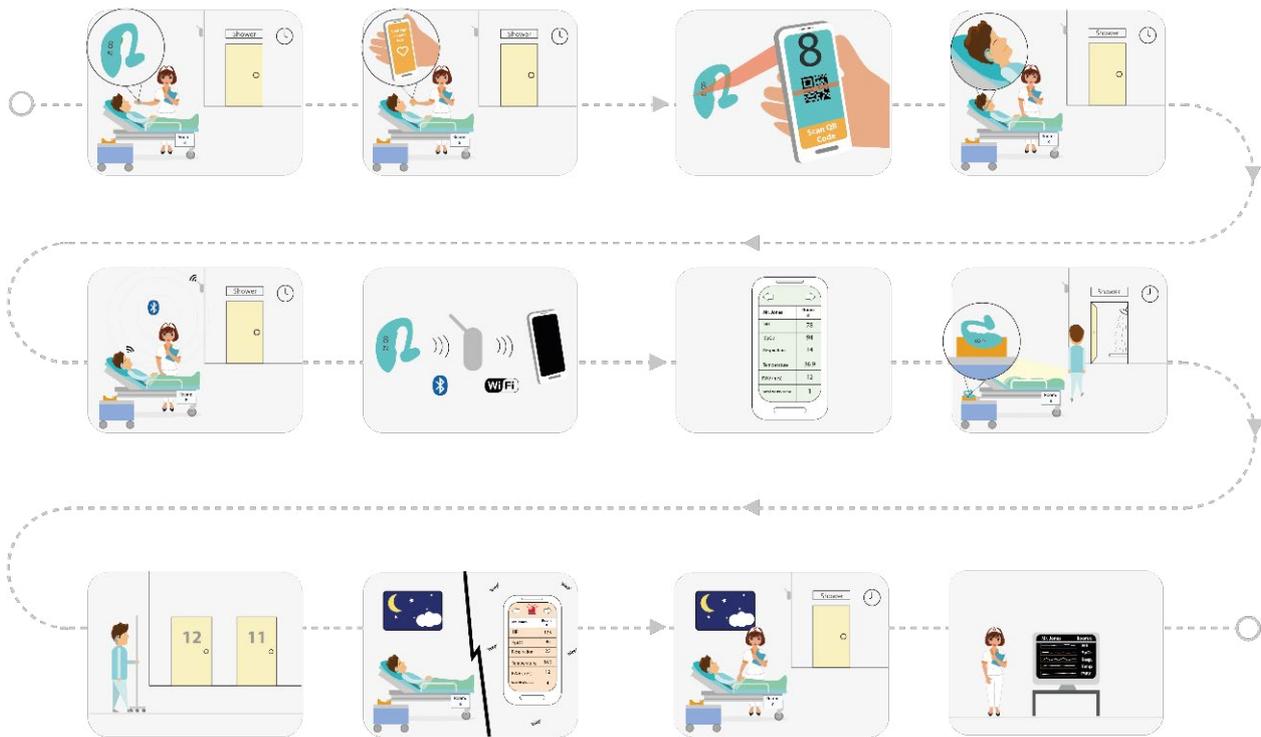


Figure 7: Storyboard of Omnivi Earable device

Since patients' health condition differ from each other, qualified medical staff are allowed to customise the limits of each vital sign. When connection is lost with the Bridge, the integrated memory is able to save the data for several hours. As soon as the connection is established, the data can be transferred to the server.

Discussion and Conclusion

During this study, a functional first prototype of a wearable device capable of monitoring the five vital signs was developed. Moreover, an ergonomic model is designed that could provide comfort for patients. In order to further develop the prototype, several aspects of the final design require more exploration and research. A possible next step would be improving the ergonomic shape of the wearable. This can be accomplished by including more polymorph models. For the average 3D model, only ten polymorph models were used. According to Dr. Huysmans, assistant professor Applied Ergonomics and Design Delft University of Technology, 50 models are needed for this type of applications. Moreover, it is

recommended to create multiple sizes for the wearable. One size designed for people with small ears and one size designed for people with average and large ears. By doing so, high comfort for patients can be ensured.

In addition, the placement of the sensors on the human body should be explored in more detail, focusing on accuracy and reliability. There existing products in the market that uses a PPG sensor in the ear to monitor the vital signs. This area could also be interesting for the wearable device.

The chosen PWV method to continuously and noninvasively measure the blood pressure with biosensors should be studied in more detail. A coordinated study is required to validate PWV as a parameter for indirect measurement of blood pressure and how this value is related to blood loss. Research has shown that PTT can be a useful indication for the detection of blood loss at an early stage. Since PWV and PTT are inversely related, it is possible that PWV can indicate blood loss at an early stage as well. This information is essential for medical staff after a surgery.

When a fully integrated prototype is designed, a pilot study can be initiated to research whether the wearable will: 1) Provide high comfort for patients during their hospitalization period; 2) Be user-friendly for nurses to install the wearable; 3) Provide accurate and reliable measurements in accordance with medical regulations. A second pilot study can be initiated when the complete product ecosystem is designed. By doing so, it is possible to research the long-term effects on healthcare, for instance whether the system will reduce costs of care or not. It is expected that nurses will save up to three hours on a daily basis. This time can be used for personal guidance and contact of patients, contributing to a better care.

This wearable device may have potential to be used in non-clinical settings, such as home care. More research is required how this type of wearable can be used by elderly or by patients who do not need to be hospitalized. Monitoring patients outside the hospital has many benefits, such as: 1) Encouraging independency; 2) Reducing costs of care; 3) Increasing work-efficiency.

Acknowledgements

We would like to thank the medical staff and the patients of the Maasstad Hospital for their contribution to the project and the participants for their involvement in the study.

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CO-DESIGN FOR SOCIAL CARE SERVICE SYSTEMS: ALIGNING BETTER TO OLDER IMMIGRANT COMMUNITIES

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Abstract

In the coming decade, the older ethnic population in the UK is set to double. This significant change in demographic and the overall growing number of older people are expected to be two of the greatest social challenges we will face (Zeeb, Rothgang, & Darmann-Finck, 2018). Research shows that conventional care for older immigrants across the UK remains inaccessible. Complex administrative systems, negatively impacting bureaucratic processes and a lack of knowledge of the existing care structure are just some of the obstacles older immigrants face in dealing with state care services (Ahaddour, van den Branden, & Broeckaert, 2016). Often evading dealing with the state altogether, this user group rely heavily on word of mouth and informal family care. These factors are shown to negatively impact on the construction of the 'self' - the lack of control and agency within a service context heightens feelings of anxiety and vulnerability (Anderson et al., 2013). This study seeks to use co-design as a means to help strengthen the citizen-state relationship and cultivate community engagement in service design by providing a knowledge of existing structures and a sense of

working together (Miller & Hamilton, 2008). Overall, participation is shown to strengthens the role of the citizens, which is identity-establishing and is seen as a part of positive community development towards citizen integration (Mueller, Lu, Chirkin, Klein, & Schmitt, 2018). A systematic review of literature and expert interviews aim to shed light on the service experience of non-native peoples, uncovering barriers in service design that impact on this often-overlooked user group. Whereas, an exploration of the UK public service system structure helps reveal challenges in system development. Additionally, a comparative case study approach of co-design projects shows best practice and makes some initial recommendations for system improvement, as well as strategies for better care service appropriateness and the overall consideration of user needs. This paper forms part of a larger study that explores co-design as a method for improving the overall system of care, helping service designers consider more effectively the needs of older immigrants.

Keywords: service design, systems design, co-design, older immigrants, social care services



COLLABORATIVE PRACTICES THROUGH DESIGN AND SOCIAL SERVICES: THE PHASES OF A COGNITIVE STIMULATION PILOT PROJECT

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Abstract

This paper describes the progress of a pilot project developed through a collaborative methodology within vulnerable communities in the Lisbon district (Portugal). As part a PhD research, this study intends to demonstrate how the multiplicity of actors from different branches facilitates the implementation of innovative projects. The question 'Can the introduction of design into social services make them more efficient?' was the spark for the case study. In collaboration with social services intervention units as a participatory practice, an experimental tool for therapeutic purposes and cognitive stimulation was designed focusing in two public targets namely, one group within the age group over 65 years with mild cognitive impairment (MCI) and the second group with cognitive deficit and declining age. The designed tool is being applied in several institutions, where the capacity for description, assimilation, and interpretation is established between two actors, the patient and the health professional. Psychomotor stimulation and memory retrieval motivate new topics of discussion and conversation

providing greater dynamics in oral communication and the exercise of different types of memory, encouraging its use in a logic of prevention and simultaneous intervention in training and cognitive stimulation. The gameplay was adjusted according to the proposed needs for the interaction activity of targeted public. The participatory design approach enabled social agents to learn more about their patient's lifetime and memories and served as a basis to accelerate the acquisition of relevant information about the patient's cognitive state and ageing. In this process, 7 entities including day centres and development associations embrace the project with the intervention of Therapists, Psychotherapists and Psychologists, impacting approximately 50 patients. Afterwards, health specialists were questioned, allowing us to conclude that the game was well accepted and that the results showed the relevance of the study and chosen methodology.

Keywords: co-design · collaborative methodologies · healthcare · active ageing · social innovation · sustainability

Introduction

According to the National Statistics Institute (INE), almost half of the Portuguese population will be over 65 within the next 60 years. This is at a time when Portugal was classified by the World Health Organization as being at the bottom of Europe's list regarding the treatment of their elderly people, which is particularly alarming since more than 45,000 elderly people were identified last year as living alone or in isolation, and data from 2016 shows that about 40% of the over 65 are alone during 8 or more hours day (Instituto Nacional de Estatística 2019; National Geographic Portugal 2019). That is, almost one million elderly people are in solitude or isolation, which according to Nunes (2017) citing Zimerman (2010) and Gonçalves (2012) potentially leads to disinterest in life and depressive states that can be fatal.

The mild cognitive impairment (MCI), corresponds to a pre-dementia phase in most cases, as an intermediate phase between normal aging and dementia being associated with an increase in the prevalence of chronic diseases, reflected on behavioural and psychosocial factors. (Petersen et al. 2009)

The intervention approach defined for the development of a project that responds to the needs of the most vulnerable groups and communities of social exclusion, is based on a pragmatic and participatory approach through the collaboration of different sciences supported by an advanced overview of the problems for the development of a proposal.

Related Work

The World Health Organization (WHO), in 2002, addressed the concept of active aging as the process of optimizing opportunities for health, participation and security in order to enhance quality of life in individuals and population groups. It allows people to realize their potential for physical, social, and mental wellbeing throughout their

life course and to participate in society according to their needs, desires and capabilities, while providing them with adequate protection, security and care when required.

Existing literature verifies that the application of mind games and stimulation with ludic activities and the use of images and photography are added value to keep a healthy life, enhancing and awakening their mind (Carvalho 2009) (Pires 2012).

In essence, Zimerman's (2000) research argues that training programs which involve the creation of playful games, triplicate stimulation on the individual, at the physical, psychic and social level. Stimulating the mind, reasoning and memory through the handling of objects, promotes physical involvement into the task, becoming a useful tool for professionals in contact with the elderly.

The aim of this study is to analyse the outcome of a collaborative methodology by integrating design procedures into social intervention with sociologists and psychologists in order to improve and update current therapeutic sessions (fine arts practices, dramatic expression activities, and others) and consequently collect more information on the state of health of patients when applied. The impact of the design intervention in the development of new tools to improve social services efficiency.

Cocreation Methodology

The work developed previously with some of the entities that operate in the field, enabled the development of a sequence of procedures to develop a new perspective of intervention (Bernarda et al. 2018). The entities collaborating in the application of the game belong to different areas of Social Development indicating the relevance of the study which aims to demonstrate that the design discipline is a relevant tool for organizations with a significant role in social action.

Design Approach

The design approach for the decision process was a participatory action research, with the purpose to describe and understand the phenomena. The joining of a researcher in the process was approved by stakeholders or members of the organization seeking to improve their patients' condition. Embracing the creation of knowledge as an active process, Design Researcher, Stakeholders and Patients, together, contribute to the acquisition of knowledge in all phases of the investigation. (MacDonald, 2012) The questions to be answered are: a) *'Considering an interdisciplinary approach, is it possible to develop a collaborative methodology in social services based on a set of new procedures with Design?'* and b) *'Interdependent operations and responsibilities distributed among all stakeholders increase the sharing of knowledge?'*. With a practice-led research, new and open understandings are expected regarding design practice, on its own, and with the other disciplines involved, in a collaborative environment. (Muratovski 2015) The phases of design process were defined on a multidisciplinary process, following the essential procedures of interdependence, flexibility, common objectives and collective ownership of goals. (Bronstein,2003) The reviewing and analyses of some of the processes integrated in the practices of intervention and elaboration of social projects by stakeholders highlighted strategic moments of openness for the integration of design. (Serrano 2008; Robertis 2011; Reznick 2016) (Fig.1)

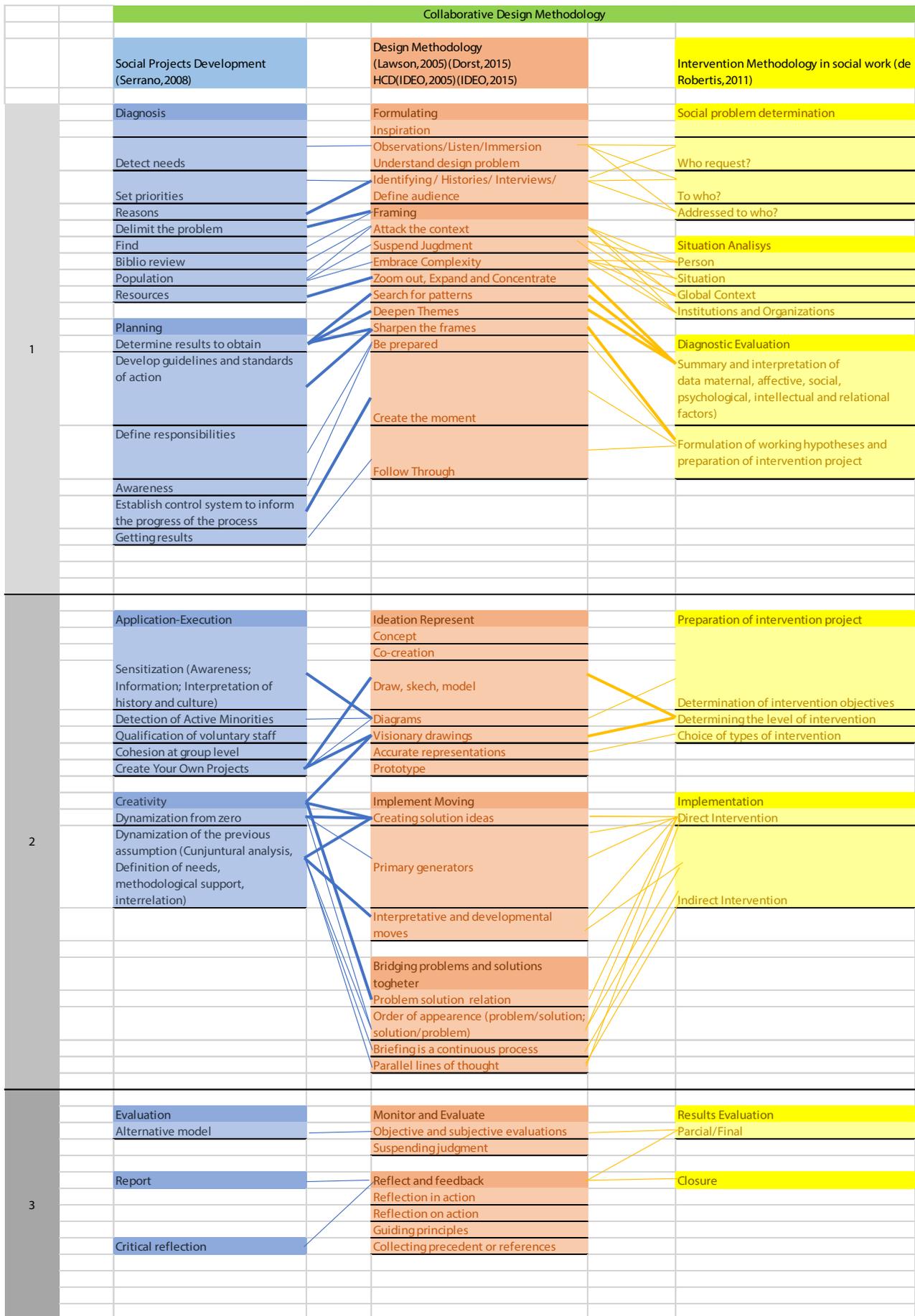


Figure 1. Collaborative interactions

The design process was based on Lawson's (1980) methodology (First insights, Preparation, Incubation, Illumination and Verification) and Dorst (2015) frame innovation approach to design-led innovation combined with Human centred design processes which facilitated their integration and acceptance (Lawson 2005; Dorst 2015; IDEO 2015).

First Insights

In collaboration with Estrela Parish Council (Lisbon) and with stakeholders of the same Social Commission with focus on social care including daycentres and retirement institutions, it was possible to identify some local situations of social vulnerability, highlighting firstly the elderly. A pattern of cognitive and memory dementia resulting from depressive causes due to their isolation has been identified in some residents who are accompanied by home visits from psychologists and therapists (Nunes 2008).

Preparation

The participatory workshop with the stakeholders revealed the problem, the type of the individual's situation and diagnosis, where the knowledge about the target was collected and organized to trigger project development and implementation stages (Bernarda et al. 2017). A first activity based on the use of personal photography's was proposed, because family is a common theme. The user and the therapist engaged in a dialogue exploring visual memory, emotions to stimulate of new topics of conversation, providing a greater dynamic in oral communication. (Fig. 2)



Figure 2. Memory Game

As it was stated by Fernández-Ballesteros (2009) activities that stimulate cognitive activity have a positive effect on cognitive functioning and are a protective factor against cognitive impairment.

Incubation

The first activities demonstrated that photographs were a good bridge to get into intimacy (lifetime, human relations and emotions); however, the substance of the details exposed were still peripheral. This report demonstrated some weaknesses by creating a format that only allows the use of passport photos and in order to overcome a situation that raised the development of a more multifaceted game.

Illumination

This new approach where specialists and patients actively participated on the prototype development allowed the user to explore in a more detailed and broader way the use of photography increasing the player's interaction with the specialist and with the game itself. After the implementation of each project, the evaluation of the results was necessary to identify changes in the various factors (material, emotional, social, psychological, intellectual and relational) that were fundamental to the planning of the next activity.

Verification Process

CASE STUDY: Cognitive Stimulation Sliding Puzzle

The co-development of the previous projects gave rise to the construction of a more operative solution for its complexity, design and versatility to be adapted to patient cultural context, which, as has been proven to be more effective and less limited (Pombo et al. 2016) A game was materialized for therapeutic purposes and cognitive stimulation on a first instance for an age group over 65.

The practice of the game is intended as a psycho-motor incentive and a speech 'unlocker' for personalities with a more withdrawn and closed posture encouraging their use in a logic of prevention and simultaneously intervention. The gameplay consists in the interaction (omission-disclosure) of sliding pieces over a photography. (Fig.3)



Figure 3 -Cognitive Stimulation Sliding Puzzle Prototype (full image)

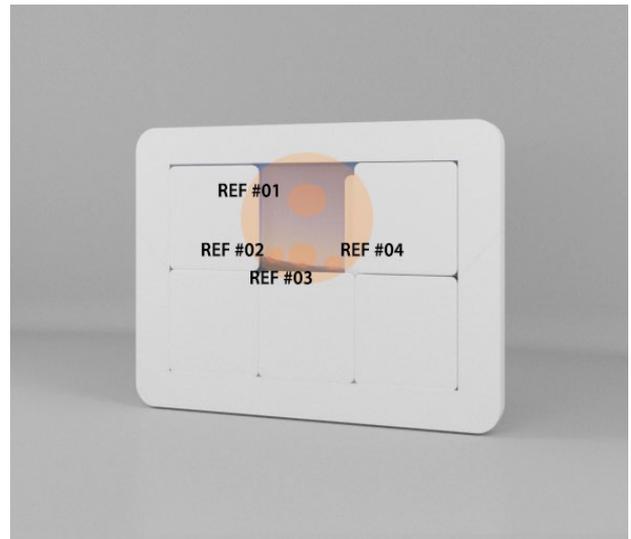


Figure 4 -Cognitive Stimulation Sliding Puzzle Prototype (full pieces)

This game differs from the previous version by exploring the image that consequently triggers the verbalization and an increased description of the same. The image is presented in only one portion and it is up to the user to slide the pieces to add information to all the visible spaces, step by step, enabling the capacity of a combinatorial construction of separate details to build the total image in his mind. This exercise enhances a more careful analysis of each portion (1/6) of the image and can even analyse the spatial magnification capacity of the single detail display (fig.4).

The procedure explores inductive reasoning aptitude, measuring how the patient can identify a pattern of similar information within a certain amount of data following logics when deducing principles from a gathering of facts. Inductive reasoning games are a common form of aptitude assessment, perhaps the next most common after numerical and verbal reasoning. The objective is to determine the continuity or pattern of an image that logically follows in the sequence. The importance of practice is also a factor to stimulate abstract reasoning skills of cognitive functions. (Fig.5)



Figure 5 –Workshop at Frei Contreiras daycentre

To understand the action's impact a report was prepared with information related to each individual activity. The analysed data is divided between the physical-temporal analysis of each photography. The ability to sort out and understand the images with the number of pieces used is reported and the image analysis or description is quantified.

Expansion of the activity

The activities developed as well as the case studies presented made it possible to evolve the implementation of this tool in other organizations, thus increasing the data for the statistical analysis of the potential of collaboration between design and other sciences in the construction of tools that are more effective in obtaining favourable results for improving the quality of life of its users. (Cross 2006)

The implementation of the game arose from needs related to cognitive stimulation of the elderly and the evolution of dementia. However, after a presentation of the first insights, other organizations with a focus on development and social solidarity requested the application of this practice and it was possible to recognize the potential in the fields of social intervention through psychotherapy.

The first application aroused the interest of other day centres such as nursing homes and retirement homes. Here, the search

for cognitive stimulation and the study of the ageing process where the indicators that were possible to verify and quantify with the first prototype and that led to the interest of these institutions in the game. In the field of social support, it was possible to collaborate with community centres, integrating the project with the same target audience. Subsequently, it was applied in different categories: mental health rehabilitation, neurodevelopmental and brain development disorders, behavioural and emotional disorders, neuro-paediatrics, psychiatry, paediatric psychiatry, psychology, social work and therapies (occupational, speech and physical therapy). (Table1)

During its development, the case study has revealed some indicators about the impact design has had on activities that are a part of daily life in these institutions. On a 6st month evaluation some of the indicators to promote resilience are included in the goals of UNISDR for Resilient Cities (Figueiredo, Honiden and Schumann 2018) – 'Ensure healthy lives and promote well-being for all at all ages', as such:

- a) Adhesion (Collaboration acceptance),
- b) Design integration on Well-Being and Inclusiveness sector;
- c) Resilience;
- d) Capacity building (Empowerment);
- e) Collaboration (Synergistic contributions) and system change (interaction);
- f) Coalition (recall for collaboration).

Methods of Analysis - Tables, Reports and Results

The analysis carried out was subjected to various levels of intervention of design, to the intermediate user - health specialists - and to the final user - the patient. Both users exposed their judgment on different interpretations. Health experts evaluated above all, the efficiency of the tool to collect more information about

the patient clinical condition, such as the different levels of Cognition (visuospatial), Reasoning (Concentration, Discrimination, Association and Categorization), Speech (Comprehensive, Expressive, Nomination, Identification, Verbalization and Logical-Expressive chain), Reminiscences (Lifetime, Affections, Human relations), Perception and Logics (Temporal, Spatial and Visual), Emotional processing (Depressive state, Self-expression) and Motricity (hand-eye coordination).

Game impact analysis - Validation

From the first design approach, the experts decided that to develop a report to analyse the impact of the action. To this end, some topics were decided within the theme of memory, which, organized in a table with qualitative and quantitative data, helped to register the activity and understand how relevant the impact of the action would be on the next sessions.

To fulfil this objective, a database analysis of the state of the memory and the evolution of the state of dementia, the degree of satisfaction with the activity and the efficiency of this new procedure.

Evaluation Table

Name: _____
 Age: _____
 Date: _____

	-	1	2	3	4	5	+	Comments
Temporal Description								
Physical / Local Description								
Figure A _____								
Figure B _____								
Figure C _____								
Figure D _____								
Figure E _____								
Satisfaction								
Gameplay								
Additional information								

Fig. 6 -Evaluation table

Game impact analysis and conclusions

The 8 reports indicated that the potential for collaborative construction capacity with design was clarifying in terms of efficiency and results.

Table 1. Stakeholders list and Design procedures

Entity	Collaboration	Duration	Patient type	Category	Participants
Estrela Parish Council	First insights, Preparation, Incubation, Illumination and Validation	6 months	Seniors w/ dementia (+75 years old)	Habits, Lifestyles, Memory, Life stories, Emotions and Affections	8 patients (1 sociologist and 1 psychologist)
Frei Contreiras Daycentre (SCML)	First insights, Preparation, Incubation, Illumination and Validation	6 months	Seniors w/ dementia (+75 years old)	Memory, Cognitive and Language stimulation, Perception (Visual, temporal, spacial), Concentration, Logic, Emotions	9 patients (1 social agent, 1 occupational therapist)
Campintegra	Validation	6 months	Mental health rehabilitation (Adults)	Cognitive Functions; Memory Stimulation; Emotional States and Human Relations	3 patients (1 psychotherapist)
APCL	Validation	3 months	Mental health rehabilitation (Adults)	Perception (visual and temporal), Verbal (identification, naming, use of concepts), Reasoning (discrimination, association, categorization)	10 patients (1 psychotherapist, 1 occupational therapist)
Diferenças	Validation	3 months	Neurodevelopmental and brain development disorders (Children and Teens)	Reasoning, Temporal Structuring, Speculation and Argumentation as well as Visual Attention, Perception and Visual Memory. Comprehensive and Expressive Language	7 patients (2 psychologists)
Cerci (Barcarena and Lisboa)	Validation	3 months	Mental health rehabilitation (Children, Teens and Adults)	Perceptual ability, Memory; Verbal Cognition / Non-Verbal Cognition; Comprehensive and expressive language; fine motor skills (eye-hand coordination)	8 patients (2 occupational therapist)
Alzheimer Portugal (Casa do Alecrim)	Validation	3 months	Alzheimer disease (Adults and Elderly)	Attention / Concentration; Appointment; Fluency; Memory / Reminiscences; Problem solving;	3 patients (1 occupational therapist)

According to 11 health specialists and 50 users who participated in this activity it was possible to collect the following data:

a) Through technical evaluation reports, handling and gameplay were analysed by health experts. Experts found that compared to previous practices there was an increase in: descriptive capacity, memory stimulation (life and emotions), development of visual perception, eye-hand coordination, greater dynamics in oral communication, concentration capacity and combinatory construction capacity (inductive reasoning ability). (Fig.7)

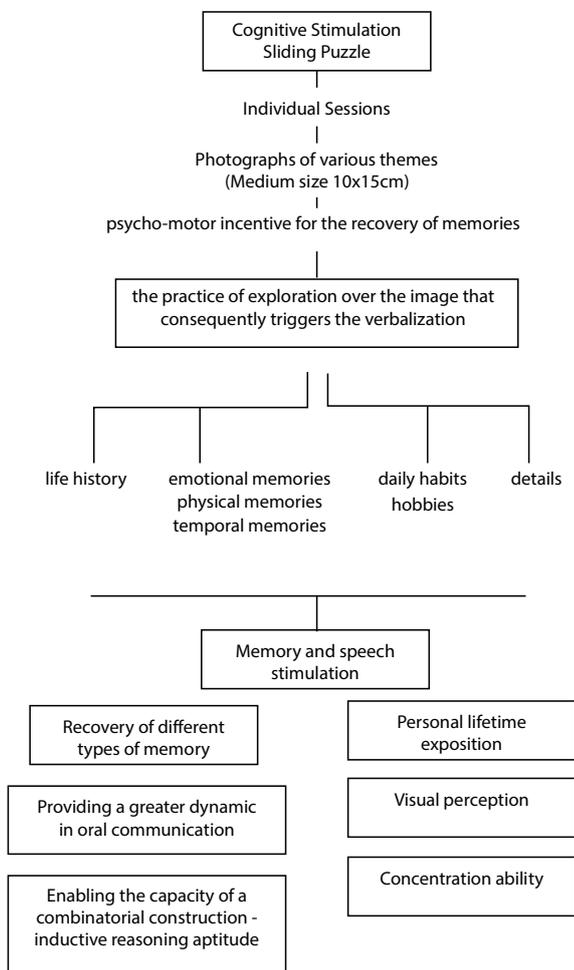


Fig. 7 -Game Analysis

b) About 92% of the health specialists considered that through this tool it was possible to collect new relevant data about the capabilities of users;

c) About 82% of the health specialists considered, having as an example the activity developed, the potential of design intervention relevant (16%) and very relevant (66%) in the construction, development and preservation of capacities and resilience in the social sector.

d) Following the proposed activity, 75% considered very relevant to develop more partnerships/activities/projects resulting from a collaborative methodology.

This project aims to demonstrate the valences and usefulness of design and its resources to integrate in social care policies viable and organic solutions in order to enable greater efficiency and better results of healthcare systems and proceedings. The result of the activity exposed the weaknesses in the ability to materialize and visualize ideas, and strengths on activities upgrade, on mutual knowledge expansion and new opportunities for collaborate, exposing potential range and opportunity for design integration. It also demonstrates interdisciplinarity to develop innovative practices and new social achievements.

Acknowledgements

I wish to express my deepest gratitude to all the institutions and professionals who embraced this project, hoping to contribute to improving the quality of life of its patients. I also thank to all patients that kindly accepted to participate in this research.

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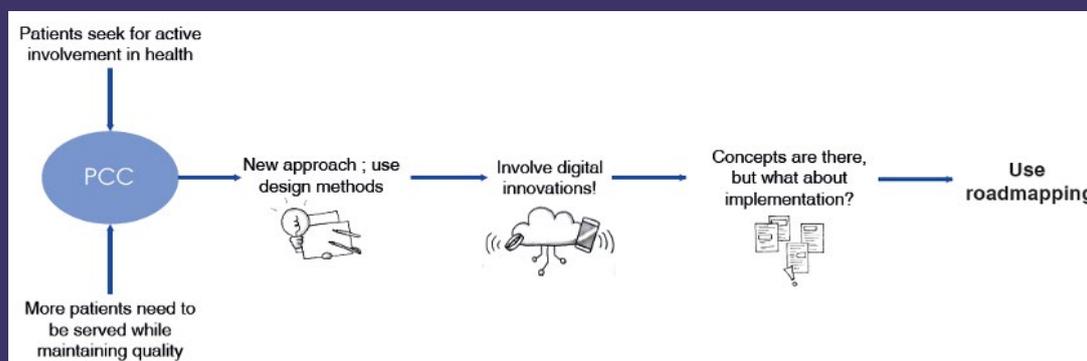
SERVICE ROADMAPPING: MAPPING THE DIGITAL SERVICE POTENTIAL OF SMART CARE CONCEPTS FOR MULTI-USERS SERVICE DESIGNS

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Abstract

Within the context of person-centred care, this paper unravels the digital service potential of smart care concepts by employing service roadmapping.



Demonstrators of smart sensor-based care concepts often imply to service more than one user with data. However, for which user which data is useful and how data is shared among multi-users in integrated in services is currently under researched.

Research question: How to identify the digital service potential of smart care concepts for multi-users service designs?

Method: This study employs a qualitative field method into the area of orthopaedics.

Table 1 shows the sample of 41 advanced concepts demonstrators and accompanying reports that resulted from the umbrella assignment to improve the patient experience journey of hip or knee osteoarthritis patients' in a focus area of care.

Figure 1: the basic model of MTC Ecosystem (2017)

Sample	Primary care	Recovery care	Smart hip care	Total
Smart care concept demonstrator	15	14	12	41
Smart care concept report	15	14	12	41
Design research report	9	9	9	27

The qualitative data related to services aspects were extracted and tabulated, categorized into service clusters, analysed on similarities and difference and mapped into visuals that expressed one service aspect. These maps were validated with 15 representatives of multi-users who indicated extend of service potentials. Then several service models were developed and mapped

in coherence with the smart care concepts on a roadmap.

Results: The service mapping evidences the multiple user aspect of the digital service potential (figure 2), and the data intensity of the demonstrators containing sensors, data and internet technology (figure 3).

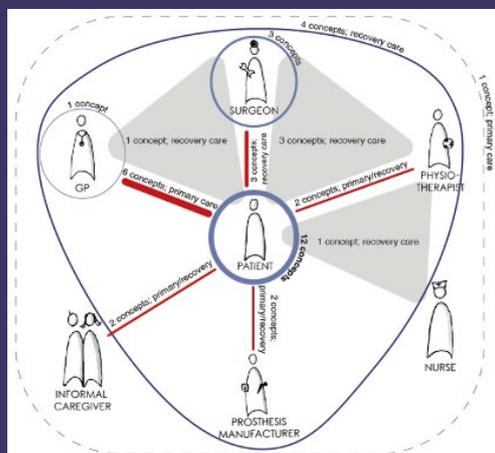


Figure 2. Multi-User service map

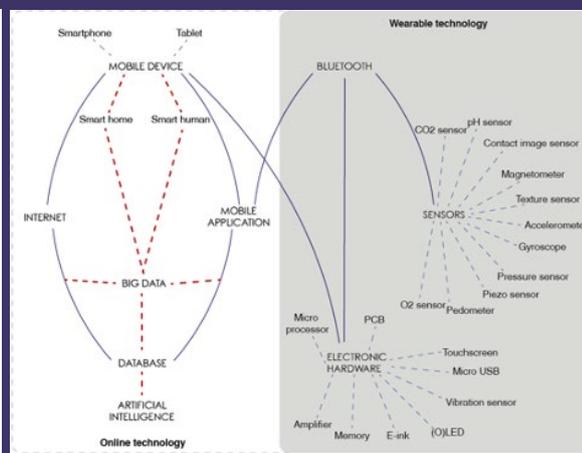


Figure 3. Deconstructed digital service Technology map

The formulation of a service roadmap communicates the cohesion between concepts and their innovation potential to eventually achieve an integrated care service delivery; meaning a service model where all service elements and stakeholders are taken into account.

Keywords: service design, person-centred care, design roadmapping, orthopaedics, smart care devices, multi-users.



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MAKETOCARE(2). SUPPORTING PATIENT INNOVATION FROM IDEAS TO MARKET

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Abstract

The paper presents the results of the second edition of MakeToCare, a research project conducted in Italy (since 2017) to explore and define a grassroots innovation ecosystem in healthcare. The MakeToCare Ecosystem is an area for developing product-services co-designed by patient and caregiver innovators collaborating with actors operating in the healthcare research system, med-tech companies, and digital fabrication spaces. The paper investigates a crucial topic for grassroots innovators in healthcare: how to evolve bottom-up solutions conceived for the individual care into real product-services that can be distributed in the market. Many solutions developed by patient innovators are designed for so-called orphan markets (Canhão, 2017; Nesta Health Lab, 2016), but the majority of them, although effective, cannot scale-up because of a complex regulation system and the long-term, challenging and expensive bureaucratic processes

required to make the solutions marketable. The first part of the paper introduces the MakeToCare Ecosystem, with 180 actors and 120 projects found in Italy, to establish the first connections with the theme of patient-innovation. The second part introduces the MakeToCare Ladder, a tool designed to analyze the innovation processes to develop healthcare solutions. The MTC Ladder consists of four phases: ideation, entrepreneurial development, regulatory verification, and distribution. It can be used to compare innovation processes developed by patient, caregivers and independent innovators. The final part synthesizes the results of the MakeToCare research while evidencing emerging issues and challenges for the user-driven and independent innovation in the field of healthcare.

Keywords: Patient Innovation, Open Innovation, Healthcare.



Patient innovation and the MakeToCare research

Patient innovation refers to people having pathologies or disabilities who decide to design and develop product and service solutions to improve their quality of life. Patient innovation is not a sector of economic activity, nor a legally formalized or regulated practice. Rather, it is a form of user innovation applied to healthcare and a form of free innovation (Von Hippel, 2016), which originates from an unmet need and develops thanks to the activation of co-design processes. Often, patient innovators do not act in isolation, but are part of a larger and more complex ecosystem, involving their families, caregivers, patient associations, doctors and researchers, as well as a number of other individuals and organizations who take care of the patients professionally or informally. The characteristic of patient innovation is the engagement of different communities: the scientific community (doctors and specialists), the patient community, the design and making community (designers, engineers, makers, craftsmen, ...) and, ultimately, the institutional system that regulates and validates the proposed solutions. All these actors operate synergistically so that the solution developed solves the problem, while satisfying the standards in force and the commercial logic of distribution¹. Another important aspect concerns the drivers of patient innovation (Olivera et al. 2015; Zejnilovic et al. 2016). Among them, the digital transformation of communication and manufacturing processes is certainly the most powerful. The digitalization not only makes patients more and more informed and connected with their caregivers, but also turns them into activators of the

care processes. We are talking about individuals motivated to develop a design agency (Latour, 2005), who operate as generators or integrators of opportunities for innovation. We can identify different levels of activation between them. In fact, patient innovators can be simple creators of a solution, developed from a personal need to improve the quality of life. But they can also be active actors in the materialization of their solutions. In few cases, the most advanced ones, they can bring this solution to the market by developing an entrepreneurial activity and thus, sometimes, becoming a “patient-enterprise” (Maffei et al. 2017). Together with validation, in fact, the access to the market is the other central issue of patient innovation. Patient innovation mostly refers to potential markets characterized by a high heterogeneity of products, responding to specific needs of a few individuals and requiring a high degree of customization.

The study of the actors and processes involved in the field of patient innovation represents one of the key issues of the MakeToCare (MTC) research. MTC is an initiative started in 2017, as a spin-off of the homonymous contest organized by Sanofi Genzyme at the European Maker Faire Rome 2016². MTC aimed to identify, map and represent an emerging ecosystem of patient innovators, independent researchers, research institutions, start-ups and new entrepreneurs, makers and digital fabrication labs. These actors experiment, design and materialize solutions to improve the everyday life and health of persons living in situations of disability.

The second MTC Report³ (released in December 2019) evolves the first maps of actors and solutions connecting this emerging ecosystem with the patient

¹ An example is the validation procedure of online platform “patientinnovation.com”. In this platform, a solution that is not accepted by the community of experts is not enabled and distributed online.

² <https://www.maketocare.it/#contest>

³ <https://www.maketocare.it/report>

innovation phenomenon, and develops the MakeToCare Ladder, a tool to analyze and synthesize innovation processes adopted to develop healthcare solutions. The goal is to define a general operational model that can be adopted by various stakeholders interested in approaching this form of innovation.

MakeToCare Ecosystem: from first definition to first implementation

As we explained, it is not possible to consider patient innovators as isolated

actors, since they are part of a wider system. For this reason, we have defined and represented MakeToCare as an Ecosystem (MTC Ecosystem, Figure 1), characterized by the convergence and interaction between: patients' needs (Patient & Caregiving System), institutional care and scientific-technological research skills (Healthcare & Research System) and the resources of new entrepreneurship operating in the field of design, prototyping and production of products and services (Making, Manufacturing & New Entrepreneurship System).

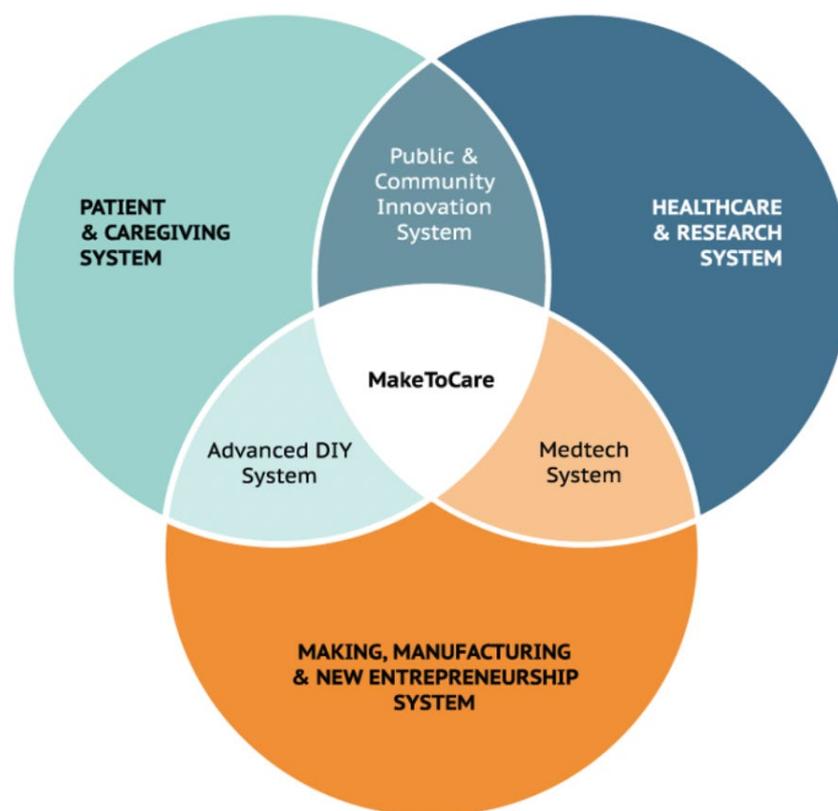


Figure 1: the basic model of MTC Ecosystem (2017)

During the second year of MakeToCare Research, we expanded the field of observation by identifying other systems of actors that, although external to the Ecosystem, are strongly connected to it. An in-depth examination of the mapped solutions underlined how their contribution is indispensable in some phases of the

path from idea to market. We have defined this set of external actors as the Enabling System (see Figure 2), to highlight their role of activation and support of the Ecosystem. This external system is therefore composed of three subsystems, each related to a specific field of intervention:

- The Regulative Institutions System includes public entities that regulate the MTC Ecosystem. They provide regulations and guidelines for the development of the solutions and apply the regulatory processes to allow the solutions to reach the market
- The Support & Development System includes actors that support and finance

the MTC Ecosystem. They contribute to the development and implementation of the solutions, also at entrepreneurial level (e.g. incubators)

- The Promotion & Communication System includes entities that promote and enhance the MTC Ecosystem through initiatives and tools for the communication of solutions.

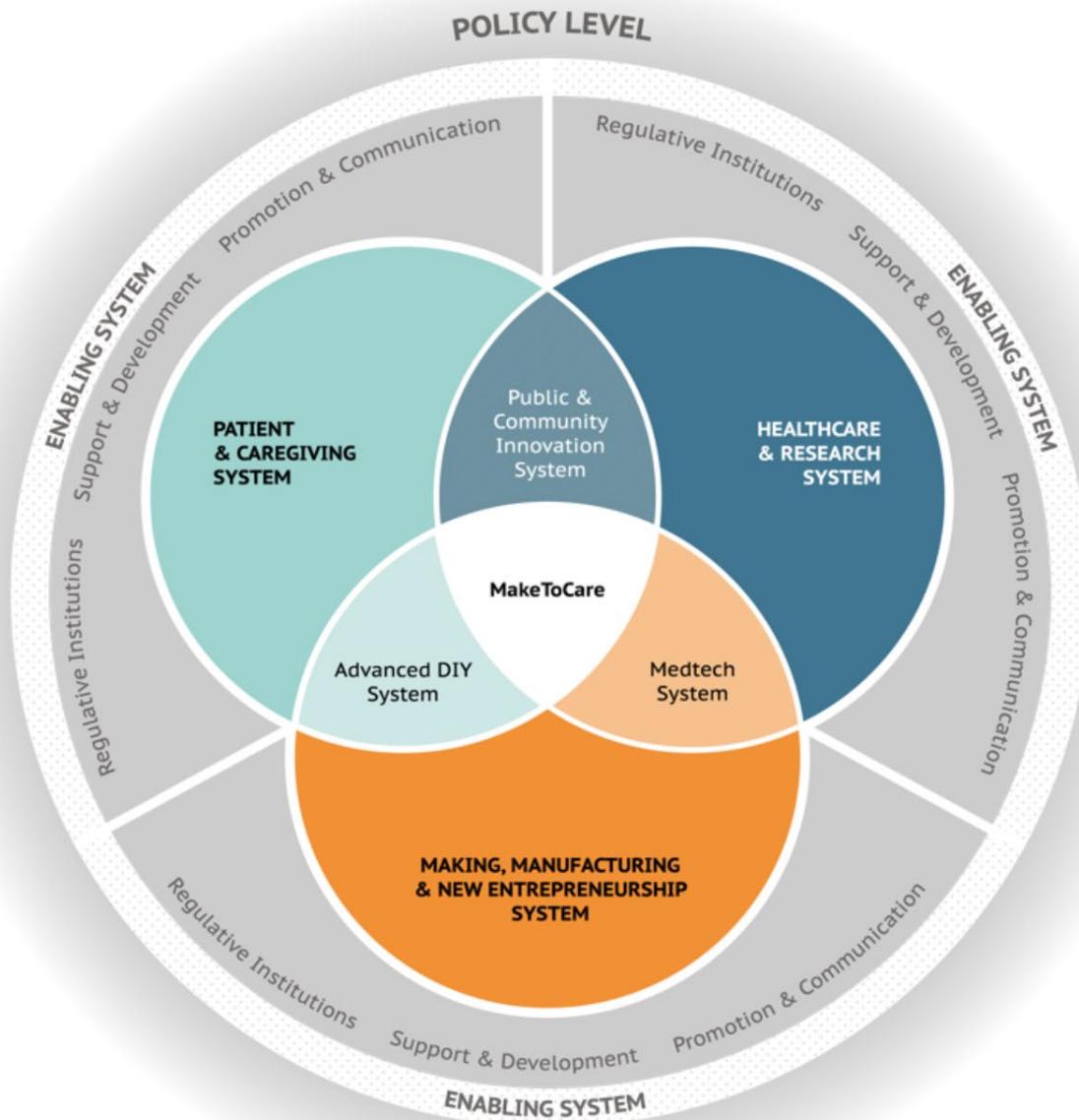


Figure 2: The full model of the MTC Ecosystem (2019)

The definition of the MTC Ecosystem allowed us to carry out a multi-layered analysis of its actors, to study their territorial distribution, their system of relations, the typologies of projects and solutions developed (see Figures 3).

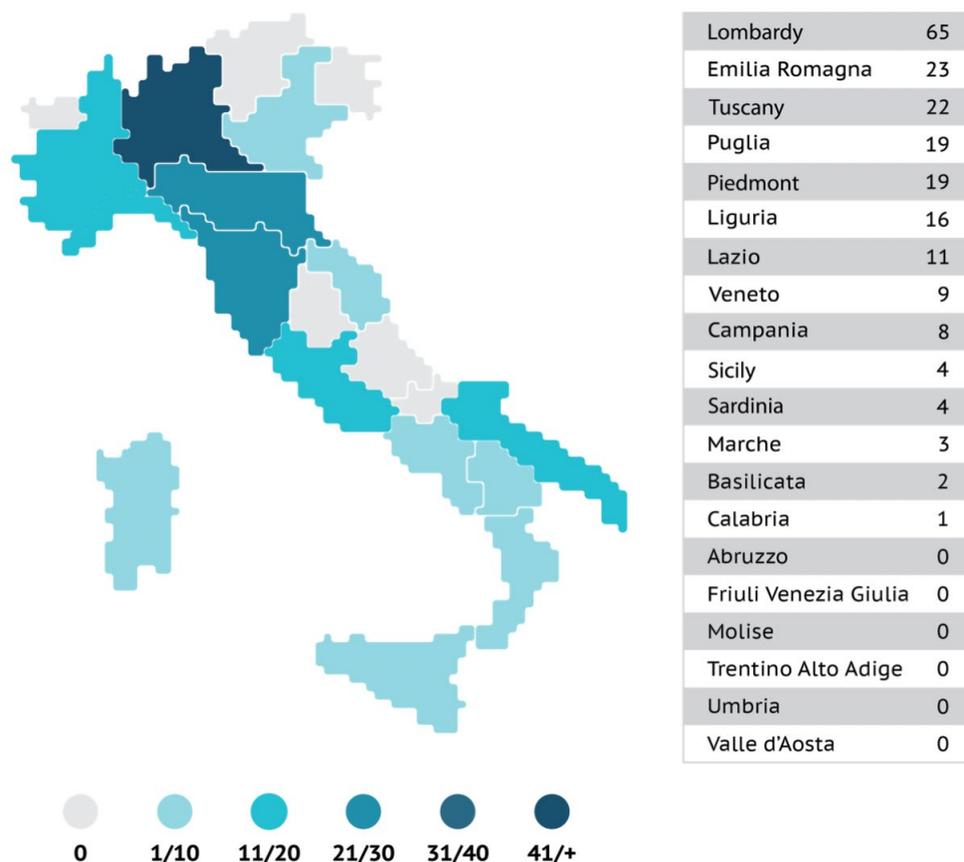


Figure 3: MakeToCare Ecosystem: regional distribution of actors

The definition and implementation of the MTC Ecosystem facilitated the selection of a smaller group of projects developed by patient and caregiver innovators among a larger population of grassroots innovators. 20⁴ out of 150 solutions mapped by MTC research have been developed by patient and/or caregiver innovators. The analysis of these solutions and their innovation processes was possible thanks to the use of a new tool called MakeToCare Ladder. This tool is conceived to analyse and verify the process developed by all those involved in healthcare innovation, including patient innovators.

Driving patient innovation from ideas to market:

To evaluate the solutions developed by

the actors of the MTC Ecosystem and its impact on the end-users, it was necessary to analyze the development of the whole innovation processes, from initial ideas to the final implementations and distribution. Generally, patient innovation processes emerge from an initial idea linked to an individual initiative or experiment for satisfying an exclusively personal need. With a deeper analysis of these processes, we intended to understand how new patient innovation solutions can reach a collective dimension, becoming products for a large number of users⁵.

The key point was to identify what is needed to make a solution evolve from the individual to the collective dimension, and finally to the market and the end user. We visualized in the MakeToCare Ladder

⁴ 9 solutions were developed by patient/caregiver innovators who created a start-up; 5 solutions by patient associations or caregiver innovators. In addition, other mapped solutions that involved patients and/or caregivers (e.g. Hackability, hackability.it) have not been attributed to the field of Patient Innovation.

⁵ Of the 20 solutions mapped, 7 are commercialized or freely released; 11 are prototypes, and 3 are between the industrialization and verification phase.

(MTC Ladder), a tool which synthesizes the development process of the bottom-up and patient innovation solutions “from idea to market”. It is fundamental to specify that we use the term “market” to describe all the different forms of access to the solutions, not only by commercialization but also through open source. The MTC Ladder identifies four macro phases that describe the innovation process “from idea to market” (Figure 3 and 4):

a) Design and Prototype Phase. This is the first step of the process, composed of two main stages. The first stage concerns the idea development and the concept refinement. The second stage concerns the verification through the first experiments and the prototypes realization.

b) Business Development Phase. The passage from the previous phase (a) to this one defines the passage from the prototype to the product stage. Within the ladder we have identified three steps for Phase B - unique product, limited series and mass production.

c) Regulatory Verification Phase. At the end of the Business Development Phase, some solutions must go through a regulatory verification process, as established by an appropriate public body to finally reach the end user.

d) Distribution and Supply Phase. After the regulatory verification, the last phase of the MTC Ladder concerns distribution and supply. In other words, when the device enters the commercial circuit it can be delivered to the patient or available for him.

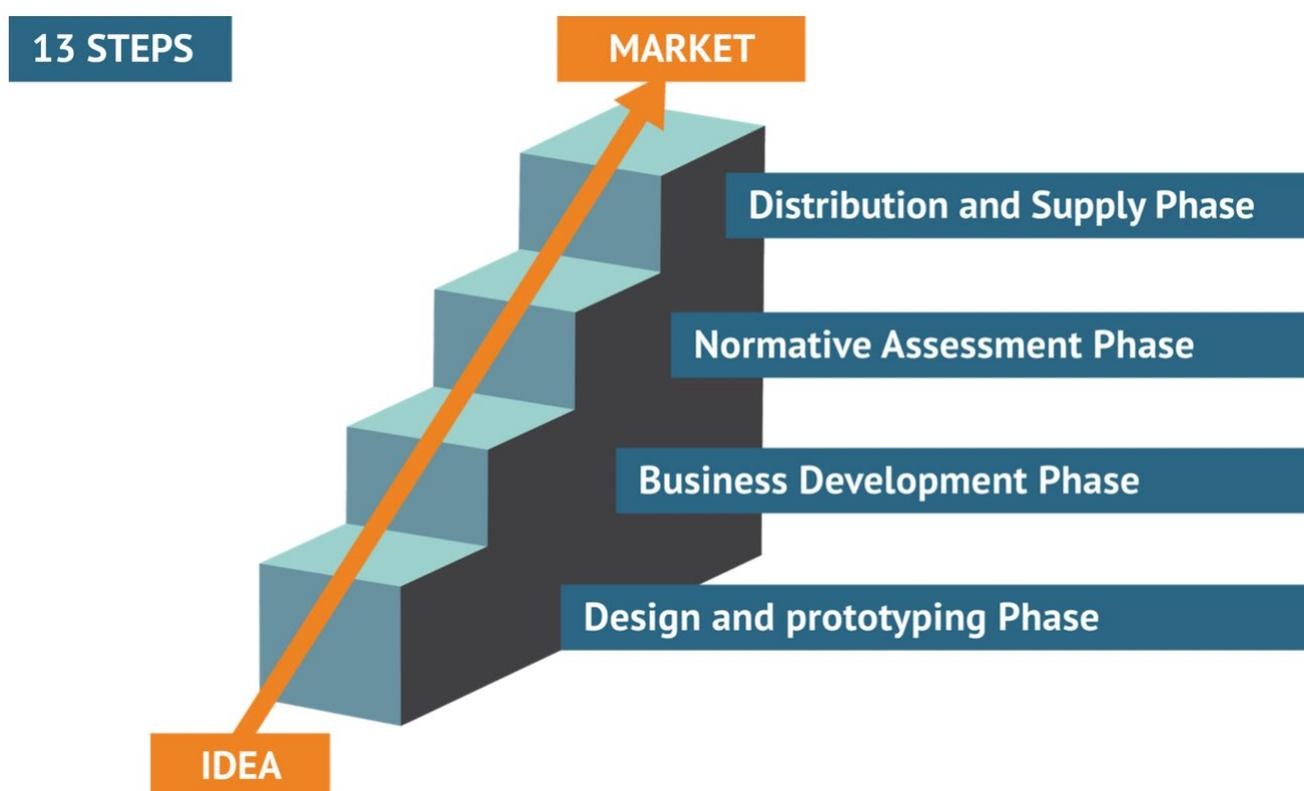


Figure 5: MakeToCare Ladder, the process from idea to market

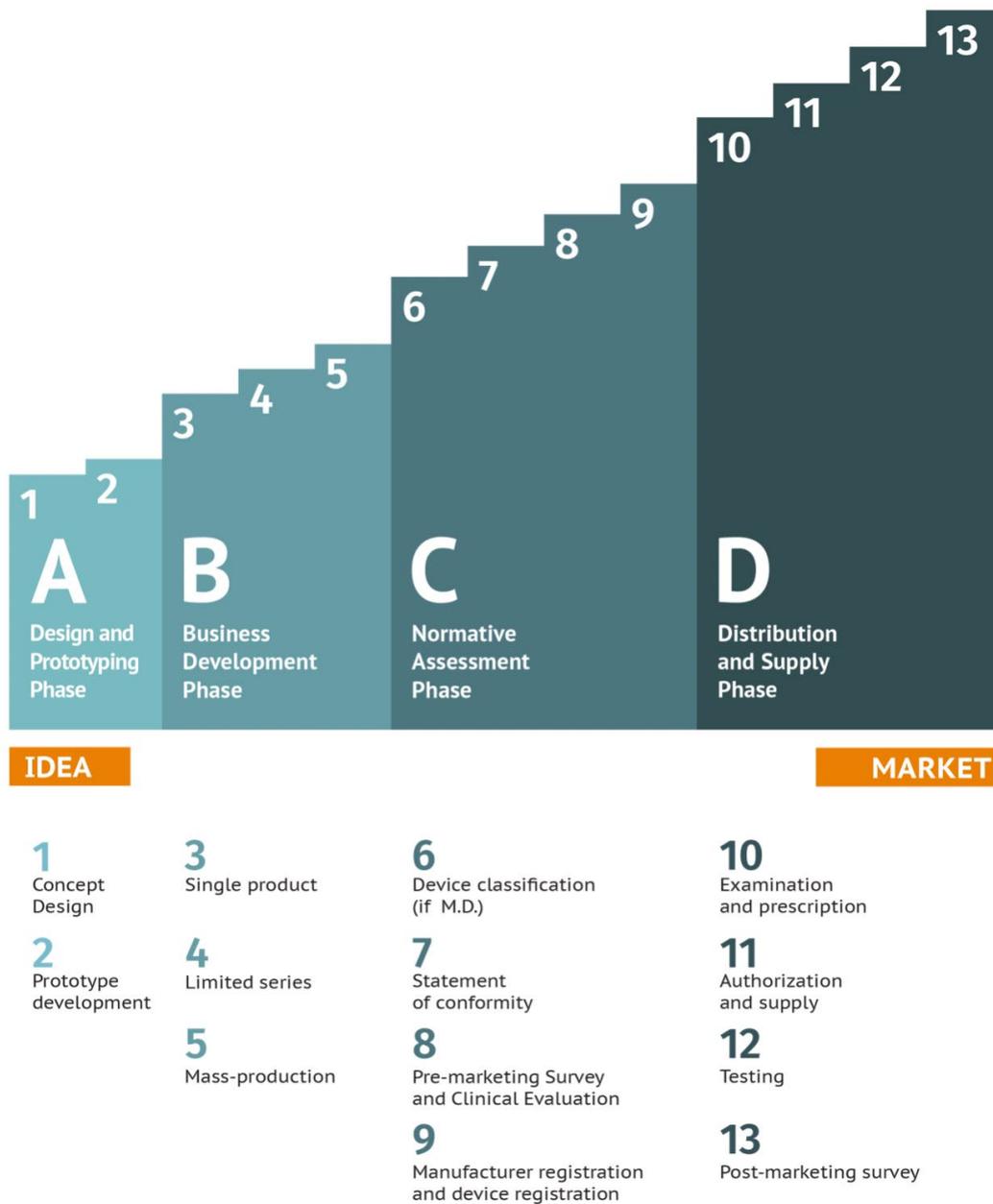


Figure 6: MakeToCare Ladder phases

MakeToCare Ladder in action

The MTC Ecosystem leads us to isolate a range of case studies that can be fully analyzed using the MakeToCare Ladder². The case studies have been selected by adopting four criteria: i.) the level of innovation (technological and/or functional) of the solution, ii.) the type of actors and coalitions involved which determines how the solution is positioned in the MakeToCare Ecosystem, iii.) the degree of maturity of the solution, which indicates

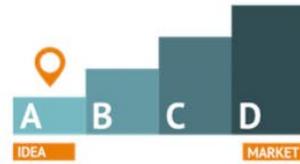
the stage of development within the ideal process "from idea to market", and iv.) the regulatory verification, which is a technical evaluation of the solution according to standard criteria of medical devices and certifications. The Table below shows a synthesis of the 8 full case studies⁶. Each MTC Ladder shows which steps/activities in the development process were actually carried out. In some cases, some steps have been "skipped" (they are displayed in light grey).

⁶ The methodology includes desk research, fieldwork and implementation of a final analysis and control format

DEBEE.IT YAGI

Open computer system that allows to view online the values detected by a glycemic sensor, in real time and remotely allowing your diabetic child to attend school safely

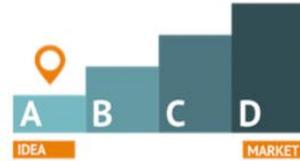
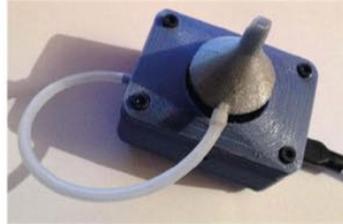
Fabrizio Casellato (President of DeeBee, Diabetes Patients Association)



Disability Mouse

A low-cost mouse, powered by mouth movement and breath, thanks to 3d printing and Arduino

Fortunato Domenico Nocera (Patient Innovator)



FIXED

Customizable rigid wheelchair

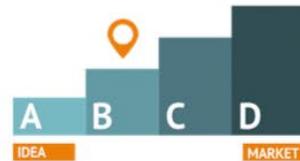
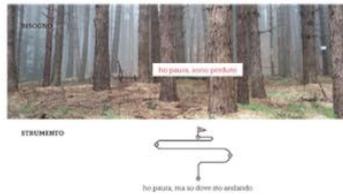
Able to Enjoy S.r.l. (Founded by a Patient Innovator)



H-MAPS

Infographic maps (hard copy and digital) to view the therapeutic course and orient cancer patients in the disease

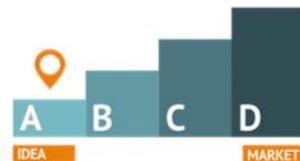
H-maps S.r.l. (Founded by a Patient Innovator)



HUBOTICS, Robotics for Human Beings

A fully 3d-printed exoskeleton for home rehabilitation of upper limbs

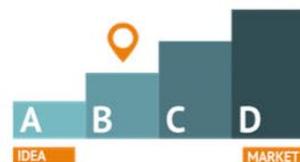
Luca and Chiara Randazzo (Caregiver and Patient Innovator)



IntendiMe

Solution for hearing impaired people, making them feel more independent and safe

IntendiMe S.r.l.s. (Co-founded by a Caregiver Innovator)



Ópponent

Orthoses to support the ankle and prevent supination and internal rotation of the foot

VívacSo S.r.l. (Co-founded by a Patient Innovator)

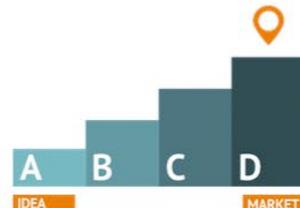


Figure 5. Summary of case studies (the full case studies are available at www.maketocare.it/eng)

Conceptualizing the dimensions of patient innovation

The following summary presents the main issues emerging from the analysis of actors and solutions within the MTC Ecosystem and through the use of the MTC Ladder:

- Design and prototype phase. This phase categorizes the majority of cases. About 65% of the 120 mapped solutions (case studies included) concern a prototype or a concept. If we observe the nature of these artefacts from a technical and design perspective, it is possible to identify both prototypes made from scratch and prototypes made by customizing or hacking existing products.

- Executive development. The development of these solutions is seldom linear and often involves the networking of skills from different actors. For example: designers and makers may be involved for the implementation phase; specialists and technicians for the verification and control phases.

- Productive and business development phase. Product development often requires several cycles of prototyping, technical verification and scientific advice before reaching a testing and validation phase. Our investigation highlights that patient-innovators must think – and in some cases act – as manufacturers to produce their solutions. To achieve this result, they can collaborate with companies or artisans, turn to digital manufacturing platforms and fablabs, or create a new business (acting as entrepreneurs)

- Distribution or release of the solution. Once the business development phase is completed, the solutions are ready for distribution. This final phase requires a comparison with the regulatory

verification and certification procedures. This step is not always manageable autonomously by those who develop the solution; which often have to rely on external consultants.

The case studies analyzed tell us about the development of complex and technological solutions that aim to simplify patients' lives. These solutions are characterized by a growing level of interactivity (in IoT products and services, in personal manufacturing processes, in physical or virtual care environments increasingly sensorized). Finally, MakeToCare² research shows us that patient innovation makes new categories of products emergent as careables⁷: open source solutions for care, developed through platforms and co-design methods incorporating logical objects of accessibility and reproducibility. The tools and case studies developed as part of the MTC Research allowed us to identify four dimensions characterizing the patient innovation processes and solutions:

- Design dimension, in which patient innovation aggregates different professional skills of the project and makes them collaborate through informal design practices.

- Productive-technological dimension, in which patient innovation uses key enabling technologies (microelectronics and digital fabrication in particular). These technologies are getting easily accessible, usable and customizable by patient innovators.

- Social dimension, in which patient innovation aggregates or builds communities and coalitions around ideas and needs.

- Regulatory and legislative dimension, in which patient innovation meets with (or clashes against) the set of rules that

⁷see: <https://www.careables.org/about-careables/>, last accessed: May 2020

can hinder or inhibit the development of a new solution. At the same time, it can protect the user-patient from negative or unforeseen effects that the solution might cause.

MakeToCare Research highlighted the potential and limitations of patient innovation to establish its real complementarity with other forms of innovation. The medical-scientific system treats the patient by increasingly adapting itself to his/her different needs, but probably does not know or use its potential as an innovation agent. The technical-productive system rapidly acquires the design and technological skills necessary to produce on-demand and tailor-made solutions, but it has not yet well understood how to use the potential the innovative patients represent. Design has a well-established tradition of designing “for” and “with” the user, but healthcare is an area too complex to be accessed without the medical-scientific skills needed to develop safe and effective solutions. Similarly, we understand that the innovative patient, while being able to design a new solution, is highly unlikely to possess all the resources and expertise needed to implement it effectively. Not all patient innovators can design a solution and/or are interested to bring it to market. In most cases, the opposite is true. In summary, the evidence emerging from MakeToCare Research tells us that healthcare is a complex and constantly evolving process, that needs to be addressed with a systemic, responsible, responsive and inclusive approach to innovation. Therefore, considering that no standard innovation model exists, MakeToCare Ladder supported us in exploring the relational dynamics and personal experiences, interests and motivations. It is a framework for defining patient innovation processes.

Emerging issues and challenges

MakeToCare Research aimed at producing knowledge on the development of independent and user-driven innovation processes in healthcare, highlighting limits and potential opportunities. The results of this research showed us a field of innovation - that patient innovation is part of - slowly but progressively consolidating and starting to produce tangible results, supported by scientific evidence and early market feedback. Finally, this work reveals a number of questions that have not yet been answered and which can be exposed as research or innovation challenges to the scientific community, the business world and the current political and institutional system. We identify three issues related to these challenges. The first issue concerns the scaling-up of patient innovation from a social and inclusive innovation perspective. The second issue concerns the evolution of patient innovation into a distributed and personal fabrication dimension, exploiting the opportunities offered by digital manufacturing. The third issue concerns the development of enabling spaces that foster collaboration between user-patients, designers and healthcare specialists. These spaces would offer a shared access to a repertoire of technologies and experiences and the possibility to create pilot projects to understand and concretely touch results obtainable through patient innovation processes.

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Photocredits Figure 5: Alos (www.alospro.com); Fabio Piana (www.fabiopiana.it); Fondazione Don Carlo Gnocchi (www.dongnocchi.it); Able to Enjoy (abletoenjoy.com); Opendot (www.uni.co.it); Wasp (www.3dwasp.com); Tactee (www.tactee.it); Tooteko (www.tooteko.com).

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MAKING MAKES ME FEEL BETTER: DESIGNING FOR WELLBEING AND SOCIAL VALUES

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Abstract

This paper presents a design-led inquiry, which aimed to explore the benefits on wellbeing for people living with early stage dementia through participatory handcraft workshops. The project took place in a historically immersive environment at an open-air living history museum involving a dementia friendly design team consisting of researchers, museum staff, volunteers and people living with dementia. Drawing on historic themes from the museum collections a range of new co-produced items were sold in the museum gift shop.

The workshop activities enabled an understanding to be established of living with dementia, the value of making and the abilities of people with dementia. Through the experiences of this small group we unpick the rich detail of the participatory activities in terms of wellbeing. Valuing the contribution of each individual and working side by side we really got to know personalities by observing the nuances of body language, recognising abilities and shifts in confidence.

We draw out the value of being ‘in the moment’ and also ‘significant moments of realisation’. Often the participants commented that concentrating on a creative activity in the moment could be absorbing, the close connection with materials was shown to be comforting.

We observed a commitment and ownership of the project and increased levels of confidence in participants where they valued learning new skills and felt privileged to work and have access to the historic collections within the museum. The co-design project received positive feedback from the local community and visitor interest through sales.

Through the project we sought to support the voice of people with dementia as one participant put it: ‘The trouble is you see, when you’re working everything is fast, you don’t have time to try new things and we’re not in a hurry, making makes me feel better.’ Participant

Keywords: Wellbeing, co-design, dementia, handcrafted, community

Introduction

This paper leverages a design-led project, which considers the role of handcrafting as a strategy for promoting wellbeing and social connectedness for people living with early stage dementia. A collaboration between researchers from Northumbria University, School of Design and the Health and Wellbeing Team at Beamish Open-Air Museum, The Living Museum of the North (England). Participatory workshops took place in the historically immersive 1940's

Orchard Cottage at Beamish Museum involving a dementia friendly design team comprising of researchers, museum staff, volunteers and people living with dementia. The living museum tells the story of daily life in the North East, the whole site is interactive and immersive; artefacts are not in display cabinets or behind glass. The room at Orchard Cottage is full of authentic sights, sounds and smells of the era, stimulating a range of sensory responses in participants.



Figure 1: Orchard Cottage at Beamish Museum

This project draws upon research that explores the role of having access to and of handling historic objects for a range of positive health promotion benefits, such as a sense of belonging, a sense of identity, creative exploration and new learning (Chatterjee and Camic 2015). Historic object handling and viewing can stimulate people to construct their own

stories and meanings into daily life. Objects carry memory through generations; studies into interaction with objects in museums suggest that they enhance wellbeing and trigger emotional and sensory responses (Ander et al. 2012). Objects and the practice of making may also have local significance as a symbol of community and of personal identity associated to local traditions,

people and places. We may associate an object or occupation to a particular geographical region (Twigger Holroyd et al. 2017). Participants in our study responded to the museum collections by placing emphasis on objects and traditions that have meaning to them, for example the miner's cricket, a small stool associated with mining heritage of the North East of England. Working in a museum space surrounded by 1940's artefacts we took inspiration from the immersive experience, which subsequently informed the co-design activity.

'This vernacular refers to the authentic, natural voice of a community, unselfconsciously communicated through everyday things that people have made.' (Gauntlett 2011, 47).

This was particularly important in this making process because participants made a connection to these objects in their own daily and working lives, they recalled stories of using and of making crickets that have been passed down through their own families. By exploring locally significant artefacts and contextually relevant themes e.g. 'Crickets' we place emphasis on social values, historical and spiritual meanings that a product or practice holds for a particular social group. (Twigger Holroyd et al. 2017)

Methods

The craft group started as a 10-week pilot in October 2018, participants were recruited who already had an interest in craft and making and had a diagnosis of mild dementia. Heritage craft skills such as woodworking, woodcarving and printmaking were used in the workshops and participants were inspired by the collections and responded to the locally significant historic themes to produce prototype products. A longer study took place between March – November 2019 where participants developed their prototypes into handmade products for sale in the museum gift shop. Working with participants as design partners during the design process we explored themes within the unique context of the museum to inform the end product (Cassim 2018). Team working in the museum context valued the contribution of each participant through meaningful making practices and social experiences for all participants in a safe environment (Kindleysides and Biglands 2015). We build on the concept of a social workshop model proposed by Cassim and Dong (2015) towards a meaningful outcome that contributed financially to the sustainability of the group. The researchers, who were experienced designers, drew on their existing knowledge to create an inclusive environment for participants' whilst carefully pacing the activity for each individual. The designers explored creative opportunities and brought a consideration of design parameters that balanced achievability with quality of outcome (Cassim and Dong 2015).



Figure 2: Workshop

Facilitating Social Connections

Research suggests that creative making activity can have a positive therapeutic value for people living with dementia, such as increased confidence, self-esteem and social participation (Craig 2001). A designed making activity is also considered beneficial to support personhood in dementia, having positive affect on self-expression, communication and occupation by understanding the relationships of participation (Wallace et al. 2013). Through this process of co-design and co-learning we reflect on the experiences of the person living with dementia and the role of the researcher as facilitator. Drawing on the existing specialist abilities and knowledge of the facilitators, and with a focus on traditional craft skill sharing we adopted a person-centred approach that

was responsive to the capabilities of each individual. The most common issue facing a person living with dementia is a lack or loss of confidence after diagnosis, they might stop doing things that they enjoy because they think they can no longer do it or people around them think that they can no longer do things. This work aimed to provide opportunities to carry on or even to learn new skills, which challenge the perception that a diagnosis of dementia is a barrier to new learning. Initial sessions established methods of co-supportive, practical and meaningful work like activity rooted in community identity and distinctiveness of the setting. We invoked a person-centred approach (Kitwood 1997) to participatory making with people living with dementia by understanding specific impairments or difficulties and individually adapting to each participant based on their abilities

rather than their disabilities (Kindleysides and Biglands 2015). This methodology addresses the diversity and the complexity of disabilities of people living with a specific impairment such as dementia (Hendriks, Slegers, and Duysburgh 2015). Really getting to know the person is key to this approach.

A Dementia Friendly Design Team

According to the Alzheimer's Society there are around 850,000 people living in the UK with dementia. As there is currently no cure this number is expected to increase as people live longer putting pressure on services such as health care. It is a challenge not only for the person living with dementia but also for families, friends and caregivers seeking ways to help them remain active and encourage independence. Dementia affects each person differently, our participants displayed their own difficulties in various ways, for example concentrating on a task or following a series of steps in an activity or struggling to find the right word in a sentence. They might try to disguise

the difficulties they are having by not joining in with a conversation, we noticed this especially at the beginning of the pilot. Participation and team working promoted communication and relationship building over time as we got to know people and drew out the value of being in the moment (MacPherson et al. 2009). Team working aimed to empower the person living with dementia by including them as equal contributors in a design process, as a valued member of a team of co-workers. Close working methods facilitated conversations and social interactions over a period of weeks as attachments were formed through the building of relationships, trust and familiarity. Researchers cannot always rely on verbal data, as many types of impairment affect participants' abilities to express themselves (Hendriks, Slegers, and Duysburgh 2015). Observation was the primary method of qualitative data collection for this study, reflecting on informal in-session conversations and different forms of body language, humour and banter.



Figure 3: Woodcarving Workshop



Figure 4: Printmaking Workshop

'I think you were surprised today?' 'Yes, but more than that it's that I've been able to do it and it was such a big task that I felt that I couldn't do it at the beginning and I've just persevered and I thought well, it wouldn't be my thing and it turned out much better than I thought it would do, I'm proud of it. It's just something that I realised that I could do.' Researcher to Participant Field Notes Wednesday 21st November 2018

The co-design project recognises the capabilities of people living with dementia by empowering them to remain an active part of society through social networks and learning new skills after diagnosis. Embodied learning through hands-on-making extends the experience of new learning and participation beyond cognitive processes and recognises the significance of the body in learning (Robertson and McCall 2018). Working side-by-side the facilitator and participant relationship was evident through conversations and non-verbal body language; we began to recognise when a participant needed support or guidance. We also noticed moments of participant-to-participant support. A lack of confidence in learning a new skill was apparent in early sessions but confidences

grew as participants built on their skills and relationships.

Working 'in the moment' during each session we celebrated small achievements and connections as they happened along with other 'significant moments' of realisation when participants recognised that they could achieve tangible outcomes and other people could appreciate the things they were making. Evident through the sales of their products in the gift shop and from feedback received at various points in the project. The method of the engagement was a valuable shared process as well as acknowledging a sense of achievement in the output of the activity was significant. Creating in-house locally relevant products to generate financial revenue through sale of products in the gift shop stimulated a sense of pride for the participants when they realised they could contribute to the sustainability of their own activity.

'I was amazed at what I had achieved. By the end I felt like a professional and it inspired me to do more. I feel more confident about doing things, I've really surprised myself.' Participant Wednesday 15th May 2019

'Mindset' was the name given to this project by a participant at one of the first sessions, having a group identity reinforced a sense of worth and belonging as a valuable asset in the museum. The first products went on sale in the museum gift shop during Dementia Action Week 2019. Valuing the contribution of the person in the design process we made a mutual decision to

identify each participant as a maker. We sought consent to use first names and a brief statement on swing tags for the products in the shop display. The museum communications team promoted the project on social media channels and in their in-house magazine, which contributed further to a sense of group pride.



Figure 5: Visitor Comment (2019) Beamish Museum Facebook

The response we've had from the public has been unbelievable. They really got behind the project and have been buying the bags in their dozens.' Retail Team Leader. May 2019



Figure 6: Beamish Museum Gift Shop - Dementia Action Week 2019



Figure 7: Cricket Making

'I love it; I get a lot of enjoyment out of it. My dad was a miner and used to use a cricket when he was digging down the mines. His would have been a lot

smaller though and was used to protect his shoulder as he lay on the ground.' Participant. Field notes 16th October 2019

Discussion

In this paper we have reflected on the experiences of a small group of participants engaging in a hands-on making activity to consider how participation can facilitate wellbeing and support the voice of people living with dementia. The project has contributed to conversations around issues of living with dementia in society and how heritage organisations can work to support local communities through meaningful activity that challenges perceived barriers. Raising awareness through the commercialisation of the handmade products gives the project a sense of value for all stakeholders and contributes to sustainability in terms of wellbeing and financial benefit. Making in this unique setting makes historical connections with regional customs and traditions of a recent past. There is a perception of a simpler time, concentrating on an activity was seen to be absorbing, a temporary distraction from other difficulties. Creating something with the hands challenges participants to be imaginative and promotes concentration in the moment and can enrich the lives of people living with dementia.

Conclusion

Participatory workshop activities stimulated a commitment, ownership and sense of pride to work with the historic collections at the unique museum setting. This model for future activity recognises the contribution of people living with dementia to society by empowering them to remain an active part of their local community through social connections and learning new skills. Furthermore, this project has helped create opportunities for people living with dementia to take part in a decision making process that builds their confidence and self-esteem over time. The role of the designers was to lead sessions by suggesting themes, introduce new skills and build on new learning gradually; over time participants became more confident

and willing to take on new challenges. The knowledge sharing that the designer brings to the project was recognised as significant in this context by guiding non-designers to express themselves creatively within a well-considered project framework. The expertise and design skills of the facilitators played an important role in identifying opportunities and developing prototypes in the workshops. The social enterprise model offers a purpose for the workshops with meaningful outcomes and contributes financially to the sustainability of the work. Although this specific scenario is situated in the North East, it could transpose to other regions or contexts by identifying the nuances and distinctiveness of a locality. Exploring the museum context to start conversations about local histories and what makes a community. This design led process contributed to a sense of pride, belonging and distinctiveness in community through a mutual appreciation of object and place.

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UNDERSTANDING INFORMAL CARERS AS WICKED ASSETS IN HEALTH AND SOCIAL CARE

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Abstract

'Dementia' is an umbrella term referring to complex neurocognitive disorders with myriad causes, effects, and manifestations. It is therefore unsurprising that the health and social care services charged with supporting people with the condition exist within equally complex, overlapping, and opaque networks of formal and informal care.

Rittel and Webber (1973) described these societal challenges as 'wicked problems' where the precise boundaries are unclear, the problems are ill-formulated, and the various actors and decision makers often have conflicting values or motivations. These characteristics support the assertion that any solutions for these wicked problems are highly context-specific, and that a solution that works in once instance may not be effective or scalable elsewhere. This overwhelming complexity feeds a general state of paralysis in public service design, where existing hierarchical structures concentrate decision-making power

amongst stakeholders who are far removed from front-line service provision, and consequently unable to respond effectively to rapidly changing needs of service users.

This paper considers the role of informal carers as 'wicked assets' - in the form of highly individual, largely unseen support structures underpinning formal care services. In the UK these informal carers - who are typically close relatives and friends of the person experiencing dementia - receive no formal training or financial support - make a collective contribution of unpaid care equivalent to £11.6bn per year (Alzheimer's Society 2014). The authors discuss possible characteristics of 'wicked assets' and consider the potential role for co-design activities in supporting and sustaining informal carers as individuals as well as within their role as care providers.

Keywords: human centred design, dementia, participatory research, informal care

ETHICAL ROADMAP: ENABLING COLLABORATIVE ENACTMENT OF ETHICAL PRACTICES IN DESIGN AND HCI RESEARCH THROUGH OPEN-SOURCE

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Abstract

Increasingly Design and HCI researchers are working in sensitive contexts, such as hospitals and care homes, involving a wide variety of stakeholders and participants as co-designers. Despite these projects involving others as co-researchers, the current interactions with institutional ethics are often one-sided and engaged with only the core institutional research team at the start of a research proposal. While this process adheres to the ethical requirements of the research institution, it does not meet the needs and approaches of design and HCI researchers once active in these sensitive contexts. This has led to a call for a more situated ethics and new ways of engaging with these diverse co-research teams.

As a response to this call, we have developed the ethical roadmap, a toolkit of resources, to iteratively engage with ethics as a multi-disciplinary team with stakeholders and co-researchers. The roadmap aims to support the enactment of ethical practices throughout Design and HCI research projects. In order to grow a community and share ethical practices or dilemmas with other research teams in comparable contexts we have made

innovative use of an online open source platform (GitHub).

The result is a way for research teams to create a living document of their views, values and agreed practices on ethical issues related to a project as a team and over time. Our online roadmap enables research teams to tailor and appropriate the toolkit to the needs of their context throughout a study, without the need for programming skills. Beyond the functionality of a website, the use of GitHub enables each project team to either use the roadmap tools as they exist or create their own adapted copy. This facilitates a more inclusive, transparent repository of examples documenting ethical thinking and practices. We will present the seven packages comprising the roadmap and discuss the potential for rethinking existing digital platforms to offer new, more inclusive ways of continuously engaging with research processes and dilemmas.

Keywords: ethics, open-source, collaboration, toolkit, GitHub, collaborative methodologies, HCI, design



CONNECTING THE DOTS FOR SEAMLESS JOURNEYS TO WORK: FROM LIVED EXPERIENCES TO SEAMLESS SCENARIOS OF MOBILITY

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Abstract

New and enhanced mobile technologies and services are continuously changing our ways for social participation, work, play and for the many aspects of our daily lives. For example, actual virtual connections allow us to access and engage with work remotely and when needed. Thus, people's social participation is no longer based on their ability to move from one place to another, but on the ability to establish actual and virtual connections. What does it mean for young people with mobility related disabilities in the context of transitioning to work? In this paper we report a design research approach to the understanding of the contextual dimensions of the lived mobility experiences of young people with a mobility related disability. We identified three context-led instances of people's mobility: task (do-what), people's mobility practice (sense-how), and the environment (be-where). We describe a scaffolded methods approach that included observations, interviews, online surveys and CIT interviews for the understanding of enabling and

disabling factors impacting young people's routine mobility experiences. A conceptual framework was produced with the use of a scenario strategy to show points of connections and disconnections in the structure of a person's mobility experience. This approach can help identify opportunities for design interventions in transport services and for future transport policy strategies. We conclude this paper with a discussion about information values that would enable digital platforms and digitally based services to transform actual disconnected journey experiences into future seamless mobilities. As we experience the disruptions to routine mobility due to current COVID-19 pandemic, our design-led method approach addresses a significant topic and offers a scenario strategy that can help us visualise opportunities for creating seamless mobility experiences.

Keywords: design, scenario design, mobility experience, journeys to work, context, disability



Introduction

Online technologies and their pervasiveness in every aspect of our daily life, prompt us to consider that in the near future, social participation will not be based on people's ability to move from one place to another, but on the emergence of new forms of social engagement and mobility (Sheller and Urry 2006; Raja 2016). This possibility is of paramount importance in the case of people enduring diminished mobility. From the perspective of mobility as accessibility to services supporting a productive life, an enhanced ability to access social engagement through digital technologies offers the opportunity to attain seamless mobility. This paper describes a research that set out to investigate the various dimensions shaping the lived mobility experiences of young people with disabilities, and with emphasis on how the use of digital technologies may enable seamless mobilities.

Research on mobility has been conceptualised as the movement of people, ideas and things, as well as the broader social implications of those movements (Urry 2010; Pooley 2020); encompassing a discussion about digital technologies acting as a supplement to physical mobility in order to promote inclusion (Kenyon, Lyons and Rafferty 2002; Pink et al. 2018). This is of critical importance to promote accessibility in the case of people with mobility limitations, where online interactions could help create scenarios and everyday experiences that minimises exclusion and support access to paid work and services.

This paper describes two parts of our investigation of the lived experiences of young people with disabilities in relation to their mobility for work. First, our pilot study led to develop a mobility scenario framework as a representation of the elements comprised in the structure of a mobility practice. Second, our three-year research titled *Seamless Journeys to Work*

for young people with Disabilities (funded project ARC LP150100168) investigated the enabling and disabling factors (policy, services and experiences) impacting young people's routine mobility experiences. The emphasis of this paper is on the mobility scenario framework informed by the findings from both projects and that provides a design strategy to visualise a seamless scenario of mobility. Such scenario framework can help connect the 'dots' of limiting and supporting situations that impact on the journeys to work, and therefore, it can inform transport stakeholders, service providers and policy makers.

Lived mobility experiences of young people with disabilities

We conducted a Pilot study that employed a qualitative approach to gain insights into people's experience of mobility issues in their everyday activities (Adkins, Chamorro-Koc, and Stafford, 2015). Through interviews, cultural probes, and self-reported diaries, the study identified the formidable level of planning that people with a mobility disability require to plan and act on in order to get to work on time. In addition, we gain insights into the sequence of supports required in place simultaneously to make mobility possible, the centrality of online and mobile resources for performing everyday routines, and the frustration experienced when the planning in place did not avoid becoming stranded on-route. Results suggested specific aspects of a person's lived experience that are influenced by context dimensions. For example: prior knowledge of a familiar place or situation evokes a sense of calm (e.g. being assisted by the same cab driver); and that environments and objects of everyday life can carry meaningful and symbolic relationships to the person. We infer that such emotional relationship with context influences the person's mobility practice.

Pooley (2020) established that the underlying structure of everyday mobility has changed little over the years. Our pilot expanded our understanding of

the structure of everyday mobility as a sequence of actions that are part of the person's mobility practice. Table 1 summarises it:

Table 1. Structure of a person's everyday mobility practice

The dots (elements in a mobility practice)	Mobility contextual dimensions (forms of connections of disconnections)
<ul style="list-style-type: none"> • Routines 	<ul style="list-style-type: none"> • Mobility practice
<ul style="list-style-type: none"> • Rhythms 	<ul style="list-style-type: none"> • Mobility social
<ul style="list-style-type: none"> • Space and time 	<ul style="list-style-type: none"> • Mobility experience

Three elements shape a mobility practice: routines, rhythms, and space and time. Routines are the sequential daily activities that are maintained in order to keep the normality of everyday tasks. Rhythms indicates the sense of attention and dedication to a daily activity or routine. For example, getting ready for work begins the night before by recharging the battery of the electric wheelchair. Space and time refer to the prioritisation of key parts of mobility planning. For example, finding out about accessibility of an unfamiliar place. These elements are the 'dots' of a mobility practice that young people with disabilities need to connect to succeed in their daily mobility. Further analysis show that these elements are connected or disconnected in three contextual dimensions: mobility practice,

mobility social, and mobility experience. Mobility practice describes how people go about their routines, which determines the available physical-virtual connections. Mobility social describe how people keep up with normal appearances through the rhythms of our daily activities by maintaining the social order of interactions according to context. Mobility experience is about the understanding of space and time, as familiar settings afford a level of predictability that enables people perform without much thought. Bringing all these elements together, in Figure 1 we illustrate a scenario framework that portrays a person's actual mobility practice shaped around three instances: task (what), self (how), and environment (when-where):

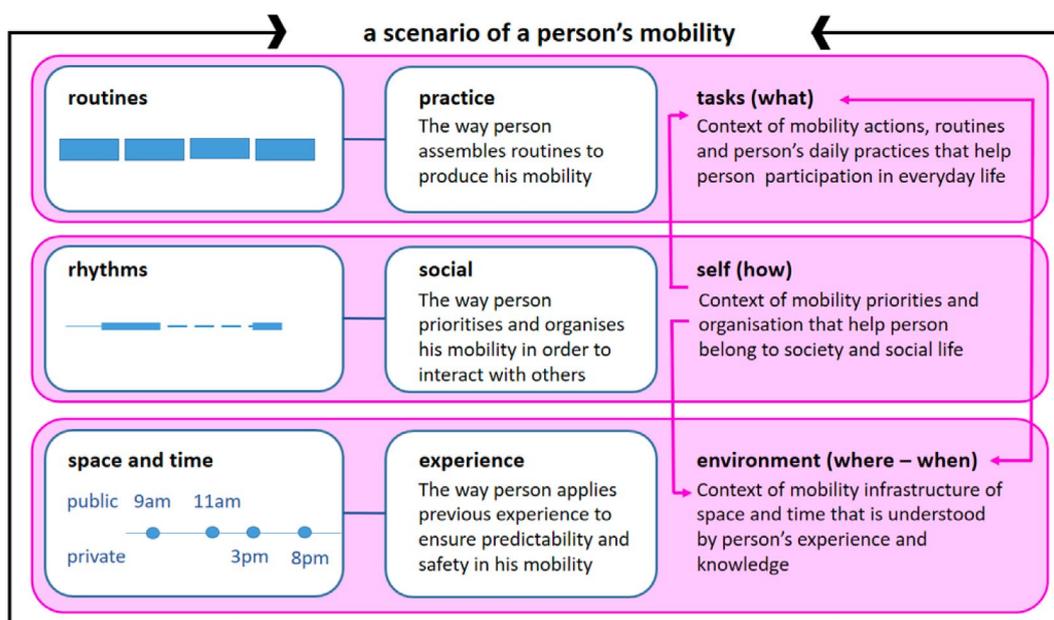


Figure 1: Scenario framework of a person's mobility

In Figure 1, if all virtual and physical elements are connected and in place (self to task, self to environment, and task to environment), a person with disabilities would be able to experience a seamless mobility experience. Conversely, when these elements are disconnected, the resulting mobility experience is limited, potentially leading to exclusion from

participation in society. For example, failing to catch the accessible bus that did not run according to the timetable is a disconnection resulting on person having to wheel his wheelchair for 30min to the next bus stop, making him completely exhausted and arriving late to work. Figure 2 shows the disconnection to environment (space and time) resulting in a negative experience:

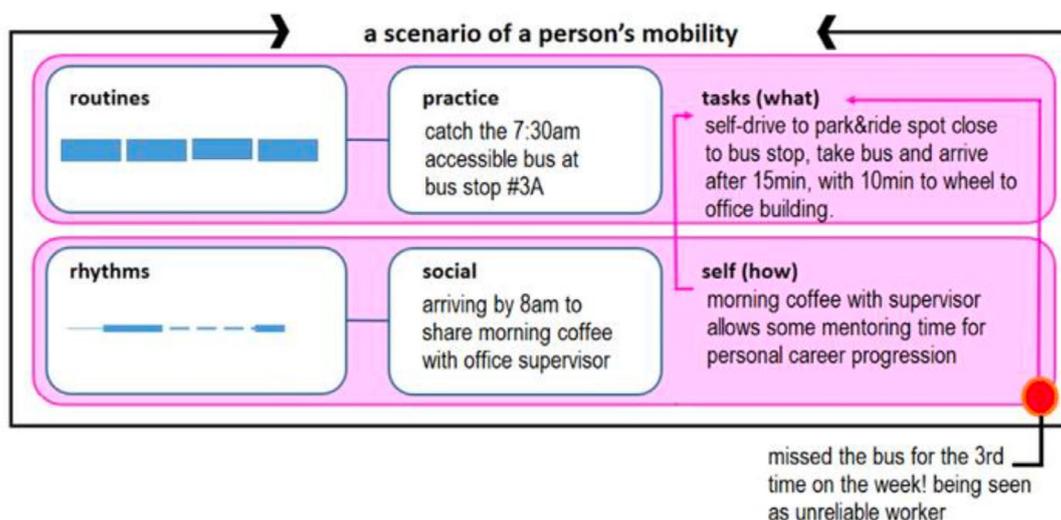


Figure 2: Scenario framework of a person's mobility disconnection

It shows that when a person with disability experiences limitation in navigating to work, their self-determination is impacted, and their sense of wellbeing is negatively affected (Chamorro-Koc, Stafford and Adkins 2015; Sartori et al. 2019). What does it mean for young people with mobility related disabilities who are transitioning to work? In Australia, young people with disabilities work participation is one of the highest rates of unemployment in the OECD (Stafford et al. 2019).

Young people with disabilities transitions to work

Researching the lived experience of young people with disabilities transitioning to work was the focus of our funded research project Seamless Journeys to Work (LP150100168). In this research we expanded our concept of mobilities to journeys and defined it as the process that young people with disabilities go

through in their transition from school to work, their pathway from pre-planning to their actual day experiences, in relation to getting to work. However, this experience takes place in an environment that entails complex interactions for young people with disabilities with other people, services, infrastructure and systems in their day-day lives, with fragmented support services to employment assistance, personal care, transport, aid and equipment (Productivity Commission 2017).

Our three-year research investigated all aspects of young people transition to work including policy analysis, service provision, and the design of online services available to support young people with disabilities access to work. Within this research we explored the lived experiences of young people with a disability everyday journeys and the role that digital technologies can play in improving self-determination as part of those journeys. We conducted

this research in three stages: Stage 1: Audit of the service and policy landscape; Stage 2: Identify people's motivations, perceptions, and expectations; and Stage 3: Understand the experience of journeys to work. In Stage 1 we analysed the relevant policy and conducted twenty-two in-depth interviews with participants from different organisations; each interview was of approximately 60 min duration each. Participants were personnel from employment service delivery and advocacy organisations (Stafford et al. 2019). Results indicated the need of young people with disabilities of being supported to self-determine their work goals; the demand for this process to account for life experiences, personal characteristics, environment, and resources; and the creative resistance demonstrated by personnel of these organisations in order to adapt policy to the needs of people (Stafford et al. 2017; 2019). In Stage 2 we focused on identifying

motivations, perceptions, and expectations of young people with disabilities about their journeys to work. We applied the Model of Goal Directed Behaviour (MGDB) to an online survey in order to examine the socio-cultural, psychosocial and environmental factors influencing young people with disabilities' journey into the workplace (Beatson et al. 2020). Two hundred young adults with a physical and/or neurological disability aged 18–35 years from all states in Australia responded the survey. The results revealed 11 factors influencing young people's motivations and attitudes about their journeys to work: attitude, subjective norms, positive emotions, negative emotions, risk aversion, past behaviour, perceived behavioural control, employer support, social support, desires and intentions (Beatson et al. 2019). The following is scenario narrative developed from the survey results:

Mia is a 25-year-old female who lives with her family in QLD. She works full time and has a Bachelor degree. In the morning Mia wakes up and gets ready for work with the occasional support from her mum. She drives herself to the train station where she parks and transfers to her wheelchair to catch the train. Her workplace is quite supportive, and her boss occasionally checks in on her to see how she is going and offers help if required. Mia is somewhat satisfied with her job and feels people are generally treated fairly at work. After work, Mia is frequently invited to join her colleagues for after work drinks. Because Mia is extremely cautious about new situations, she often avoids attending those events. When Mia needs to go to new places on her own, she researches where they are going to ensure the place is suitable for her and that she can travel there safely. She finds easy to use transport apps to assist with this.

Figure 3: Scenario narrative of a person's Goal Directed Behaviour about her journey to work

This example indicates how psychosocial, socio-cultural and environmental factors all play a significant role in people's desires and intention to independently commute to work and establish themselves in the workforce.

In Stage 3 we identified factors enabling people's self-determination in their actual

journeys to work experiences, which included the use of digital tools. We employed a Critical Incident Technique (CIT) method approach (Flanagan 1954), which included self-reported field observations and interviews that asked participants to recall stories that can be positive or negative experiences of their journeys

to work. We identified the negative experiences as limiting situations and the positive experiences were identified as supporting strategies. They were also asked to describe how they adapted or dealt with unexpected events during journeys and whether they use digital platforms to help them plan their journey. The participants described their journeys from the moment they prepare to leave, to the moment they arrive at their destination. They also included other moments when they felt their self-determination was impacted; for example, when going to restaurants and booking hotels that were not accessible in the way they needed. In total, 65 usable incidents during people's journeys to work were identified using this process. The largest limiting situation identified across all CITs was about the need for more digital platforms during journeys for planning and decision making (29.1%). As a result, we

refined our concept of journeys to work to encompass: the activities that people perform before and during a commute, including planning, familiarisation with the route, getting from one place to another, and any other activities included in this process (Sartori et al. 2019).

From lived experiences to scenarios of seamless journeys

In this section we present a conceptual scenario framework of seamless journeys that brings together all aspects identified from the lived experience of young people with disabilities mobility practices a. From Stage 3 we mapped young people's journeys to work including the identified CITs. Figure 4 illustrates a journey map showing the enablers as well as limiting factors that a participant encountered at different moments of a non-routine journey.

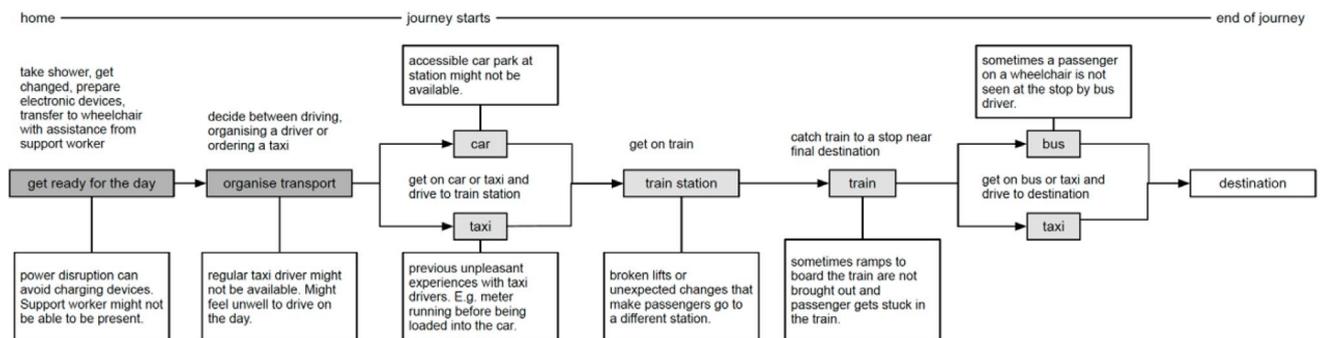


Figure 4: A persons' non-routine journey map

Table 2 presents a segment of this journey map and relevant CITs in the scenario framework illustrated in Figure 1:

Table 2. Scenario framework and limiting CITs of a person's non-routine mobility

Routines	Mobility Practice	Tasks flowchart (what)	
			<pre> graph LR A[organise transport] --> B[car] A --> C[taxi] B --> D[get on car or taxi and drive to train station] C --> D D --> E[train station] </pre>
Rhythms	Mobility Social	Self-determination (how)	<ul style="list-style-type: none"> Pre-trip, planning: getting ready and organising transport tasks are of same importance as it is a daily repetitive task On the train: unannounced changes are out of her control – the implication of changes lessens her personal sense of control over the journey
Space and time	Mobility Experience	Environment (where-when)	<p>Specific CIT causes disconnections in the participants' journey:</p> <ul style="list-style-type: none"> Accessibility: broken lifts, or unexpected changes at the train station requires that passenger goes to another station <p>Other CITs on previous tasks add to the negative experience of this disconnection:</p> <ul style="list-style-type: none"> Preferred (trusted) driver is not available No accessible parking spots Taxi running meter is 'on' while loading wheelchair

This scenario representation of journeys is helpful to illustrate the different problems that a person with mobility disabilities might encounter. We compared it with the CITs of the supporting structures

identified by young people with disabilities in their journeys to work and produced the following journey map with the use of digital tools:

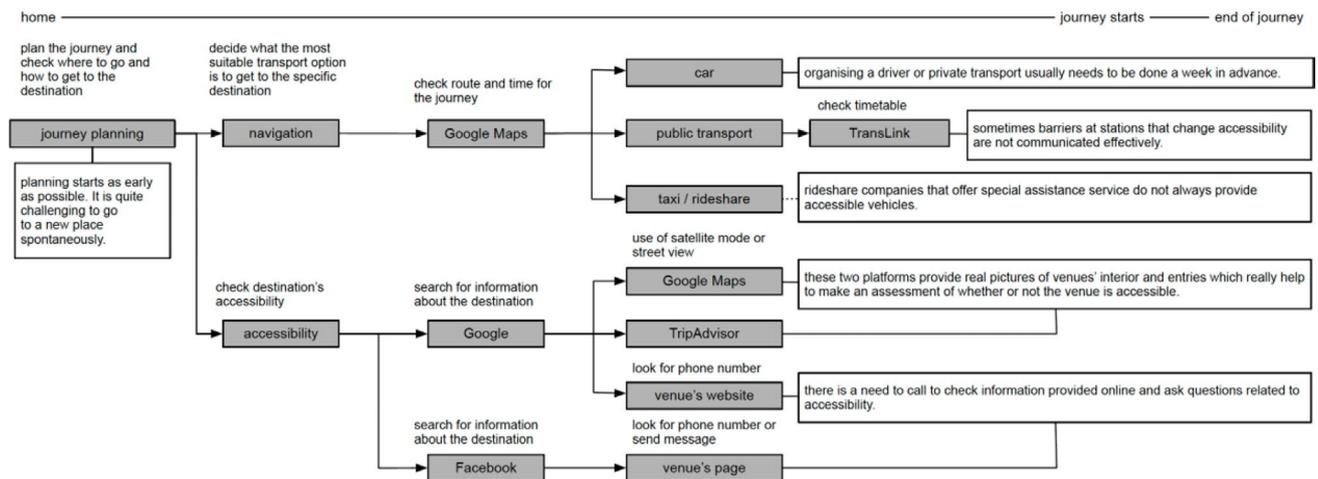


Figure 5: A non-routine journey map showing assistance of digital tools

We positioned a segment of this journey into a scenario framework diagram to further understand the relationships afforded by the technologies identified in Figure 5:

Table 3. Scenario framework and enabling CITs of a person’s non-routine mobility with digital tools

Routines	Mobility Practice	Tasks flowchart (what)	
Rhythms	Mobility Social	Self-determination (how)	<ul style="list-style-type: none"> • Pre-trip, planning: more transport choices are available to match with personal preferences • Improved sense of control over situation afforded by online information
Space and time	Mobility Experience	Environment (where-when)	CITs: supporting structures: <ul style="list-style-type: none"> • Google maps • Facebook • Trip advisor • Venues website • Rideshare / taxi • Public transport schedule

The inclusion of CITs in the scenario framework diagram facilitates identification of various elements shaping and influencing the person’s journey. Future scenarios of seamless mobilities enabled by virtual-physical connections can be explored with this framework as it provides a structure for designers and service providers to envisage desired scenarios of future mobility options for all commuters. By considering routine, rhythms, space-time elements of a journey, and combining with context-led mobility scenarios (practice, social, experience), transport planners and service providers can inform their decisions on how to cater for different people’s mobility needs.

As a design tool, this scenario approach can help to: visualise the impact of a new technology for transport services in peoples’ daily life mobilities; and to identify areas where technological innovation can help support emerging patterns of enhanced virtual-physical connections.

Conclusions

In this paper we have described the lived experiences of young people with mobility disabilities in their journeys to work. Our research uncovered different types of limiting and enabling factors that provide a more detail insight into those mobility experiences of young people with disabilities. We have presented a design-

led approach that employ scenarios to demonstrate the structure of a mobility experience and how actual and virtual connections can influence people's mobilities choices.

Pink (et al. 2018) states that as digital technologies are increasingly part of our everyday worlds, activities thought of as work, leisure and play become entangled in new ways, and experienced using mobile media at home. What does it mean for young people with mobility related disabilities in the context of transitioning to work? Due to COVID-19, at the time of the writing of this paper, most people in the world are relying on mobile media and internet at home to conduct everyday routines; businesses, services, families, workers, students, children, are interacting on internet for work, communication and leisure. As we experience disruptions to routine mobility, it is in this context where we can appreciate the significant importance of further understanding how to devise better scenarios for seamless mobility of people with disabilities. Information values about infrastructure, services, social connectivity with peers and family, as well as real-time knowledge of the places and space surrounding the person's commute are key in shaping a seamless mobility experience. This paper illustrates a design approach to empirical research that captures scenarios of current patterns of people mobility and opportunities to visualise connections across different mobility experiences with the use of online resources. This design research approach contributes to current debate between transport and mobility research and to efforts from transport services stakeholders by providing a description of the level of detail that can be achieved with this approach.

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RETHINKING INNER CITY PSYCHIATRIC BUILDING PROVISION

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Abstract

Outpatient services and services linked closer to primary care provide key components of early detection and continuous support. So, how do we shift the system from a configuration that operates backwards to a preventive and early intervention one? And how this could influence the buildings?

This project describes the research conducted to inform the pre-brief consultation initiated by an NHS Mental Health Trust at a stage of building asset redevelopment. It aimed at gathering the state of the art, including best practice and innovative approaches on psychiatric buildings to inform an extensive multi-stakeholder and patient inclusive, co-design process that would promote early intervention and community integration.

Research followed a qualitative methodology gathering best practice in community mental health globally. Literature review focused on

healthcare built environments. Best practice case studies were analysed. Selected International experts were interviewed.

Data -both visual and scientific- were evaluated using the SCP model, a tool specifically developed for the evaluation of psychiatric buildings. Findings were organised under 32 key themes, further digested in two sections -design learnings and visual support. Then, these informed a matrix of design recommendations for wards and community hubs to support user/stakeholder consultations. By treating design and place-making as a therapeutic tool we could challenge the way people consider psychiatric buildings. Creating the means to disrupt a normally segregated architectural dialogue was essential.

Keywords: healthcare architecture, mental health buildings, psychiatric design, outpatient services



Introduction

Mental Healthcare presents a complexity transferred to all its' individual and interconnected components. For start, it is a service environment in which all actors and recipients are highly interconnected so that the action of one can change the context of the other, similar to any healthcare environment as described by Plesk (2006). As in healthcare, the technical system is interrelated to the social system (Hicks et al. 2015). Part of this technical system is its' built environment. It is important to consider the design of healthcare buildings simultaneously with that of services, as poor connections between these two may lead to issues with service delivery (Caixeta 2013).

With mental illness being on the rise (WHO 2001), removing stigma surrounding mental illness would facilitate earlier diagnosis and therefore, more effective treatment for those who need it (Shrivastava et al. 2013). Especially, in a period where people have also to deal with the direct and indirect psychological and social effects of the COVID-19 pandemic affecting their mental health in the present and in the future (Holmes et al. 2020). More integrated facilities, closer to what people perceive as accessible and inviting (Chrysikou, 2014) might support the target of asking for help earlier. Buildings with those characteristics might also help people remain engaged with services if required.

Community mental health facilities in particular should be in position to optimize the health and well-being of community members. They should be in position to help people deal with the many anticipated consequences of quarantine, social distancing and physical distancing measures governments around the world had to take so as to deal with COVID pandemic. Those have been anxiety, depression, self-harm, domestic abuse, financial stress (United Nations, 2020). A significant way to enable that is their integration to the health and social care

system as well as to the community they serve. By locating health and social care services in the same physical space, users and their carers can easily access related supports and forge linkages among different service providers, minimizing both time and transportation costs (Lum and Ying 2014). Shifting integrated mental health care to the community is unequivocally the most sensible economic decision, as community mental health services are up to five times less expensive than hospital-based care (WHO 2008; Goering, 2004). WHO recommended that Europe should offer effective care in community by implementing specialist community-based services, accessible 24 hours a day, 7 days a week, with mobile multidisciplinary staff to care for people in need of mental health care and effective partnership with primary care services (WHO, 2005).

To achieve this integration, day care and outpatient services provide key components of a comprehensive support service for mentally ill and older people, along with their carers and families (Thorncroft et al. 2016). The need of provision of care on a daily basis for the mentally ill, the underserved populations, people with comorbid long-term conditions and people with physical disabilities who live in their own homes, is well established.

The built environment of these facilities in the community plays an important role in the user's wellbeing and the best possible delivery of services. Studies carried out mainly by psychologists show that building features have psychological effects on users (Francis et al., 1999). As Scher (1992) suggests, environments can be assessed as having positive attributes to well-being by promoting healing in patients, enhance the performance of staff and promote caring behavior in carers. Recent work by R. Ulrich (2018) confirms that. What could architecture do to facilitate a shift from institutional to inspiring healthcare environments in the community? With this academic consultancy project the

research team aimed to set some light on how to improve, with practical steps, the quality of the psychiatric facilities in the community along with the neighbourhoods that surround them. We were most interested in a) best practice examples of community mental health facilities globally that aimed to challenge the custodial image of psychiatric facilities and b) the state of the art on the subject. Looking at these two different streams we would be able to cluster built environment characteristics that new hubs in the community should consider so as to facilitate the best possible outcome for both service users and staff (Chrysikou et al. 2019).

Methodology

Research followed a qualitative methodology gathering data on best practice in community mental health facilities. First, an extended literature review was conducted from November 2018 to February 2019 in relation to healthcare architecture focusing on the built environment of community mental health facilities and the services they provide. It involved grey literature, sources such as UCL Library Services, PubMed, Academia.edu, ResearchGate, Emerald Insight, SAGE Journals, specific journals, i.e., Health Environment Research & Design Journal, BJPSYCH International, World Health Design etc., the relevant NHS Health Building Notes and books. The following research keywords were searched: mental health clinics, mental health hubs, community-based mental healthcare, psychiatric casualty clinics, clubhouses, behavioural health, warming centres, mental health centres, rural health clubs, high end mental health facilities, outpatient psychiatric clinics, day centres, treatment centres.

Furthermore, best practice case studies regarding community mental health facilities globally were selected. Data available online was gathered. Then, these were classified under the following categories:

services, primary care integration, location, accessibility, entrance, façade, outdoor areas, layout, environment/therapeutic milieu, spatial characteristics, navigation, window view, staff areas, rooms for families, therapy rooms, reception design, storage, design for wellbeing, lighting, art, adjustable heating, air quality/energy-water saving, sound and noise levels, privacy, safety, furniture, colours, amenities to visitors/caters, technology, engage different groups, design for adolescents, design for older people. Forty four case studies from fifteen countries were selected. More specifically, examples from the following countries were further studied: Norway, France, Spain, Italy, Slovenia, Denmark, Sweden, Germany, Belgium, Netherlands, UK, Canada, Australia, the US and Japan. Additionally, interviews with five international experts from the field of psychiatry or medical architecture, from both Europe and the US, have been conducted in parallel, providing valuable data from their research activities and personal experience in operating at their local area.

Data collected was further evaluated using the SCP model (Chrysikou 2014), a tool specifically developed for the classification of the psychiatric built environment (Figure 1). The tool is used for the evaluation of mental health facilities, identifying the relation between policy, care-regime and patient-focused environment. The model was named after the acronyms of three variables: Safety and Security (S), Competence (C) and finally Personalization and Choice (P). It is a three-dimensional model and each of these variables comprises one dimension of a cubic problem space occupied by the three axes (x, y and z). The SCP model can help define enabling environments for what staff and service users perceive as best practice and suitable for their environments of care (Table 1).

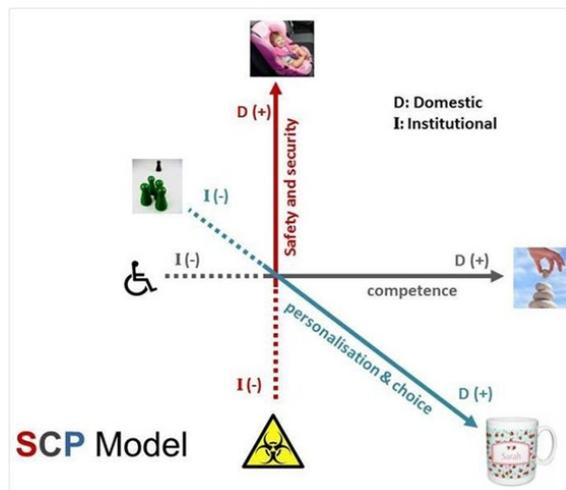


Figure 1: [The SCP Model as a 3d space where psychiatric facilities can be placed according to their individual characteristics in domestic (+) vs institutional (-) scale]

Table 1. Percentage of participants (N=15) who disagree or agree with the statement or are neutral.

Research method	Description
Literature review	Relation to healthcare architecture with focus on the built environment of community mental health facilities, delivery and services they provide
Desktop analysis	Selection of best practice case studies regarding community mental health facilities globally
Interviews	Interviews with international experts from the field of psychiatry and medical architecture, from Europe and USA
SCP model	Evaluation of visual and scientific data using the SCP model, a tool developed for the evaluation of mental health facilities, identifying the relation between policy, care-regime and patient-focused environment

Findings

Findings in relation to the built environment of mental health facilities and how they could become inspiring reference points within the community they serve, were selected and organized under 32 key themes. Each key theme was organized in two sections: i) the first comprised a set of recommendations deriving mainly from scientific sources and ii) the second presented relevant case studies accompanied by photos showing how these recommendations have been implemented. Each recommendation has been further analysed using the SCP model, by including at the end the acronyms "SCP" and by highlighting in bold the most dominant parameter among the three for each one.

More specifically, research conducted highlighted a variety of different services that could be adopted and would be beneficial for users. It is important to treat users holistically by providing:

- options for therapy- such as individual or group psychosocial therapies, recreation therapies (art therapy, music therapy, etc.),
- areas for physical activity (especially for units that do not have access to secure outdoor areas as exercise has positive effects on people's well-being),
- outreach spaces such as a shop or café, where users could both work, run business but also relax and sell artwork or other craft objects they are doing at occupational therapy sessions (Figure 2).



Figure 2: [Skrbovinca Care gift shop, Ljubljana, Slovenia: a joint work of the City of Ljubljana and the four Ljubljana Workers Protection Centers. A place to socialize, exhibit, and also sell creative achievements of adult people with special needs or other overlooked social groups]

As already stated, integrating mental health care to primary care should be considered as the first step forward. Data showed that many countries, such as Norway, UK, Scotland, France, USA etc. have already taken action to that direction. The Mental Health Commission of Canada (MHCC) (2017) highlighted the priority for community mental health services to be available at the primary and community care levels, as this is where most people with mental health problems prefer to access services. In Italy in 2009, the Emilia-Romagna Mental Health Action Plan 2009-2011 was approved by council, basically focusing on the integration of health and social services (Servizio Sanitario Regionale, 2011).

Another finding involved built environment recommendations related to location and accessibility. Mental health facilities are, in most cases, hidden and difficult to access (Chrysikou et al. 2017). Research shown that ease of access for families, carers and staff, including availability and access to public/private transport and parking, is key consideration. Access ramps and space to enable wheelchair users to move within the building are necessary. Site location should also be taken into account: points such as proximity to the catchment area the facility serves (as close as possible to the users' home), proximity to regular public transport, even to other health or community services,

should be taken into consideration.

Exterior building characteristics, such as entrance, façade and outdoor areas were also included. Findings showed the importance of the first impression. Façade should be attractive and clean, marking the entrance with a piece of art or a canopy for example, so as to promote wayfinding but also to make users feel more welcomed and blended in the community. Safe outdoor areas with accessible green spaces offering a place for socialization should also be incorporated.

Data on layout characteristics were also gathered. The importance of therapeutic environment – one that positively contributes to the healing process, pays attention to users, staff and visitors, provides safe gender design and prevents violence- was highlighted. Spatial characteristics that should be taken into consideration during the design process were noted. Research showed the positive impact of larger, open activity areas instead of small, enclosed day rooms. Treatment rooms shouldn't feature a long and narrow corridor without daylight but a place for users to hang out and socialize. Spaces for social interaction is best to vary in size and activity taking place, so as to provide more choices in relation to users' needs. Findings also showed that simple navigation signage, properly designed and positioned, could support the feeling of security to users.

Landmarks within buildings could serve as wayfinding elements, providing positive distractions and autonomy that reduce stress levels. The positive effect of window view for all users was highlighted.

The interior characteristics of the hubs play also an important role in making them more appealing to users. Findings showed the importance of designing staff areas that are genuinely staff-focused so as to create a positive working environment (with immediate effect on better treatment outcomes): windowed work places, open nursing stations for enabling better observation, private staff break rooms - both indoor and outdoor- located in close proximity to medical areas, adequate space to secure personal possessions. Rooms for families are suggested, especially in cases where adolescents are involved. Findings showed that smaller, intimate areas for families, instead of larger ones, are preferred. The design of more effective therapy rooms was also pointed out: better to be built in a multi-purpose way, to provide flexibility for more activities in the same area.

Attention to detail could also play an important role in improving the built environment of mental health facilities to make them more inspiring. With light having a profound effect on human biology, lighting - both natural and artificial- along with views of nature are two of the most significant design factors that should be considered during the design process. Findings displayed that suitable art selection for mental health settings can positively affect the physiological and psychological health of users and staff. The importance of effective air quality control measures and ventilation systems in mental health facilities was also highlighted, especially in crowded spaces or at spaces with strong odors. Keeping low noise levels is also important as it helps in stress reduction. Additionally, data showed that furniture should be safe and durable but at the same time comfortable and domestic in style as

possible, arranged in a way that support multiple levels of interaction. Colours and textures may also help differentiate spaces and help in wayfinding. The role of technology was also studied, from WI FI connection and area with computers, to the use of suitable VR/AR applications in mental health hubs.

Finally, data selected showed the importance of engaging different groups of people during the design process. A community mental health hub should be designed with and for the community, taking into account the various groups that use them and their needs, as different groups with different ages (older people, adolescents etc.) interact in fundamentally different ways.

All the above data were analysed and combined, generating a matrix of recommendations concerning the design of community mental health hubs and wards. The researchers classified them by giving to each recommendation either an S (for strong) or R (for recommended) or O (for optional).

Conclusions

Findings of this research highlighted ways to improve the quality of the psychiatric built environment along with the neighbourhoods that surround them, so that users are drawn to them by hope and not despair. In most cases, psychiatric buildings tend to go unnoticed or appear hidden, demonstrating clear signs of vandalism and located far from tube stations, adding to the time staff, users and their families need to access them (Chrysikou et al. 2017). Through the matrix of recommendations for the design of community mental health facilities, the researchers generated a valuable tool for everyone involved in the planning, design and management of psychiatric units - from Healthcare & Estates to architects and stakeholders involved, including service users - that could have a greater impact and help long

term minimise the community levels of stigma and discrimination surrounding these types of buildings. By treating design and place-making as a therapeutic tool we could challenge the way people consider psychiatric buildings and we could create the means to disrupt a normally segregated architectural dialogue.

Finally, we need to think of environments in their detail in a complete manner. Sometimes we do not have the evidence base to address all the pixels of the image and come up with a 100% evidence base solution. Sometimes the pixels might be too few casting the final picture as too fragmented. In the meantime, we need to look at the existing evidence and best practice through a more theory based solution, utilising all available tools from evidence to inspirational and occasionally contradictory examples and people's experience and practice-derived expertise. This project was foremost an exercise on reaching to and synthesising all that. The final product was a report that was used to facilitate, enrich and provide food for thought one of the most important steps of a healthcare planning project, the staff and patient consultation.

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CO-CREATING POETRY FOR COMMUNICATING INDIVIDUALS' EMOTIONAL EXPERIENCE OF LIVING WITH HIV

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Abstract

We report on three 'co-creation workshops' that aimed to qualitatively understand self-care practices for living well with HIV. Taking a participatory, arts-based approach, the research team formed a partnership of designers, peer researchers and experts in the lived experience of HIV. 17 adults living with HIV participated in the workshops in total, engaging in creative making activities and responding to questions about self-expression, self-care practices, receiving care, and the role of healthcare professionals in this care. This co-creative work resulted in three visual poems that are intended to inform the person-centred design of supportive care management services. Our innovative analytic method draws on Found Poetry and Visual Inquiry, to make sense of material artefacts that participants created to represent their experiences and the group discussion that took place. Creative responses to the data, formed by participants and by the researchers (a communication designer, a peer researcher who is a poet, and an

interaction designer with expertise in social psychology), captured idiographic understandings of lived experiences. The poems communicate the psychosocial dynamics within self-care practices, plus the challenges of sharing such practices with healthcare professionals. Our contribution is two-fold. First, we offer new qualitative insights into the practice of self-care for living and ageing with HIV, a health context remaining underexplored at Design4Health. Such insights are transferable to wider discourses on supporting the management of long-term conditions. Second, we offer reflection on the efficacy of our co-creative methods to deliver findings about complex experiences through a medium that retains emotional resonance in its expression. We consider the transferability of our methodological insight for utilising Poetic Inquiry in research.

Keywords: co-creation; poetic inquiry; self-care; HIV; long-term condition



Introduction

Through effective treatment, the Human Immunodeficiency Virus (HIV) has been transformed into a long-term condition with normal life expectancy for the majority of UK-based people receiving treatment (May et al. 2014). The focus of HIV care has consequently shifted towards maximising quality of life for people as they age (Lazarus et al. 2016), supporting self-management and self-reporting about living with the condition to HIV clinicians (NAT 2016). There is a growing interest in using self-care strategies for supporting whole-person care to live well with HIV (Schnall et al. 2018), going beyond viral suppression to understand experiences of daily life and routines.

In this paper, we report on three 'co-creation workshops' that were conducted in 2019 to qualitatively understand self-care practices for living well with HIV; the workshops formed the first phase of a 30-month research programme to design supportive digital services. Grounded in Phenomenology, and taking a participatory approach, the workshops served to explore how individuals living with HIV engage in and make sense of their own care. We also aimed to 'co-define' key research questions and terminology to inform the research programme going forwards. 17 adults living with HIV participated in the workshops in total (11 women, 6 men); they engaged in creative making activities and responded to questions about self-expression, self-care, receiving care, and the role of healthcare professionals in care. Outputs from these sessions were analysed using Poetic Inquiry combined with Visual Inquiry (Butler-Kisber 2010; Margolis and Pauwels 2011). This co-creative work resulted in three visual poems that are intended to inform the person-centred design of supportive care management services.

Herein, we present the three individual poems and describe how co-creative practice has enabled us to develop

understandings about the practice of self-care for living and ageing well with a long-term condition like HIV – a health context remaining underexplored in the Design4Health community. We further endeavour to demonstrate the potential value of the outputs from our co-creative methods for communicating these empirical understandings.

Methods

Co-creation workshops to understand and define HIV self-care practices

The workshops were organised in partnership with two partnering HIV organisations: Blue Sky Trust (www.blueskytrust.org) and Terrence Higgins Trust (THT) (www.tht.org.uk), to ensure that the provided settings for participants were private and safe. Two workshops took place in Northern England and one in Southern England, over a 2-month period. The two-hour workshops were facilitated by this paper's authors, representing multi-disciplinary expertise; the lead author is a communication designer and researcher; the second is a peer researcher who is also a poet; and the third is an interaction designer and researcher with expertise in social psychology. To clarify, a peer researcher practices research skills whilst sharing similar lived-experiences with participants (Ibáñez-Carrasco et al. 2019).

Hosting workshop sessions in two UK regions enabled us to encourage socio-cultural diversity across geographical locations. Participants were ethnically diverse, with age ranging between 24 and 68 and had different sexualities (e.g. heterosexual, bisexual, pansexual). Overall, we involved more women - a group that is historically less visible in HIV research (THT & Sophia Forum 2018). The workshops also provided an opportunity for older participants to voice their experience of ageing with HIV - important as the UK

is witnessing the first wave of long-term diagnosed people (pre-1996) who are growing older with the condition (THT 2017). All participants were receiving clinical care, and most lived with other long-

term conditions such as diabetes, chronic pain and depression. People with HIV are at increased risk of developing comorbidities, which greatly impacts their quality of life (Frontline AIDS 2018).



Figure 1: Ice-breaker activity package given to each participant (left). Two brooches created by one participant (right).

The workshop featured creative and ‘hands-on’ activities, intended to help participants communicate their experiences through verbal, non-verbal and embodied means. We designed a set of material resources for these activities, to scaffold self-reflection and self-expression.

The workshop method had a three-part structure:

- Part 1 was an ice-breaker activity inviting participants to create artefacts (i.e. brooch, badge, fridge magnet or keyring) to express aspects of who they are (i.e. Self-Identity) (Figure 1).
- Part 2 invited discussion about practicing self-care and self-management of HIV in daily life. In pairs, participants were first invited to discuss what the term ‘self-care’ meant to them whilst thinking about the care they provide to themselves and receive from others (Figure 2). Individually, they were then prompted to complete a mapping exercise, to draw their ‘Circles of Care’ (Tulusan 2004) (i.e. networks of care visualised as overlapping circles).

- Part 3 prompted participants to think about the types of information that people with HIV may find valuable to share during a routine clinical consultation, and to highlight the information that they did not currently have the opportunity to share with clinicians.

After each activity, participants shared what they felt comfortable with.



Figure 2: Two participants working together in Part 2 of the workshop.

In practice, we found that the dialogical and generative nature of the three-part

method enabled participants to collectively contribute to a conversation and provided an opportunity for peer-education whilst we learned from them. Overall, the sessions were well received, as described by one participant:

'Very enjoyable. It was fun to be creative and the process of making things helped us to bond with other participants. The creative tasks really helped manage the discussions and allowed everyone to play a part – they also helped to keep people on topic, avoid over-sharing or focusing on negative experiences.'

Making and sharing the artefacts with the group prompted participants to take turns to talk about the personal values that they held, what they felt was important for their wellbeing (e.g. mindfulness and the emotional growth since diagnosis). The activities also prompted discussion about the medical context of living with HIV, and showed different experiences based on individuals' locations and particular needs, as highlighted in feedback: 'Everyone is an individual and this approach enabled us to be individuals and express our respective views.'

Each workshop was audio-recorded; material outputs were photographed. We devised a method for analysing the data through which our experience-centred, participatory and generative orientation was sustained.

Analysis and synthesis through co-creative practice

Poetry is a language that presents 'a window into the heart of human experience' (McCullis in Miller 2018, 383). Researchers in the social sciences have increasingly recognised the value of using Poetic Inquiry (Butler-Kisber 2010; Sjollema et al. 2017) for analysing and representing qualitative data generated from interviews. Poetic Inquiry is part of Creative Analytic Practice (Richardson 1994), and is recognised for providing researchers with means to acknowledge the embodied and emotional

dimensions of their research:

'Poetry has forever had the power to attract humankind because of its ability to convey poignancy, musicality, rhythm, mystery and ambiguity. It appeals to our senses and opens up our hearts and ears to different ways of seeing and knowing (Butler-Kisber 2010, 82).'

By using Poetic Inquiry, we aimed to generate new dialogical understandings of experiences that appreciated how individuals make sense of the world (Sjollema et al. 2017). Poetic Inquiry can encourage reflective practice (Butler-Kisber 2010; Sjollema et al. 2017) and address power relationships; final poems may intertwine both the participants' and the researcher's voices (Glesne in Butler-Kisber 2010). We aimed to foreground emotional experience and emerging empirical themes whilst ensuring that individual participant voices were not dissipated through the analysts' collective voice (Butler-Kisber 2010; Sjollema et al. 2017).

Analytic method

Our analytic practice engaged with a dataset of: (anonymised) transcripts of audio recordings of the workshops, plus photos of the artefacts made by participants. We appropriated an existing method (Sjollema et al. 2017) whereby Thematic Analysis is combined with Poetic Inquiry to interpret and disseminate insights from transcripts. We combined two types of Poetic Inquiry in conjunction with visual-based methods (Butler-Kisber 2010) to devise a method involving two steps. First, we used Generated Poetry to create collective poems that addressed our research questions. Second, we used Found Poetry to produce a set of individual poems; these conveyed three participants' (one from each workshop) particular experiences of practicing self-care. Within the limits of this paper, we explicate the second step in our method. We give an overview of our process before sharing our insights and reflection.

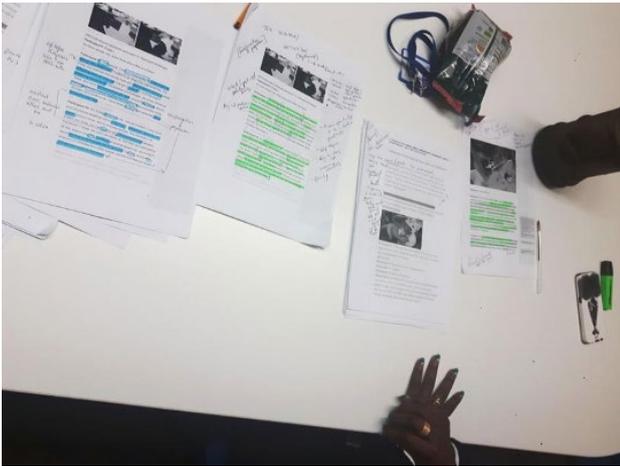


Figure 3: Preparing the data for the Found Poetry engagement.

Found Poetry to convey participants' unique journey

Gearing in by collating data: Each transcript of a workshop included photographs of each artefact created by each participant, in the timecode in the workshop where it was presented.

Immersing ourselves through coding: Guided by our impetus to address our research questions, we utilised Deductive Thematic Analysis (Braun and Clarke 2006) to code the transcripts; using the commenting tool in Microsoft Word, we attended to how participants talked about their journey. This resulted in a set of themes that illuminated experiences and definitions of HIV self-management and self-care.

Enhancing coding through Poetic Inquiry: This process allowed us to capture verbal and non-verbal cues, including pauses and speed of speech, and the metaphors, imagery and repeated utterances. Individually, we also commented on our recalled feelings in facilitating the workshops, highlighting emotive moments, which we found relevant.

Preparing data for Found Poetry: We shared the annotated transcripts between us and selected three participants, one from each workshop; these represented diverse profiles and experiences. For each, we focussed on all their captured utterances

and expressions. At this stage, we selected extracts that conveyed the emerging theme of a sense of self and self-growth (Figure 3).

Drafting individual poems: We selected previously coded utterances that we felt would 'breathe life into the poem' (Butler-Kisber 2010) whilst conveying the themes. The peer-researcher drafted poems, developing compositions that used participants' original words and phrasing, but slightly altering the order in which they were spoken.

Forming a visual responding to the poems: A further creative step was to respond to the poem using Visual Inquiry (Butler-Kisber 2010; Yuen 2016). A visual response led by the communication designer interpreted metaphors and evocative feelings portrayed by the poems. Visual Inquiry enabled a creative engagement with text and with the non-verbal utterances that had been noted and reflected on previously. Within the scope of this paper, we do not report on the outcomes of this step; we focus on the content of poems presented in Figures 4-6.

Sharing and disseminating the poems: The poems were created in collaboration with our participants. We shared draft versions with them and invited their creative response and feedback. This informed the finalisation of each poem and its visual presentation, for future dissemination.

Discussion and Concluding Thoughts

Qualitative insights

We suggest herein that the three poems, 'To persevere' (participant 1, P1), 'The teacher' (P2) and 'Becoming the advocate' (P3), work to communicate qualitative insights about individuals' sense making on practices of self-care for living and ageing with HIV. Arguably, each poem incorporates key phenomenological themes, as presented in in Figures 4-6 (themes are indicated on the right).

To persevere represents the challenges of living with comorbidities, which, in the case of P1, is more challenging than living with HIV (Figure 4, theme highlighted in blue). The poem also conveys the role of the HIV community in empowering P1 to self-manage and practice self-care. The teacher highlights the central importance of connecting with others and sharing experiences as a source of self-empowerment and to help with getting support that is needed (Figure 5, theme highlighted in green). Self-care is described

in terms of self-responsibility and agency, starting with oneself (e.g. 'Unlock it, then you start getting all this support'). Becoming the advocate captures a sense of a personal journey over time shared by participants; the poem emphasises how emotional growth and self-reflection enabled P3 to build his resilience in the face of adversity, and to grow confident about his HIV status (Figure 6, theme highlighted in orange). Below we present the three poems. The annotations highlight key themes.

To persevere

not hmm give
 give together two faces
 No!
 I want just one
 as I am
 going through every, every
 every obstacle
 – obstacles
 I will be me

Challenging stigma, being myself

Developing resilience

I have
 28 years of HIV
 Self-care is very hard for me
 things are good with me, with my HIV
 Self-care is too hard for me
 my diabetes

An ongoing journey, long-term diagnosed

Comorbidities, reaffirming that HIV (with access to treatment) is a manageable chronic condition

Sometimes I go down
 it influences my – my blood sugar
 going on hypos
 No come up, you can't go down
 I must take care of me
 I am lucky I think and I am happy
 I have so much strength around me
 from YOU ALL
 Today is a good day to care of me
 I go on
 as I believe I am

Feeling of gratitude

Peer-support, being empowered by others

Self-care involves self-responsibility for looking after oneself

Figure 4: 'To persevere' (P1) emphasises the challenge of living with comorbidities (blue text).

The teacher

The myth can fall aside
The world has not ended
I'm moving forward
unlocking potential
that won't go away from me
the potential other people have got
un
lock
it
something to put into practice

Challenging stigma and poor
mental health related to diagnosis.
An ongoing journey

Shingles
We need to – we need to test for HIV
immediate support there were the doctors
unlock it
then you start getting all this support you see!
Every week I'm doing goal setting
planning for my health
ahead of time
Every Monday, every Thursday
they cook hot meals here
serve hot meals
free to every service user
they pack you food
unbelievable!

Living with commorbidities

Self-care starts with yourself
Self-responsability

Self-stigma they call it
I heard situations where families deject when they hear
my immediate support was my family
number one!
Continue self-stigmatising myself
I would not have got it
the support that people come to give you!
They're fully supportive

Vulnerability, possible latent message
of poverty, support required

Being grateful

Go and get out
unlocking the positivity
anything you want to add there?
love there
unlock it
support
what you've unlocked from other people
changes the world, for the better

Peer-support, supporting others is
empowering

Figure 5: 'The teacher' (P2) emphasises peer support and connection to others (green text).

Becoming the advocate

Coming from the blue
self-reflection

Coming from the blue
self-discovery

Coming from the blue
cost two people their jobs

I didn't know who I was

Coming from the blue
Obviously the treatment wasn't available straight away
Big one for me is being listened to
I need a treatment discussion
it was really rushed
slowly starts to deteriorate
long-term side effect
I go every six months
a consultant that just doesn't trust my judgment!
I'm trying not to get my activist hat on but...

Coming from the blue
my affinity to the sea
Spiritual connection with the elements
A very spiritual journey
Massive fifteen year journey
He's been an absolute constant
my fluffly
he's been an absolute constant
he is always there

I am back at work
Coming from the blue
getting myself brought off my antidepressants
I love what I do

I disclosed on my application
my interview
even disclosed to my line manager
Don't have to
this is me
part of my life
it's nothing to be ashamed of
if I can change things from the inside I will

Mental health, double entendre:
participant is a former navy and refers
to his mental well-being

Stigma, highlighting the loss of
opportunity and connection due to
stigma

Reaching out for support

Being vulnerable

Personal journey, emotional growth

Companionship provides emotional
support

Maintaining good mental health

Challenging stigma, sense of pride,
growing confidence

Figure 6: 'Becoming the advocate' (P3) emphasises the personal journey and importance of self-reflection (orange text).

Practising co-creative analysis: closing reflections

Reflecting on our co-creative inquiry, we highlight herein how we attended to each other's positionality, subjectivity and expertise in visual design, creative writing, and social psychology, respectively. We built on previous work (Miller 2018; Sjollema et al. 2017) to acknowledge the importance of trusting our intuition and empathetic engagement as practitioners: we were emotionally engaged to form creative responses; we took interpretative steps in dialogue and creative exchanges; we took turns to engage with the data, and considered each other's perspectives. We (i.e. the three researchers) were involved throughout all stages: from devising the workshops, to their delivery and analysis. Moreover, as a peer researcher, the poet is living with HIV, which helped us build relationships of trust with the participants and facilitated dialogue.

Reflecting on our emotions when engaging with the data and acknowledging how they shape interpretation was critical for negotiating ethical tensions in this work. We developed awareness of how our relationships with the data encouraged reflective practice between us (Schon 1983). Externalising our feelings helped us retain a closeness to the data and individual participant voices.

Finally, we recognise that 'knowledge claims are conditioned and partial' (Lichterman 2017), meaning that we are 'knowledge co-creators' with the participants. We engaged in 'ethical crafting' (Sjollema et al. 2017), nurturing a dialogue with them. Looking forwards, we identify the value of co-creative analytic practice for design-led research, to communicate and disseminate research findings in a way that retains the original voice of the idiographic account, and places emphasis on emotional experience and how this is made sense of in dialogue and remains open to interpretation. In closing we

highlight the potential of alternative platforms for disseminating poems as empirical outcomes, and considerations around their performative reading to particular audiences. We encourage other Design4Health practitioners to appropriate Poetic Inquiry for capturing the complexity of lived experience, in ways that acknowledge how participant-researcher-subjectivities are illuminated in co-creative research practice.

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MAKING IN THE MOMENT: INSIGHT FROM PARTICIPATORY ARTS FOR CO-DESIGN PRACTICE IN DEMENTIA CARE SETTINGS

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Abstract

Design for dementia literature calls for greater degrees of personalisation and participation for people living with dementia, while acknowledging that 'alternatives are also needed to the one-on-one approaches, often used in the development of highly personalized outcomes' (Kenning 2018, 2).

We respond to these provocations by reporting on a qualitative study in a care home setting that informed Inclusive Design directions for dementia care. The professional practice of conducting participatory arts workshops in this setting was empirically observed and analysed, to deliver transferable insights that may advance co-design methodology for dementia care design contexts.

This paper presents an autoethnographic account taken from a year-long participant observation in a residential care home in Northern England, by a designer volunteering for a creative ageing charity that runs participatory arts workshops. In presenting the designer's account about his involvement in the development of a large-scale

participatory artwork with this charity, and his facilitation of 30 workshops, the paper captures empirical insight and learning from working alongside experienced creative professionals. We critically reflect on this insight, discussing its relevance to co-design practices in residential care contexts, and calling for designers to draw their strategic focus away from identifying notions of 'good; or 'bad' design outcomes, and towards celebrating the act of creative intent and voice-giving through co-design practice. We offer methodological insight for Design4Health that is grounded in a recognition of the importance of authorship and autonomy of people with dementia: the facilitation of creative expression should ensure that there is reciprocity within co-design methods, between those who are involved with creative practice in the form of one-to-many, or many-to-many.

Keywords: dementia, co-design, participatory arts, care home, creative ageing



Introduction

We report on an autoethnographic account following a year-long participant observation by the first author in a residential care home specialising in advanced dementia care. This work was conducted alongside professional participatory artists from Equal Arts, a creative ageing charity who have been delivering arts workshops in care homes for over 30 years.

We critically reflect on how insights from this participatory arts practice may advance co-design methodology for dementia care contexts. Drawing on this case, we highlight three key challenges for design research, relating to the value of participatory arts practice in dementia care contexts. These challenges are to: (1) accommodate a greater focus on the moment of making and intentionality in co-creative practice; (2) recognise the key role of facilitators to creative expression, appreciating how this social practice has impact beyond each participatory activity; (3) understand the importance of increased personalisation in design practice while confronting the reality of the scale of deployment needed to benefit those living with dementia.

Background

Dementia and The Arts

With no cure for dementia, UK policy making focuses on finding ways for people to live well with the condition (NHS 2018) primarily following the framework of Person-Centred Care (Edvardsson, Winblad, and Sandman 2008). There is a substantive body of practice and research in the field of dementia and the arts which support such person-centric approaches (All-Party Parliamentary Group on Arts Health and Wellbeing 2017).

Arts practice has been empirically shown to aid communication, expression, confidence, social participation, and a sense of freedom (Zeilig, Killick, and Fox 2014). Benefits to

quality of life are observed through the act of participatory creative practice, with a broad range of arts therapies in dementia care reinforcing 'sense of control, life meaning, and personal satisfaction' (Cowl and Gaugler 2014, 308). Arguably, it is the job of the facilitating artist in a dementia care setting to enable each person 'to do what otherwise he or she would not be able to do, by providing those parts of the action - and only those - that are missing' (Kitwood et al. 2019, 109).

Co-design practice for People with Dementia

Design literature has called for greater personalisation and participation to allow people living with dementia increased creative expression: 'Design [which] allows for individualisation is likely to be useful for people with dementia and acknowledges the multiplicity of experiences which people with dementia and their families may face in the course of the condition.' (Morrissey, McCarthy, and Pantidi 2017, 1328). Craig calls for designers to 'see individuals' creativity and resilience, have confidence in design ... to offer individuals structures and vehicles through which to be heard.' (Craig 2017, 62). Hendriks et al note the benefits of creative expression and acknowledge the need for designers to build embedded relationships in care settings (Hendriks et al. 2018, 59–60). Arguably, the need for embeddedness conflicts with the call for these design projects to be adopted at a scale with the potential to benefit the growing number of people living with dementia (Zeisel 2010; Wey 2006), especially those most vulnerable who are living in under-funded residential care homes (Thwaite 2017).

In presenting this study that engages with professional participatory artists' practice, we contextualise calls for design research to push further towards forming empathetic, creative collaborations with residents (Swaffer 2016). Our insight builds on work that discusses the heightened emotional

experience of living with dementia through creative practice (Killick and Craig 2012; Kitwood et al. 2019) and that acknowledges its potential to influence social dynamics within the care home (Bratteteig and Wagner 2012). We also wish to highlight challenges for designers delivering greater personalisation to people living with dementia in light of the shortage of resources in the care sector.

The Study

Each workshop involved 5 to 20 residents, one or two professional arts practitioners, activities coordinators, and the first author in a dual role as Design Researcher and Volunteer Facilitator. Thirty workshops were documented over a year-long period in which a large-scale collaborative textiles artwork was produced with residents.

Our key research questions follow.

1. How can we design to deliver greater degrees of personalisation and participation for people living with dementia at a scale commensurate with the context?
2. How can techniques from professional participatory arts practice translate into co-design practice in a dementia care setting?

Methodology

Our approach was informed by Sensory Ethnography (Pink 2015), which allows verbal and non-verbal communication to be considered equally. Pink's methodological focus on the relationship between the material and emotional experience of selfhood guided particular a focus on sensorial qualities and interactions when documenting field notes. This was valuable in the arts workshops, which were rich in multi-sensory stimuli, including music, aroma, textural exploration, food and drink, embodied movement and dance alongside visual activities.

Participant Observation enabled embedded research practice, for building relationships over time within a community of residents.

Interpersonal dynamics were focused on in workshops alongside the needs and expressions of individuals.

Field notes were interpretatively coded following completion of the field work. Notes and codes were then re-coded using Ethnographic Analysis (Ghodsee 2015) to form an autoethnographic account, extracts from which are presented here.

Ethics

This research received ethical approval from Northumbria University and was conducted within the Ethical Working Guidelines of our partner Equal Arts. All names, places, and identifying details within the account presented have been pseudonymized.

Autoethnographic Account

The following vignettes have been chosen from the first author's autoethnographic account to elucidate key methodological insights. Note that the authorial voice shifts to the first author in this section. Key moments have been selected to demonstrate the artists' methods put into practice.

Extract 1

Emily and Pip had initially been asked to decorate a fabric starfish that lay untouched beside them, but they had instead taken control of the direction of their work.

Pip leaned in to watch as Emily moved two pieces of fabric from position to position on the table in front of them like a chess game. They used a fabric maple-leaf Pip had previously made, with deep autumn colours chaotically scribbled onto its spiky form and a plain offcut of peach-coloured felt.

Emily used deliberate gestures to describe the relationship between the two pieces, moving her hands in unison to carve a neat circle in space around them to make her meaning clear, something that would often elude her in strictly verbal communication.

'Similar? Balanced? Opposing? Unified? Playful?' I suggested.

'They're nice, the way they play together.' She nodded.

They continued experimenting throughout the workshop, discussing the layout intensely; adding, and amending, elements they found. Eventually settling on a composition both were satisfied with, showing it off carefully.

Seeing their pride, I asked what they thought should happen next.

'Ooh, you could see it properly then, if it was up on the wall! You know, ironed and pressed and in a frame...'

Facilitators had the ability in the space to encourage, prolong, and celebrate these moments of creation.

I helped carefully pin the design onto a piece of blank calico, with Emily correcting me as I made mistakes. Working as the facilitating artist I was guided by Emily to help realise the piece as she saw it.

Emily is usually quite shy, though when we held the final piece up for everyone to see she admitted;

'I'm not that bad, am I?' with her shoulders raised.

Extract 2

Artists were able to personalise the pursuit for creative expression while enabling collective participation and contributions, afforded by the careful choices of material and spatial interactions.

Residents each chose a fallen autumn leaf and traced around it onto fabric, then coloured their artworks in using marker pens.

The spatial arrangement of the activity was very clear to interpret; the leaf and resulting drawing ended up exactly equal in size as a result of tracing, and all of the residents chose to use colours closely matching their leaves at first, resulting in highly figurative artworks.

If people drifted in and out of engagement with the activity, they could get back on track easily as the materials in front of them were physically suggestive of the activity in hand without having to vocally question what was going on, or what to do next. This resulted in a particularly high uptake which, in turn, encouraged yet more residents, often less keen to take part, to engage with the activity.

The relaxed atmosphere of joining-in encouraged greater creative exploration, with some residents moving away from the representative into more abstract and self-expressive imagery within subsequent artworks.

Extract 3

Convivial group activities were sometimes at odds with individualized interactions, where artists sought and identified discrete authorship among collective work.

During a drawing activity Claire was searching restlessly through the papers at her table. I saw she was strumming her thumbnail along the corner of each sheet of paper in turn to see if any individual pieces were actually two stuck together. After some time, we were able to work out she was looking for the artwork she'd started in the previous week's workshop.

She tried in vain to describe to me what it was she was looking for; it took a long time checking each piece of paper in the room with her until finding the drawing she was looking for. Once recovered, Claire recognized it instantly and started working again as soon as she had it back. What was particular about the artwork was how small and gentle it was, yet still completely recognisable to her. The artwork was just four tiny circles, lightly drawn in pencil towards one corner of an A4 page, no bigger than a coin.

The beauty of created artworks was foregrounded in interaction by residents and artists; built over time through empathy. Artists sought to simultaneously

hear the quietest voices while bringing group activities to as many residents as possible.

Discussion

We present three transferable insights for co-creative practice, framed as challenges for the community and highlighting structural tensions in the context of co-design methods in dementia care.

1. Making in The Moment

During our workshops artists' key focus was on the making; resultant perceived aesthetic beauty in the objects was derived from collective celebration and careful curation. This was, at times, in tension with the perceived agenda of external agencies in the project, whose focus was typically more on the material manifestation of artworks, rather than the moments of creation.

A conscious focus on celebrating the moments of creativity during a making process can define the collective experience of participants and foster a sense of designers being open to and sensitized to ideation by those moments. We echo extant reviews of arts practice reporting benefits to 'personal sense of control, life meaning, and personal satisfaction'(Cowl and Gaugler 2014, 308) regardless of the material arts process employed.

Inputs from participants may be critical during creative processes to define the design response, rather than that being led by the designer on a problem-solving trajectory. We encourage designers to step back and give more control on the direction of design work, creation and decision making to participants in co-creative practice.

2. Curating Social Spaces

Significant expertise is needed to orchestrate social activities which are collective, while also bringing individual meaning for many participants. The degree

to which interactions are carefully tailored reinforces the necessity for skilled creative practitioners to 'be there', to share in and observe moments of making. Co-creative work in dementia care has the potential to ensure reciprocity between actors.

Key moments of the workshops were those where individuals felt comfortable enough to; break rules, question, and disrupt established expectations. Playful and joyful creativity came about through mutual encouragement, facilitation, and openness. Artists were attuned to the emotional and therapeutic potential of making and creating together (Killick and Craig 2012). We suggest that design researchers can also deliver in this regard, given the right approach, by learning from other creative disciplines and practices.

Dynamic flexibility is needed to invite people living with dementia to meaningfully disrupt and personally explore the bounds of creative practice. The artists in our study keenly encouraged social dynamics in which people were supported to develop and express individual creativity, often challenging the discourse of the space at the same time as working within it. Recognition of the importance of authorship and autonomy superseded preconceived expectations.

Listening to the choice of each person living with dementia was transformative for the first author. Co-design has the potential to position individuals as experts, navigators, and inventors. Surrendering ideas of good or bad design, and rather advocating for designing itself, we have an opportunity to disrupt power imbalances. Handing over the reins and letting people in can lead to aesthetically pleasing processes and unexpected happy results. Significantly, the act of making is democratized and can be celebrated aside from any material outcomes.

3. Personalisation at Scale

Designers are well placed to approach the daunting problem of delivering individualized participatory practice at scale, appropriate to the numbers of people living with dementia in residential care.

This undertaking involves confronting key tensions within the existing discourse, and real-world context of care homes. With limited resources available, we invite designers to embrace personalisation and participation, at a scale commensurate with the context of care. We call for future work that creates opportunities for more people with dementia to benefit from these moments of creation which 'should work to enrich this co-presence rather than provide a facsimile of it' (Morrissey, McCarthy, and Pantidi 2017, 1328).

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FINDING SYNERGIES BETWEEN INDIGENOUS & DESIGNERLY WAYS OF KNOWING

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Abstract

In Canada, Indigenous people experience significantly poorer health outcomes than non-Indigenous people due to colonial policies and systemic racism which permeate the healthcare system today. The policies that severed many Indigenous peoples' ties to their culture and communities have resulted in ongoing, multi-faceted and adverse effects towards mental, emotional, spiritual, cultural and physical health. Entrenched within its colonial history and present, the healthcare system fails to acknowledge culturally-specific knowledge and practices including Indigenous perspectives on health. This paper highlights two projects in which a participatory design approach is used to complement Indigenous-led approaches, in efforts to address issues of cultural safety and discrimination within and access to health and community services.

As the role of design expands to address larger social challenges such as health equity and community building, new opportunities are created for weaving our processes, ways of knowing and sharing together. This includes foregrounding Indigenous knowledge in projects that span Indigenous and non-Indigenous community contexts.

While being aware of the differences between design approaches and Indigenous ways of knowing, we have identified synergies, including values of relationships, lived experience, storytelling, and making. Through showcasing these two projects, we posit that the future of design can support complex cross-cultural initiatives for health equity in collaboration with Indigenous communities.

Keywords: participatory design, Indigenous, Aboriginal, First Nations, health equity, cultural safety

Introduction

In Canada, Indigenous peoples' ties to their culture and communities have been severed due to colonial policies and systemic racism, resulting in ongoing, multi-faceted and adverse effects towards health. The healthcare system fails to meet the needs of Indigenous people, in large part by overlooking culturally-specific knowledge, perspectives and practices around health. Indigenous people report experiencing pervasive racism, discrimination and (re)traumatization when trying to access healthcare and social services. There is a clear need to improve health care and experiences for Indigenous peoples in Canada; in this work, healthcare providers, researchers, and designers can and must learn from Indigenous worldviews, which have supported Indigenous health and wellness for thousands of years. Indigenous approaches to research are especially well-suited to surface the nuanced experiences of people navigating hostile systems, helping to illuminate the intangible and hard-to-measure impacts of policies and practices.

Much like Indigenous ways of doing and knowing, participatory design — as an approach to research and problem solving — is often overlooked and underutilized in health contexts. Designers continue to expand their scope of inquiry, moving beyond product-oriented outcomes toward projects that address larger societal needs, such as health equity, cultural safety and education. While it is challenging to successfully combine colonial research methodologies and Indigenous epistemologies, there are synergies between design approaches and Indigenous ways of being that offer new opportunities for cross-cultural, interdisciplinary collaboration — learning to weave our processes, ways of knowing and sharing together.

Throughout this paper we will use the terms Indigenous people(s) and Indigenous communities to refer broadly to the Indigenous peoples living in British Columbia (BC), Canada.

Case Studies

The Health Design Lab (HDL) at Emily Carr University of Art + Design (ECUAD) is a research centre that applies human-centred participatory design approaches to address health and healthcare challenges in collaboration with community and industry partners. HDL has begun collaborating with Indigenous leaders and communities within BC, exploring ways that participatory design approaches can amplify the voice of Indigenous peoples within the health system. In this paper we share lessons learned from two projects in which a participatory design research approach is used to complement Indigenous-led approaches.

Avenues of Change

Avenues of Change (AoC) is a multi-year, multi-phase project funded and guided by United Way of Lower Mainland that focuses on supporting early childhood development within communities. HDL and the Social Planning and Research Council of British Columbia (SPARC BC) were co-contracted to lead family and stakeholder engagement sessions in Squamish, BC, to identify the needs of families with children 0-6 years of age.

HDL was primarily responsible for engaging directly with families to uncover opportunities for improvement. From the onset of the project, it became apparent that the biggest challenge would be connecting with families to participate — in particular creating a space for Indigenous families to feel respected and invited as key contributors. Ultimately, we were able to work closely with Squamish Nation's community leaders to arrange a series of activities including an Indigenous-led Talking Circle, co-design activities and a Blanket Ceremony. This phase of work resulted in a series of action strategies for how local organizations could address systemic challenges facing families in Squamish.

Cultural Connections

Cultural Connections explores how Indigenous-led arts and material practice workshops can foster open dialogue between non-Indigenous healthcare students and Indigenous community members in Prince George, BC. The goal of the project is to develop an Indigenous-led model for cultural safety and humility training that leads to fundamental changes in healthcare providers' understanding of Indigenous perspectives on health; results in positive changes in healthcare experiences for Indigenous people; and can be scaled and adapted to the unique needs of Indigenous communities across BC.

The team on this project is composed of Indigenous leaders from the Aboriginal Gathering Place (AGP) at ECUAD and the College of New Caledonia (CNC), designers from HDL at ECUAD, external consultants working in healthcare and community planning, and Indigenous artists. The project is currently in progress, having completed the first of four pilot workshops. Preliminary insights and lessons are shared here as we learn how to work as a mixed team of Indigenous leaders and designers.

Synergies

'The use of design within the context of Indigenous communities raises concerns. This has to do with the characteristics of design to 'improve' lives and its emphasis on innovation... We thus have to find ways to deal with such concerns, especially when working with groups where the notion of colonisation is sensitive.' (Reitsma et al. 2019)

Through these two collaborations, we reflect on our role as designers, as well as the application of design methods in Indigenous community contexts:

Where do designerly ways of knowing fit and align with Indigenous ways of knowing?

Where are the synergies that can lead to impactful collaborations?

Where must we be aware of colonial approaches within design?

How can we maintain an Indigenous-led approach?

Synergy A: Storytelling and lived experience is valued

While lived experience is often overlooked in Western research, Indigenous communities are activating their story-based traditions for research purposes. Story-based traditions and oral histories are a fundamental aspect of Indigenous ways of nurturing relationships, knowledge and culture. Lived experience stories-as-research respond to the need for authentic interpretation, representation and analysis of Indigenous knowledge systems. (Archibald et al. 2019)

Design approaches also differ from many dominant Western research paradigms for valuing lived experience and storytelling. One of the core philosophies within participatory design research is the notion that in order to gain an understanding of someone's perspective and experience, we must include them in describing and sharing that experience (Sanders et al. 1999). We acknowledge that we are not experts in any given experience and thus must seek to learn from those who are. This respect for community voice and the sharing of knowledge in a variety of forms — including through oral and visual experience — aligns with Indigenous research methodologies.

In many Indigenous communities, Talking Circles are a ceremony where each person is given an opportunity to take an uninterrupted turn in discussing the topic (Wilson 2018). In our projects, we have found this to be a critical method for engaging participants when led by Indigenous leaders.

In the Avenues of Change project, we collaborated with Joy Joseph-McCullough (Associate Education Director, Squamish Nation), and Charlene Williams (Culture and Language Worker, Squamish Nation)

to plan and lead a day-long co-design event with 16 Squamish Nation parents. Joy led the Talking Circle, inviting everyone to share their truths and experiences around parenting as they received the eagle feather being passed around the circle. While everyone listened intently without comment, each participant spoke empathetically, candidly and openly about a variety of issues they faced. Many community members mentioned they often felt alone in their struggles; having the time, space and opportunity to share these experiences was extremely valuable and created a sense of connection and support among everyone present.

The Talking Circle was originally scheduled for 45 minutes but lasted for 2 hours. Allowing the Talking Circle to last as long as needed was important for everyone to share their stories in as much depth as they wanted and needed, knowing they had the support and undivided attention of everyone in the Talking Circle. It was immediately evident that the Talking Circle was an effective and culturally appropriate way to hear from families, and some of the design activities that were originally planned for the day were no longer needed. Being prepared with a repertoire of design activities was important for this session – but so was being able to release control, be adaptive and flexible in the moment, and rely on intuition to guide the day.

Storytelling also plays a critical role in the Cultural Connections project. Marlene Erickson (member of the Frog Clan in Nak'azdli First Nation and Executive Director of Aboriginal Education at CNC) is skilled in oral tradition, the practice of retaining the history of Indigenous peoples by passing cultural information orally from one generation to the next. Throughout our pilot workshop, Marlene shared her Nation and clan's connections to the land, teachings and language, family history, and ecological knowledge. Her stories helped participants understand the sophistication of traditional teachings and approaches

to health and healing, deepening their understanding of Indigenous perspectives on health and wellness. Storytelling also created a gateway for participants to reflect on their experiences. In the workshop, participants drew parallels between their current health system experiences and the way community health and care is/was organized through the clan system.

At least one Talking Circle was programmed each day, inviting participants to share their experiences. A key learning from the use of Talking Circles in this project was on our involvement as design researchers. As researchers, we seldom share our own thoughts and perspectives when working with participants. However, we were encouraged by Indigenous leaders to share our experiences to build a safe environment for participants to open up about theirs. The reciprocity in sharing created a stronger community bond between project participants, researchers and organizers.

Through these projects we learned that Talking Circles, storytelling and oral forms of knowledge transmission are important methods for engaging with Indigenous communities and are also beneficial in the design research process. These can be very powerful tools for gathering insights and fostering dialogue when led by Indigenous leaders, with designers in an appropriate support role as story-listeners. It is critical not to overlook the value of these practices, particularly as designers often tend toward more 'creative' or 'hands-on' strategies.

Synergy B: Collective Making enables Dialogue

Collective making plays a critical role within co-design processes. Within a co-design process, making is understood as a strategy which allows participants to express themselves in new ways, often leading to deeper insights and expressions of ideas and experiences. We have observed that making as a co-design strategy can be effective in collaborations with Indigenous communities.

When working with Indigenous communities, the benefits to participants of collective making as described by Langley et al. (2018) – including levelling hierarchies, therapeutic value, engaging hearts and minds, giving voice and enabling different perspectives – are particularly relevant. Historically, Indigenous peoples have been subject to research that is done ‘about’ them and ‘on’ them, rather than ‘with’ them. This has understandably created tension between many Indigenous communities and research participation.

When we began our Avenues of Change project, we experienced this tension in our initial meetings with Squamish Nation. Joy and Charlene were sceptical that our project team would be able to recruit families to participate in research activities, given the

low turnout in past partnerships in which researchers utilized Western approaches. However, when presented with tactile and discussion-based engagement options that were grounded in storytelling and building connections, the response towards the project and recruitment shifted. Through ongoing dialogue and collaboration, we were able to plan a full day event including a Talking Circle, co-design activities, a family feast and Blanket Ceremony.



Figure 1: Hopes & Dreams Co-design Activity

The use of co-design activities for engagement created a community dynamic that interested families. It allowed them to share their voice, hearts and minds in a

way that was culturally safe and relevant. For example, one activity used a metaphor of rocks and balloons to help families consider and express their hopes and

dreams (balloons) for their children, as well as the 'on-the-ground' support (rocks) needed to help realize these dreams. These design activities provided some structure for gathering more focused insights that complemented those gathered through the Talking Circle.

In our Cultural Connections project, the ability for collective making to level hierarchies is particularly pertinent. In a typical healthcare context, there is a significant power imbalance between healthcare professionals and Indigenous people. However, by bringing everyone together outside of a health context to learn about Indigenous material practice, we are able to shift the focus of power towards an Indigenous perspective.

Each day of the pilot workshop, a different local artist guided participants through a making activity. While projects were

typically completed individually, the act of making them together in the same space was an instant icebreaker, fostering conversations about craft skills and aesthetic preferences. Some activities – such as softening elk hide for drum making – brought about opportunities for collaboration amongst participants, which in turn led to moments of pure, shared joy. The varying skill levels of each participant also equalized any perceived power dynamics in the workshop. For some non-Indigenous participants who found activities challenging, it was a true lesson in cultural humility. The activities accelerated rapport between participants, researchers and organizers meeting for the first time, and created an inviting environment to share personal experiences.



Figure 2: Softening Elk Hide for Drum Making

Through these projects, we observed that participatory design and planning methods can be combined effectively with Indigenous material practice, to create space for deeper learning, interpersonal connections and understanding of complex experiences.

Synergy C: Relationships & Flexibility

When working within Indigenous communities, it is essential for non-Indigenous researchers to prioritize relationship building, and to work toward a collaborative and culturally appropriate engagement process. This process must be intentionally rooted in a shared set of guiding principles that honour the voices of community and that act on principles of inclusion, truth, reconciliation, and decolonization.

As Wilson articulates in *Research is Ceremony* (2018), the building of relationships is a key element of research, ensuring that it is done respectfully and with reciprocity. He explains,

'While forming all of these relationships, you can understand the responsibility that comes with bringing a new idea into being (or articulating/making visible an existing one). The new relationship has to respect all of the other relationships around it. Forming and strengthening these connections gives power to and helps the knot between to grow larger and stronger. We must ensure that both sides in the relationship are sharing the power going into these new connections. Without this reciprocity, one side of the relationship may gain power and substance at the expense of the other.'

Working with Indigenous communities often means working in new ways and reconceptualizing what it means to collaborate, well beyond a typical client-designer relationship. Along with this comes the need to work flexibly, adaptively and slowly, ensuring that the correct

relationships and foundations are laid before anything can move forward. Once the foundation has been laid, we have found great success in collaborations, but the initial relational groundwork cannot be rushed.

The Avenues of Change project was initially slow, as we worked to find a balance between the proposed timeline provided by the project funder and the pace of the community. Moving at the speed of trust (Brown 2017) with our Squamish Nation partners, the engagement activities began to crystalize. The project gained momentum because respectful communication led to deeper trust and mutual understanding.

Likewise, with the Cultural Connections project, collaboration was critical and in this case was built upon two decades of relationship-building by the AGP at ECUAD. Our project team has continued to approach the work through an Indigenous-led, relationships-focused process. Examples include meeting with Indigenous leaders to hear concerns prior to starting the project, hiring local consultants and organizations to build capacity in the area, and adjusting the workshop plans based on feedback from our Prince George-based Indigenous team leaders. Prioritizing these actions has deepened the team's existing relationships and goodwill with local Indigenous communities, while setting relational precedents for new project team members to learn and incorporate into their professional practice.

Conclusion

Recognizing and respecting the deep knowledge that already exists within Indigenous communities is fundamental to effectively address any social challenge and health inequity faced by Indigenous peoples. For researchers and designers working in Indigenous contexts, it is essential to centre and uplift Indigenous ways of knowing, while offering rather than imposing designerly ways of doing

research. Designers must be careful not to allow their passion for design approaches to overtake Indigenous approaches, becoming just another colonizing methodology, and also must take care to avoid lifting and appropriating Indigenous methodologies in design work without permission or Indigenous participation.

Identifying the synergies between participatory design methods and Indigenous approaches – which both value storytelling, community voice, making, and relationships – can help non-Indigenous designers in their own learning journey when working in Indigenous cultural contexts. Ultimately, engaging with respect and humility from the onset of collaborations forms the basis for developing shared understanding between designers and Indigenous community partners. Only then can relevant and meaningful work begin.

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JOURNEYING THROUGH DEMENTIA THE STORY OF A 14 YEAR DESIGN-LED RESEARCH ENQUIRY

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Abstract

Journeying through dementia is a design-led research enquiry that interrogates the role of design and creative practice in post-diagnostic dementia support. The broader enquiry spans a period of fourteen years, from the utilization of participatory design research methods to co-create the intervention with people living with dementia through to work with policy makers to develop tools for operationalization.

This paper begins by providing an overview of the broader context of the research before focusing on the most recent element of the enquiry that sought to understand the role of design in enabling clinical staff to facilitate the intervention. In this phase of the research, a thinking-through-things methodology named exhibition in a box was employed

to understand the requirements of clinicians in delivering Journeying through Dementia. These findings were translated through an iterative co-design process into a series of curated creative tools for clinicians, which were then tested in mainstream health services across two health boards in Scotland.

This is the first design-led research enquiry to interrogate the role of design in clinical post-diagnostic dementia support. Reflections are offered on design as translation in research and the paper shares critical insights in relation to the complexity of co-design in this context.

Keywords: Dementia, design-led research, participatory design, thinking-through-things, co-design



Introduction

Dementia is a term used to describe a group of syndromes including Alzheimer's disease, which are characterized by deterioration in cognitive functioning. Dementia affects memory, mood, comprehension and communication and has been identified by the World Health Organisation (WHO, 2017) as one of the major causes of disability worldwide, impacting on both the person and their caregivers and families

At present it is estimated that 47.5 million people have dementia (Alzheimer's Disease International 2015). In the absence of a cure, emphasis has been placed on the development of approaches and interventions that focus on quality of life. Post-diagnostic support, where individuals are supported to develop strategies to live well with the condition, has formed the basis of global health policy (Department of Health 2016).

Whilst there is a growing interest in the role that design-led interventions can play in promoting quality of life of people with dementia (e.g. Treadaway, 2018), to date little attention has been paid to the role of design in post-diagnostic support in the context of health-care services.

Background

The enquiry described in this paper has its origins in 2006. At that time, the peer led self-care support programme for people with long term conditions named the Expert Patient Programme was garnering support and a plethora of interventions were being designed for people living with chronic health needs. However, in spite of this growing interest, self-management approaches to enable people to live well with dementia were noticeably absent (Mountain 2005).

Our research therefore sought to build understanding of the experiences of people living with dementia and the interventions that they considered to be important

and helpful soon after diagnosis. The overarching question our study posed was whether it was possible to support people at an early point of their dementia journey to develop design-thinking skills that could be applied as their dementia progressed. If these skills could be developed and retained whilst people were cognitively able to do this then there was a possibility that they might be enabled to effectively re-design their lifestyle and the broader environments in which they lived to accommodate and respond to the challenges that dementia might bring.

Ethical approval was obtained to undertake the research and over the period of six months people with dementia shared their experiences of living with condition.

An iterative participatory co-design research process with people recently diagnosed with dementia generated a series of topics that individuals identified as being important to support wellbeing. These topics formed the basis of the clinical intervention named by participants as *Journeying through Dementia* (Craig and Mountain, 2012).

The final programme, *Journeying through Dementia* comprised of a 12-week group programme facilitated by a qualified occupational therapist, in which individuals recently diagnosed with dementia would meet for two hours a week and select topics from a range of themes they would like to explore. The intervention sought to enable individuals to develop the necessary design thinking skills and coping mechanisms required to enable continued engagement in meaningful activities. A menu of themes developed from the research was provided so that each group could effectively design their own programme. Consequently, rather than individuals fitting into a group, the group would meet the individuals' need. Topics were broad and wide-ranging and included: redesigning the environment, building community connectivity, designing communication strategies as well as themes exploring the relationship between creative activities and wellbeing.

Two small empirical research studies to test the efficacy of the intervention were undertaken by the first author (Craig 2014) and by Sprange et al. 2016. The qualitative evidence over these studies indicated that participants experienced a number of benefits. These included increased self-efficacy post diagnosis. Analysis of interviews post-group showed that individuals experienced increased self-confidence:

‘What you’ve done for us has got me to the top... it’s put me back where I used to be... what we’ve been doing in here and saying and thinking has done me so good. if you’d seen me not too far back... off my food... coming here is the thing that got me back to the top.’ – Journeying Through Dementia participant.

Individuals with dementia reported value in sharing of experiences within a group context, vital to wellbeing and valued the opportunity to learn new skills and techniques to mitigate against some of the effects of dementia;

‘Clubs help you to meet other old people but they are also nothing like this. Here we meet other people who also have dementia. Rather than just talking, I’ve been able to learn new things. It’s like gold.’

‘You know you’re telling me things that could alter my life.’

However, it was also recognized that there needed to be greater access to groups of this nature. Sprange et al (2016) concluded that adults with early stage dementia could successfully engage in this person-centred self-management group intervention. The programme met the heterogeneity of needs of people with dementia by being tailored to individual requirements as well as those of the overall group. A successful application was made to the UK National Institute of Health Research to undertake a Randomized controlled trial (RCT) to test the intervention led by Mountain. It also formed part of the Connecting People, Connecting Support dementia strategy document for Allied Health Professionals across Scotland and it is to this latter initiative and research undertaken in relation to its implementation here that this paper now turns.

Reflections on the research

If the design double diamond is seen as the overall research framework it could be argued that through a co-design process, issues had been explored, problems defined, and an intervention had been developed and tested to good effect.

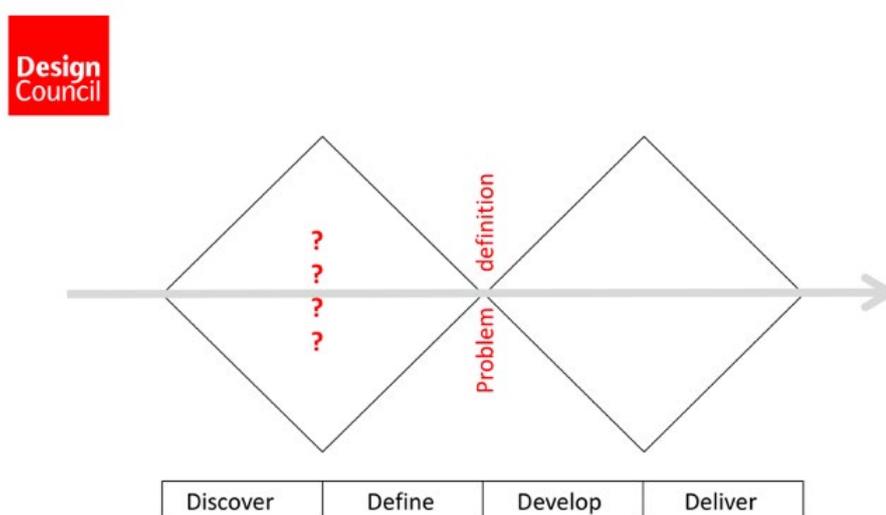


Figure 1: Design Council Double Diamond (Design Council 2015)

However, as the first author began to up-skill researchers and clinicians in the delivery of the intervention for the national RCT, it became apparent that facilitators required more than a manual, setting out weekly intervention plans and paper hand-outs to aid delivery. Facilitators highlighted the challenges of engaging people with dementia in a group setting, questioning how to support differing communication needs of group members and ways to engage with and reach individuals with different levels of cognition. Concerns were also expressed in relation to the amount of time it would take to develop materials to support sessions. The issue was how to turn the themes that had emerged from the research from a 'flat and largely abstract intervention supported by a few hand-outs' into something that had an interactive element and could be delivered in practice.



Figure 2: Up-skilling Researchers and Clinicians

Current research

Funding was received from National Education Scotland in 2017 and two sites were identified in Scotland by the Allied Health Professions policy lead for dementia. The aim of this element of the enquiry was to build understanding of the requirements of occupational therapists facilitating the Journeying through Dementia intervention in practice. The design-led research sat within a broader improvement science test-and-learn methodology. Twenty occupational therapists from older people's

mental health services across Fife and Aberdeenshire participated in four iterative co-design research workshops.

A major breakthrough in the development of this research came when the methodology of 'exhibition in a box', by Chamberlain and Craig (2013) was applied in this study. Inspired by Duchamp's 'Boîte en valise', it is a form of object elicitation and in this research was used to curate a series of creative activities (quotes, images, objects), to scaffold thinking and prompt conversation. 'Exhibition in a box' provides a tool and structure for design and health practitioners to creatively engage with older people.



Figure 3: Aberdeen June 2018

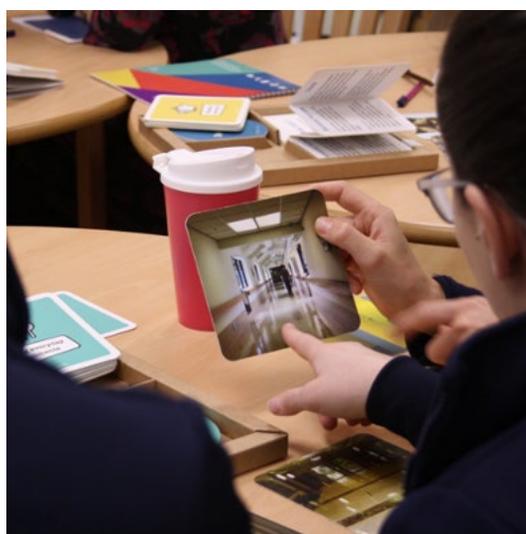


Figure 4: Aberdeen September 2018



Figure 5: Fife November 2018

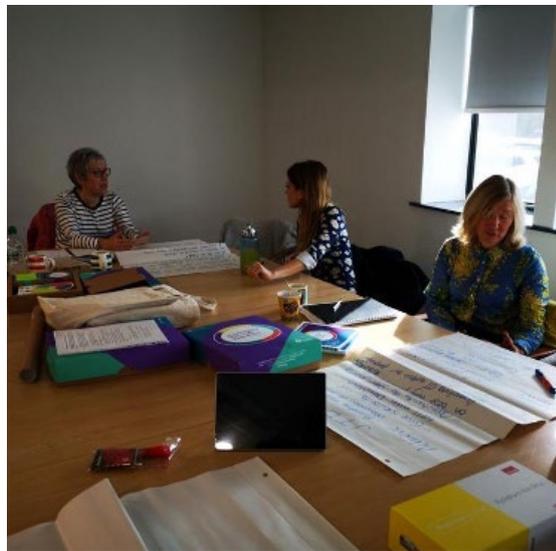


Figure 6: Wales October 2019

A range of quotes by people with dementia from earlier phases of the research, as illustrated below, acted as powerful provocations about messages the materials needed to reflect.

You need to focus on the ability and the contribution that we can make rather than what we can no longer do.

I felt disempowered because people that spoke to me about dementia always spoke about my loss. Nobody ever said 'there are things you've lost but there are also things you could gain'. They never really took me from the loss of power into action.

Photographs of activities people had found meaningful offered an opportunity to discuss broader needs and perspectives and how the facilitators might support their needs. A range of objects prompted discussion relating to value and values. Consent was given to record conversations and notes were taken throughout the co-design workshops with participants encouraged to include written comments in response to the artefacts that were shared. After each workshop this data was collated and analysed using a simple thematic analysis (Braun and Clarke 2006) and the next iteration of objects and materials were crafted to embody and respond to this feedback.

The final iteration culminated in a research-informed set of materials, which formed the basis of the intervention used by therapists in the delivery of Journeying through Dementia in Scotland across two demonstrator sites. An evaluation of the impact of the intervention was undertaken by the therapists using measures in quality of life (QoL-AD) and the therapists were interviewed by the policy lead in relation to their experiences of facilitating the programme with the materials.



Figure 7: Demonstrator Sit Pilot Kit 2019

Findings

Analysis of the data collected during the co-design workshops identified four main themes, which were then incorporated into the design of the materials:

Communication through research

Participants in the workshops identified the need for materials to act as prompts to promote engagement and scaffold communication. An iterative process culminated in sets of images and word cards to support individuals with dysphasia or anomia. Fact or Fiction paddles were created to enable participants with limited speech to respond to True or False

statements shared by the therapists and in doing so to enable group members to untangle and to challenge some of the myths surrounding dementia. These elements were reflective of the range of sensory and learning styles of participants. Feedback by the therapists was positive:

‘The quotes open up a conversation...I feel like that too’ - (Participant, Fife)

‘The photographs help to get conversations started about difficult topics’ - (Fife)

‘The fact and fiction paddles allow you to talk about dementia in non-threatening way’ (Participant Aberdeen)



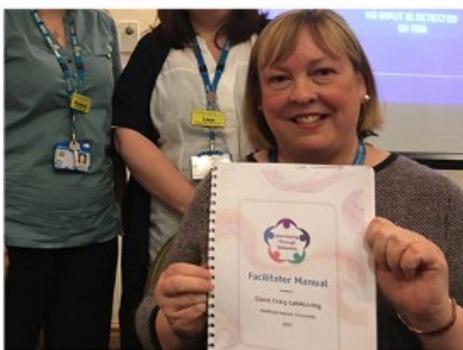
Figure 8: Demonstrator Site Pilot Kit Elements 2019

Communication about

The materials communicated important messages about how people with dementia attending the groups were valued. Therapists described how challenges in resourcing services meant that information for groups frequently comprised of photocopies of photocopied material. Not only was this a challenge for participants in groups who had sensory impairments such as poor eyesight but staff expressed concern that poor quality materials carried hidden messages about lack of professionalism and potentially undermined participants sense of worth. Early designs, which were based around

a simple cardboard packaging structure, were rejected as it was felt that the material was 'too basic' (see Prototype 3 in Figure 9 below). The final selection of materials sought to redress this balance. Responses to the final design were overwhelmingly positive both in the context of participants:

'It's kind of ageless, the design is not stigmatising'; 'The design inspires hope and creates excitement' and also for the therapists; 'I feel that it will add to the quality of life of my patients as well as to my working life'; 'It's an excellent resource for patients and to celebrate the good work that OTs do offer.'



Facilitators with Journeying Through Dementia 2017



Prototype 2: February 2018



Prototype 3: September 2018



Prototype 4: March 2019



Final Kit: September 2019

Figure 9: Journeying Through Dementia Kit development 2017-2019

The incorporation of the colours and symbols of the policy document Connecting People, Connecting Support (CPCS) as part of its visual identity was highlighted as a particular strength. Therapists felt that it embodied professionalism and communicated to managers the evidence based nature of the intervention:

'It is so great to have a resource we can use to move towards early intervention and demonstrate we are implementing the CPCS policy.' (Participant, Fife)



Figure 10: CPCS policy themes

The importance of detail

One of the key themes emerging from the research was the overwhelming importance of subtle details. Clinicians shared how the distinctive colour palette that ran throughout the resource (including the invitations) was key for participants especially as invitations to groups were often lost amongst other appointments because they all looked the same. Signage not only directed group members to the toilet/bathroom but also the way back to the room. Lamination of elements of the materials ensured that they met with stringent health and safety requirements in many settings and increased durability. As one therapist highlighted,

‘This may sound ridiculous but it is these details that can make the difference between whether something sits on a shelf and remains unopened or whether it is used in practice.’ (Participant, Aberdeen)



Laminate signage



Laminate signage in use



Portable kit

Figure 9: Journeying Through Dementia Kit development 2017-2019

Balance

The final theme emerging from the workshops was the importance of balance. This was achieved through the inclusion of fun elements (spinning wheel and true and false paddles) as well as the more serious components of the intervention addressing the symptoms of dementia. Feedback was positive;

‘The resources are so well designed and engaging’ (Participant Fife)

‘There needs to be some fun. Talking about dementia can be very depressing.’ (Participant Fife)



Topic of Conversation Spinner



True or False Paddles

Figure 9: Journeying Through Dementia Kit development 2017-2019

The final theme

Finally, the materials needed to have sufficient structure to support the therapists to deliver the intervention but not so prescriptive and restrictive as to prevent the therapists from exercising their clinical reasoning skills and enabling customisation to the context. Feedback from therapists was that the materials achieved this. The overwhelming strength was the multiple ways that the clinicians felt they could use the materials, achieving a level of personalisation.

'I really like the layers of options'
(Participant, Aberdeen)

'It's very adaptable and can be responsive to the situation' (Participant, Aberdeen)

'Person centred and easily adaptable to various settings' (Participant, Fife)

Testing in practice

Five therapists then tested the final iteration of materials across two demonstrator sites in Aberdeen and Fife. Evaluation of the intervention by the Allied Health Professions Lead for Scotland concluded that;

'Journeying through Dementia has been a key component in the delivery of the dementia strategy for Allied Health Professionals in Scotland. Evaluation of its impact in the first 2 demonstrator sites in

Scotland showed that 71% of participants who engaged in the programme reported improved quality of life (QoL-AD)'



Figure 13: Facilitators and contributors in Fife

The evaluation highlighted that Journeying through Dementia was a high-quality resource, which provided a structure to each session but also offered flexibility in being able to adapt that to the needs of the participants and incorporate 1:1 and out of venue sessions to support programme delivery. The topic wheel and booklets proved beneficial to support initial discussions around selecting appropriate sessions but as the facilitators and participants built relationships this process became easier.

Having a 'menu-led' approach was incredibly valuable in supporting a person centred approach, the dynamics of the

intervention in which the participants were very much supported and encouraged to select sessions most applicable to them and be active participants in the groups further empowered people to take ownership of the group as the weeks progressed. The power of being able to share experiences, proved invaluable and was commented on frequently by the participants (Grey et al 2019).

Discussion and conclusion

This paper has explored the value of design in the development and implementation of a dementia post-diagnostic support interventions. From co-creation of the intervention with people with dementia through to the development of materials to operationalize the Journeying through Dementia programme, it demonstrates the importance of involving stakeholders throughout the research process and in adopting a truly integrated approach. Involvement of Therapists in this phase of the study identified key requirements the materials needed to fulfil to enable operationalization of the intervention. The significance of this phase of research cannot be underestimated as the subtle design requirements identified highlight. One therapist summed this up when they said;

‘it’s the difference between being only being given a recipe-book and being given the recipe book with the utensils and ingredients required to create something.’

There is a danger that much research fails to be implemented because it ends when an intervention or product has been created without due attention being paid to the final phase, an understanding of the needs of the clinicians and facilitators who will ultimately deliver this. This can result in a lack of adoption as described by Frank et al. (1996). A similar picture can exist in healthcare. One of the challenges of implementation research is that large scale experimental studies often remove variables that make them relevant to the range of

contexts to which they might be applied. As a consequence, ‘interventions which fit closely to the content of one setting e.g. are acceptable, operationally feasible, affordable and culturally congruent, may be a poor fit in another setting’ (Goodyear-Smith 2015).

This study has reinforced the value of the involvement of design researchers throughout the enquiry, particularly in the phase prior to implementation. The exhibition in a box methodology offered a mechanism through which key messages could be communicated. Further funding from the Scottish Self-Management Alliance has been awarded for roll out of the intervention across a further nine sites in Scotland and the research is being replicated in Wales. Our journey with Journeying through Dementia continues.

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CO-DESIGNING TOOLS FOR DISSEMINATION

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Abstract

If the potential of design for health is to be fully realised in the future it is necessary to find a language to communicate our research across disciplines. This paper describes the outcome of a study that explored the role of design in communicating the findings of a positive deviance clinical research study in the UK.

Positive deviance is an asset-based, bottom-up approach to behavioural and social change within communities. Whilst the approach has demonstrated much potential in public health and broader community contexts few studies have sought to apply the principles of positive deviance to in-patient healthcare settings. In the handful of studies that have sought to apply its principles to medical and clinical practice, issues have arisen in relation to how to disseminate and implement the findings of the research.

This paper describes a study examining the role of creative practice and co-design methods in communicating findings generated from a positive deviance research study undertaken across medical wards in the UK. Baxter's study (2015) had identified 14 positively

deviant behaviours enacted by staff across medical wards, which led to improved patient outcomes. The challenge was how to disseminate these findings, given the abstract nature of these behaviours.

Design researchers from Lab4Living worked with staff across medical wards in hospitals in the North of England and through an iterative co-design research process generated a series of artefacts that embodied/reflected the positively deviant strategies. Ward teams evaluated these. The artefacts provided a mechanism through which to promote and scaffolding conversation, thereby promoting engagement with the research. In the final phase of the research the artefacts were shared with staff from other hospitals who had not been directly involved in the co-design workshops. The paper will reflect on the design methodology and its potential to be applied to other contexts.

Keywords: co-design; communication; inter-disciplinarity; positive deviance



Introduction

Positive deviance is an asset-based, bottom-up approach to behavioural and social change within communities. It draws on individual and community strengths and pre-existing resources considered positively deviant (Tuhus- Dubrow 2009; Singhal et al. 2009).

The approach assumes that problems can be overcome using solutions that already exist within communities. Despite facing the same constraints as others, 'positive deviants' identify solutions and succeed by demonstrating uncommon or different behaviours (Baxter et al. 2015, 2).

This approach holds much promise and attention has turned to how it might be applied within health service contexts. However, whilst there is a growing interest in a positive deviance approach within healthcare, there is still 'limited guidance on how to operationalize each step' (Baxter 2015, 2). To date the majority of studies demonstrating positive change based on this approach are located in public health and in business. However, some promising studies of research in healthcare settings with specific reference for treatment of acute myocardial infarction have recently emerged. Within these settings a four-stage approach has been proposed as illustrated below (Bradley et al. 2009).

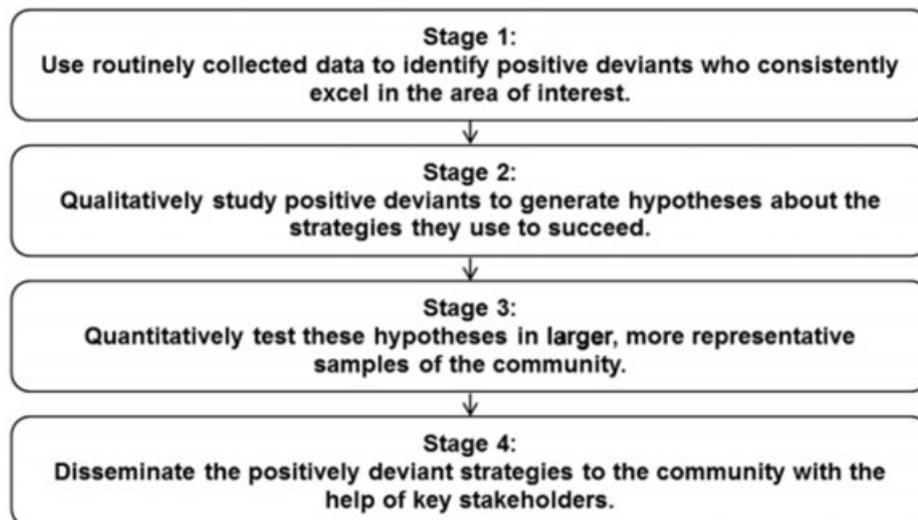


Figure 1: The 4 stage approach to positive deviance

Whilst there is a growing body of literature in relation to identifying positively deviant strategies and building understanding as to how they succeed, what is less clear from the literature is how these are disseminated and how research teams move beyond stage three of the model (Baxter et al. 2015).

If the potential of the positive deviance approach within healthcare is to be realized it is necessary to find ways to identify positive deviant wards, cultures and individuals within complex and ever-changing systems and create mechanisms to communicate what these are to create the potential for their implementation.

Current study

This paper describes a study that investigated whether creative practice and co-design methods can be used to support the dissemination of positively deviant strategies for improving quality and evidence about newly characterized best practices within elderly patient medical wards. It focuses on the potential for design methods and co-creation approaches (Zanetti and Taylor 2016) to support knowledge-transfer amongst autonomous ward teams.

Co-creation is an approach that seeks to involve all stakeholders in the design process to help ensure the results match their needs and is usable. A key tenet of co-design is that users are experts of their own experience and are therefore central to the design process. Involving ward staff in the design of materials and strategies to disseminate research findings seems a highly appropriate approach and reflects well the bottom-up, asset-based nature of positive deviance.

The starting point for our study was a research project undertaken by Baxter (2015) who examined whether a positive deviant approach could be used to identify ward teams in the UK who were performing exceptionally well on patient safety. Using a multi-method observational study, she assessed the concurrent validity of identifying positively deviant elderly medical wards using NHS Thermometer data and staff and focus groups.

Hypotheses about strategies, behaviours, team cultures and dynamics that facilitated the delivery of safe patient care were generated and 14 key themes representative of positively deviant elderly patient medical wards were identified. These were: Knowing Each Other; Trust; A Multidisciplinary Approach; Integrated Ward Based AHPs; Working Together; Feeling Able to Ask Questions or for Help; Setting Expectations; It's a Pleasure to Come to Work; Learning from Incidents; Acquiring Additional Staff; Stable and Static Teams; Focus on Discharge; Directorate Support; and Keeping Patients and Relatives Informed.

Whilst Baxter's research demonstrated success in relation to the first two stages of Bradley's model, she also identified that there was 'limited guidance on how to operationalize each step' (Baxter 2016, 2) particularly in relation to the implementation of findings. Our study investigated whether creative practice and co-design methods could be used to

support the dissemination of positively deviant strategies within elderly patient medical wards. We were interested in understanding the experience of staff involved in the process of co-design. We also wanted to understand whether there was a difference in the experience and impact of the critical artefacts between wards engaged in creative practice and co-design of creative interventions and those that were not.

Two elderly care wards at different hospital sites within the North of England were recruited to take part in this study. These were chosen because they best reflected the population of Baxter's original study. An intervention was co-designed with site 1 that was then installed in site 1 and site 2. This was to build understanding of whether the artefacts developed through the co-design process had a validity that extended beyond the site of creation.

Study intervention development

The overall study design followed the UK Design Council's Double Diamond process model (Design Council 2015] with the initial phases of the research adopting a more exploratory approach, asking questions, conceptualizing possibilities rather than offering solutions. A thinking through things methodology based on 'exhibition in a box' (Chamberlain and Craig 2013) was utilized throughout the study

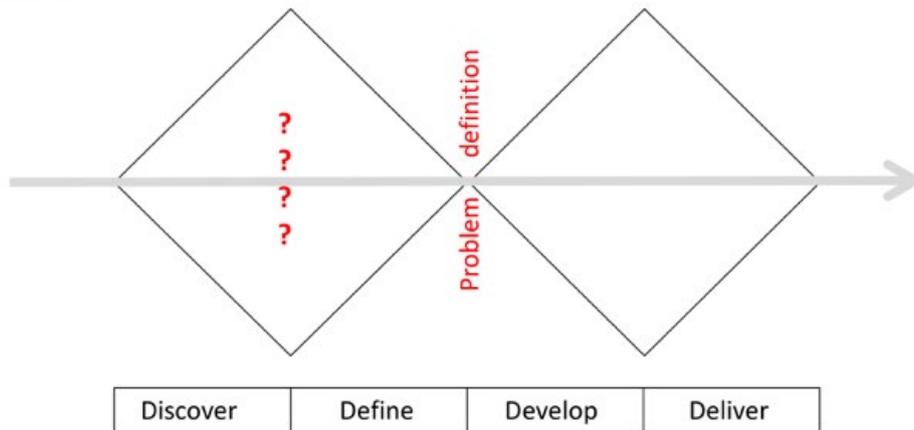


Figure 2: Design Council double diamond (Design Council 2015)

Discover

During the immersion phase of the research, site visits by the Lab4Living research team provided the opportunity to build understanding of Baxter’s themes in the context of the hospital setting (site one). During these visits it was noted that

the ownership of space varied across the hospital and poor décor and the busy visual language were also highlighted as considerations. The research team developed a series of critical artefacts (Chamberlain and Craig 2013) based on these observations for the first co-design workshop.



Figure 3: Critical artefacts

The purpose of the first workshop was to identify and prioritise positively deviant ward behaviours, practices or characteristics. Eight ward staff participated in the workshop which briefly consisted of

an introduction to the project and verbal consent, three themed tasks, written consent and de-brief. The workshop was audio recorded and visually recorded (figure 4)

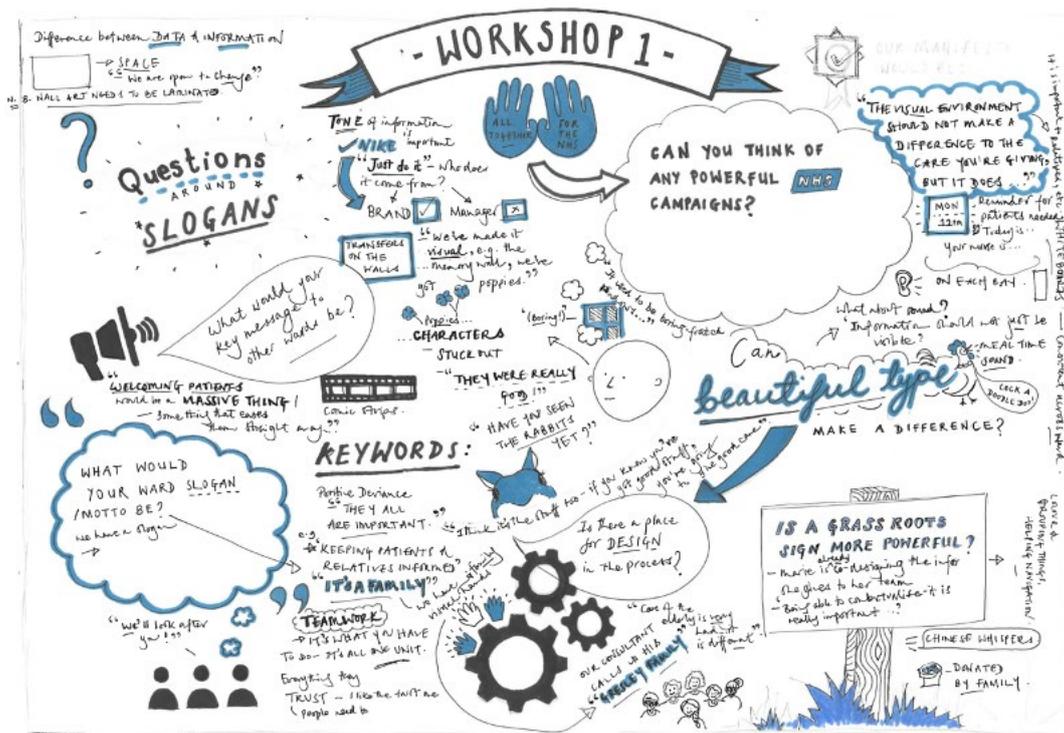


Figure 4: Recording of the workshop

Ward staff shared how they currently send and receive generic information in both their work and private lives. Information was shared and mapped on blank cards from the co-design tool kit developed by the design researchers. Baxter's positive deviant themes were discussed in detail and revealed insights set against the context of the ward. The ward staff confirmed that all 14 positive deviant themes were relevant and important but when prompted to select the most important they selected 'Trust' and 'Working together'.

'probably one of the most demanding wards'...'we wouldn't get through it without your colleagues'(workshop participant)

Identity was also an important theme. Significantly this was not one of the original themes noted in Baxter's findings.

Define (post workshop)

The workshop further confirmed that any intervention developed to promote the dissemination of the positive deviant themes would be challenged by the

limitations of ward staff time to engage with the intervention. Additionally, it highlighted that the ward itself was the only viable location to site an intervention where the staff had some level of autonomy and control. However, space to accommodate any form of intervention was at a premium on the ward. Consequently, the design research team began to focus on how to paraphrase information through poetry (Grisham 2006), metaphors and data visualization.

'Trust' and 'Working together' emerged as key themes from the co-design workshop along with a strong feeling of identity. In response, the design researchers developed a personalized ward logo (figure 5). In addition, the notion of a welcome pack for staff and patients was developed. The pack included for example a mug, pens, maps, poetry book, notebook, water bottle and lanyard.



Figure 5: Refreshed personalized ward logo

Develop (workshop 2)

Four members of staff from site one participated in the second workshop. Due to staff sickness and staff shortage, the number of participants in attendance was smaller than scheduled and this is a limitation of the study. Three of these participants had been present in the first co-design workshop.

Design interventions inspired by the co-design workshop 1 were shared with participants and feedback collected and collated. The concept of the staff/patient welcome pack was very well received however the co-design activity highlighted

problems with much of the contents. For example, the ward staff had recently ordered a new set of mugs, distributing water to patients in jugs was the normal practice, content and purpose of maps for patients and staff was conflicting. The participants suggested other items could be added for patients such as hair and toothbrush for example. However, the most significant challenge identified was that of the sheer number of packs that would be required for patients and the logistics of cost and supply. Further interrogation revealed creative potential and relevance in terms of the study objectives in focusing on a staff welcome pack.

Logistical consideration played a core part of the co-creation activity where the participants imagined where and how the range of interventions might work in practice. For example, ward staff access to printing facility, rules and regulations on fixing to walls, hygiene regulations, location of electrical, power sources. Another focused survey of the ward and surrounding spaces, kitchens, staff rooms, toilets once again revealed the extremely limited space available to utilize for an intervention. As in workshop one, the session was audio and visually recorded.

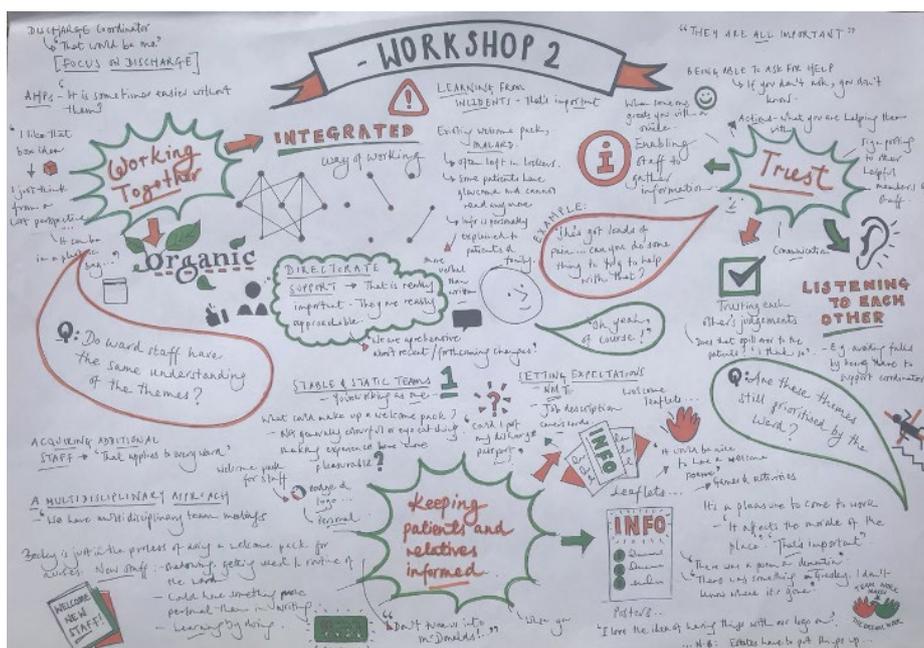


Figure 4: Recording of the workshop Figure 6: Visualization of Workshop 2

Develop (post workshop 2)

The second co-design workshop had further highlighted the logistical challenges that would significantly influence the design of the intervention. The ward environment presented an enormous amount of visual and textual information, and to achieve the aims of the study it was important any intervention would have to compete with the visual noise across the ward.

Following the second co-design workshop the design research team focused on the delivery of the final intervention which sought to embed Baxter's 14 positive deviant themes in a precise visual form within the restraint of a visually cluttered ward. The intervention would have meaning an identity for the site one ward, informed by co-design workshops but hopefully have relevance for the site two hospital ward also.

'Team working' and 'Trust' which were highlighted by the co-design workshop participants as particularly important would be manifested in a staff welcome pack, which would also reflect and disseminate the 14 positive deviant themes.

Intervention (Deliver)

The final intervention that emerged through the process of co-design activity with the site one ward was a welcome pack for staff (and a framed illustration/artwork, which embodied the themes of Baxter's (2015) research (figure 7). The illustration/artwork was produced A2 size to allow more scope for siting within the wards. The two interventions would offer an individual and shared approach to support the dissemination of the positive deviant themes.

The playful staff welcome pack would offer opportunity for staff to recognize and reflect upon the creative activities and positive deviant characteristics they already engage in. In addition, the pack would prompt communication between individuals in the ward teams. The artwork reflected the busy working of a hospital and illustratively conveyed the 14 positive deviant themes for staff and patient engagement.



Figure 4: Recording of the workshop Figure 6: Visualization of Workshop 2



Figure 8 : sharing of the final artefacts with ward teams

The interventions were well received by staff:

‘The books have gone down a treat with established members of the team as well as new starters’.

‘The picture is a real talking point - every time you look at it you see something else and you have a different conversation’.

Discussion

Whilst there is a growing interest in positive deviance approaches within healthcare, there is still ‘limited guidance on how to operationalize each step’. There is an increasing body of literature related to identifying positive deviant strategies and Bradley et al. (2009) propose a four-stage model for operation within these settings. What is less clear from the literature is how these are disseminated and how research teams move beyond stage three of the model.

This study set out to explore the value of co-design in supporting the dissemination of positive deviant strategies, as stage four of Bradley’s (2009) model, within a health service context.

The study has highlighted the challenge of conducting co-design within a healthcare setting due to the prohibitive access to potential participants. Whilst enthusiastic to engage in creative collaboration, the workload of ward staff meant opportunity for collective gatherings are difficult to schedule. Exploring other modes of communication to continue dialogue between co-design workshops proved unsuccessful. Consequently, it was important for the design researchers to maximize the limited opportunity for co-creation with the ward staff and involved thoughtful preparation and development of co-design tools for use in the workshops.

Healthcare systems and environments however present many challenges for new innovation. The risk adverse culture in healthcare makes it difficult to adopt new, untried and tested ideas. The design researchers witnessed across the two hospital sites involved in this study a proliferation of diverse information which range from text to visual, corporate to amateur, important safety information to trivial decoration. While there is sound evidence to support clear graphical communication, generally information was ad hoc with little thought to hierarchy of importance.

This visual noise created makes it difficult to constructively intervene with yet more information. This finding from this study suggests the visual illiteracy in the hospitals needs to be addressed to be more effective and a more informed considered approach to how information is displayed in hospital environments through the development of design guidelines might be explored through further study.

In the search for a solution that had meaning for the ward, the co-designers explored local history as inspiration to create an identity for the intervention. However, in the final design of the intervention, the welcome pack and the illustration/art work, references to local history were dropped in favour of more subtle visual references to the ward team. This presented greater opportunity for translation and adoption to site two and potentially other hospital wards.

Conclusions

It is difficult to determine within the limits of study any change to the ward teams as a result of the co-design from the pre and post study data collected. However, the post interviews with the participants reveal some encouraging positive outcomes.

Despite the extremely challenging restraints to deliver a series of co-design workshops within a healthcare setting, a creative intervention to disseminate Baxter's 14 positive deviant themes was co-created with hospital ward staff. The post installation interviews with staff suggest the key themes identified in the co-design workshops were shared and disseminated. Further evaluation at a later stage may reveal further dissemination of the positive deviant themes as will determine whether the dissemination of the positive deviant strategies have a measurable lasting impact on the ward. The design rationale was to co-create interventions that prompted conversation that in itself would promote the likelihood of dissemination.

The interview participants however did find the co-design workshops 'enjoyable and thought provoking'. Consequently, their personal reflections on current ward practices may in time demonstrate positive impact.

Increasingly co-design is employed as a method within research studies. There are a number of reasons why co-design in the context of healthcare is very challenging noted in this paper. The role of the designer has evolved into a more democratic role, which turns the designer into a facilitator, conversationalist and provocateur within co-design. Consequently, in an attempt to facilitate authentic co-design it is important appropriate and effective tools are designed and utilized to prompt creative conversations between participants. In this study, due to limited access to the ward staff participants, there was little opportunity for co-production and consequently it relied on the design researchers to act as interpreters utilizing their design skills to synthesize the thoughts and ideas generated in the co-design workshops into tangible outcomes.

Acknowledgements

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TOUCH AND GO COLLABORATION: A METHOD THAT BRINGS FLEXIBILITY NOT FRUSTRATION TO COLLABORATIVE ENDEAVORS

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Abstract

When solving problems for a community or group of users, it is highly beneficial to work collaboratively through interprofessional education. Throughout the process of collaboration, participants contribute their unique strengths, perspectives, and expertise to create innovative solutions to identified problems. Collaborative problem-solving methods are nothing new, but alternative collaborations structures are critical. In the Design + Nursing Collaboration (D+NC), we developed the Touch and Go Collaboration method. This method strategically brings designers and nurses together then breaks them apart at appropriate moments to enable them to focus and excel in their area of specialty. The collaboration method allows students to come together and solve wicked problems as a large team. This method needs a diverse voice that can appreciate the broad view and address significant challenges from various perspectives.

However, to reach a deeper understanding of the problems, disciplinary experts need to shine without compromise. They need to break away and perform the tasks in their field of expertise. This break is the Touch and Go Collaboration Method developed by the D+NC.

In this paper and presentation, the authors will outline the robust "Touch and Go" process. Moreover, to demonstrate the process and outcomes, they will use three case studies from Summer 2019 D+NC Studio.

These case studies will include a premature baby transport system, a system to help promote healthy sleeping, and an innovative solution to diabetic care. The focus of these collaborations will be the process and how it moved the solution farther faster.

Keywords: Inter-professionalism, Collaboration, Health and Wellness, Design, Nursing, Pedagogy

Introduction

For the past ten years the Design+Nursing Collaborative (D+NC) has explored and iterated on developing an interprofessional collaborative method that fulfills the academic requirements of two major disciplines; Design and Nursing. It positions students to learn collaborative skills and leverage specialty skills to address the challenges of community health.

Throughout the D+NC's evolution, a collaboration method evolved that enabled student designers, nurses and faculty to work in a unique way. In many collaboration methods, interprofessional teams are encouraged to work together exclusively, work out differences, and ultimately trust each other's expertise. If not managed effectively there are drawbacks, especially in academics where collaboration time is limited. In this limited time, it is challenging to create positive team dynamics while pushing for well thought out solutions. When operating under a typical collaborative model, the authors observed trying to solve problems that were completely out of their areas of expertise. While this can be positive, in more times than not it slowed the process. Sharing ideas was helpful, but when base level solutions collided stalemates occurred, students did not understand the logics foundation. It was found that by splitting teams at critical points of ideation, then regrouping for validation moved the ideas farther faster. Teammates understood each other through completing deliverables. This clarified roles and highlighted the value of their complementary discipline. They could see solutions and ask 'why'. Then bolster the ideas by injecting their expertise. We coined this method 'Touch and Go'.

What is Interprofessional Education (IPE)?

Interprofessional education provides students an opportunity to collaborate on group assignments to enhance future

partnerships. The benefits of implementing IPE include improving beneficial collaboration Knowledge, understanding other discipline's roles, and encouraging the consideration of different points. According to Khan, Shehnaz, and Gomathi (2016),

'a successful curricular innovation requires support from all stakeholders, as well as reinforcing collective ownership of IPE activities.'

Although challenges exist for institutions to implement IPE, such as scheduling of courses, the authors are supported by their respective Colleges to provide this unique learning opportunity to students.

What is Touch and Go Collaboration?

Touch and Go collaboration combines intense collaborative interactions with discipline-specific breakouts. Forcing strict collaboration rules in areas of research, validation, and final presentations enables a quick understanding of complementary knowledge and skills. This is most effective in early research activities resulting in team-building topic understanding.

In phases where students split and focus, they immerse themselves in their specialty. They know the success parameters, and the curriculum keeps unity. During this split, teams communicate weekly, sharing ideas and feedback. The collaboration effectively transitions to enable more discipline-specific focus

The Touch and Go Process

The Set-up

For this collaboration 3rd year Industrial Design students and Accelerated Master of Science in Nursing (MSN) pre-licensure students are recruited. The design students are in their final studio before senior capstone with skill levels at their highest. Our MSN students are individuals who have typically had work experiences in other fields and have decided to extend their career paths to focus on nursing.

Each student voluntarily chooses to enrol. This enrolment ensures participating students are passionate about the subject matter. Our past experiences show that when students are picked or not given a participation option, negative disruptions occur in team dynamics, quality of work, and an overall drag on the collaborative community.

Community health needs and topic appropriateness typically drive project selection. Topics gravitate towards those that require physical products, service, or experience solutions. In the topic selection, students must have access to patients, users, caregivers, family, and other appropriate stakeholders. This facilitates a user-centred approach throughout the development process and satisfies design and nursing student requirements for in-depth, user/patient-centred projects with direct participation from stakeholders.

Once a topic area is determined, fundamental principles of community health are applied: Primary, secondary, and tertiary care interests determine how teams are divided. This division enables the collaborative to dive deep into one specific topic, such as youth American football and concussions. In this actual case, the class split into two teams for each prevention category and focused on that prevention area. In other cases, the collaborative offered several topics and allowed students to 1) select a focus, 2) research that focus, then 3) determine a primary, secondary, or tertiary project direction. Both showed positive results.

Process Phases

Understanding- Inquiry//Population Pyramid

Design+Nursing Intense Collaboration

Understanding is an 'intense' collaboration phase. Here, design and nursing students work closely together. They conduct secondary research and limited primary

research. It is here where students gain an understanding of their problem's importance, its pathophysiological attributes, those most affected, current mitigation practices, and opportunity gaps. Most importantly, they develop a list of development requirements. These requirements focus designers and nurses on producing a solution that will not only address the problem but also integrate into the users' lives.

In this three-week process, students are briefed on content to uncover and deliverables. Stressing the importance of delegating responsibilities is critical. Students must work outside of class to complete the phase, so group communication is also of high importance. This is where groups show their dysfunctions and faculty intervene. Intervention is provided to ensure everyone understands the process and roles. Most importantly, they understand the success of the project lies in the team, not with the individual.

Conceptualization – Preliminary Intervention plan

Design-Conceptualization

This is the typical design conceptualization phase. Students reflect on understanding findings and specified design requirements. They use this information to develop conceptual iterations of product service and system solutions. During this time, monitoring clinical aspects comes from design students updating their nursing collaborators at least once a week.

The conceptual exercises begin with thumbnail ideations. These ideations are vetted by the entire team and refined into explanatory concept sketches

'In general, a more schematic way of drawing is applied in explanatory drawings. That way, pure information can be isolated for clarity. Archetype or icon-like drawings can ensue neutral or

not judgmental communication. Several drawing together can form a storyline like a visual script' (Eissen and Roselien 2007).

After this vetting process, students are introduced to the collaboration iteration tool called Systematic Inventive Thinking. This process reverses the analogy of 'thinking outside the box' to 'thinking inside the box.' In their book 'Inside the Box' Boyd and Goldenberg (2013) write

'The traditional view of creativity is that it is unstructured and doesn't follow rules or patterns....We believe just the opposite, We'll show you that more innovation--and better and quicker innovation--happens when you work inside your familiar world". This system includes Five thinking tools; Subtraction, Multiplication, Division, Task unification, and Attribute dependency.'

The introduction of his method occurs during conceptualization. The collaborative teams convene to evaluate the current concept directions using the SIT process. By having the design students provide initial concepts, the collaborative teams can iterate new directions.

Especially useful for our nursing students, it enables contribution without hands-on design skills. Of the five thinking tools, Subtraction has proven to be the most effective.

This exercise gets the teams thinking in new directions. It involves everyone, and sometimes the result changes the course of the project in unexpected directions.

Concluding this exercise, the teams develop one last round of refined concepts. They narrow the total to 3-5. These concepts are internally vetted, visually understandable, and serve as the primary research tool in subsequent phases.

Nursing-Preliminary Intervention Plan

During this phase, the nursing students develop population pyramids based on results from initial research, as they collaborate to determine the target population.

'A population pyramid is a graphic presentation of the age and sex composition of the human population for a specific region. One benefit of using a population pyramid is that it can be utilized for revealing historical and future trends' (Korenjak-Cerne, Kejzar, and Batageli 2008).

Nursing students also provide in-depth content on pathophysiology, feedback regarding stakeholder use, and community education models.

Concept Validation – Intervention Validation

Design+Nursing Intense Collaboration

Validation introduces round two of intense collaboration. Here concepts and interventions are stakeholder tested for validity. Recruiting users and scheduling face to face meetings is critical. Students realize meetings must occur at the participants' convenience, not theirs. Hence, during this last week of Conceptualization, students contact participants and schedule interview times.

Lectures on interviewing techniques, survey targeting, and question development occur.

Face-to-face interviews are stressed. Jamison et al. (2017) noted an additional benefit is that the interviewer has the flexibility to modify the direction of conversation during the interview.

Using online surveys is necessary, as well. The faculty assists teams in locating blogs and organizations and make sure their questions are group-specific. Online surveys also provide access to difficult-to-reach groups. Jamison et al. (2017) reported in a recent study that both face-to-face interviews and online surveys are reliable methods to answer research questions; however, the online forum was better able to communicate participants' viewpoints from a wide geographical area. Each project is solely a collaboration between students, and the information gained from these interviews with the end-users was essential in providing students with direction for their projects.

At the end of two weeks, students present their findings. They review significant insights, potential concept refinements, and a determination of their one final direction.

Concept Refinement – Intervention Plan Refinement

Design

Designers start honing their selected concepts using CAD, Explanatory imagery, animations, and model making that bring together the vetted solution. Nurses collaborate as refinements proceed. Students may need guidance to stay true to the user's voice, but they are to complete this independently from an execution perspective.

Nursing

Nurses carefully review the selected concepts and collaborate to develop interventions. Other activities include patient education materials, instructions for staff training, and other assets required for safe concept use. Teams have developed simulations and videos demonstrating correct concept use and training modules.

Concept Refinement – Intervention Plan Refinement

Design

Designers start honing their selected concepts using CAD, Explanatory imagery, animations, and model making that bring together the vetted solutions. Nurses collaborate as refinements proceed by ensuring clinical requirements, and the user's voice is honoured.

Nursing

Nurses and designers review the proposed intervention results. They determine what aspects need refinement and develop a plan. Concluding evaluation, nurses develop a refined intervention that coincides with the design solution.

Concept Finalization – Intervention Finalization

Design+Nursing Intense Collaboration

For the final presentation, teams review their semesters' breakthroughs, drawbacks, and results. The D+NC developed a partnership with regional research, and commercialization centres whose representatives participate in the final review.

'Speed dating' is our most successful format. Teams develop a comprehensive 10-minute presentation. Selected students present a project overview and faculty review ground-rules. At the conclusion, reviewers vote on their favourite projects. This system exposes teams to experts that can fund a project.

Process Results

Project 1: Premie

Industrial Design Students: Josephine Edelbrock, Katie Sprang, and Sophie Fain
Nursing Student: Karen Collier.

Why the product resonated

To ensure a safe parent, child, and equipment travel, a premie travel system was needed. Premature infants often leave the Intensive Care Unit (NICU) with feeding tubes and breathing apparatuses. Upon discharge, parents/caregivers receive care instructions, including managing artificial airways, suctioning, monitoring low oxygen levels, and providing supplemental oxygen. Parents also receive the necessary equipment for this care.

Another aspect of travel is the car seat. National regulations make this area challenging, but premie parents expressed concern over safely securing a premie in current seats. An insert could be placed in the car seat to accommodate a growing premie and ensure safe positioning. An app was developed to monitor oxygen and provided parents/caregivers with specific instructions when oxygen levels fell.

Final Collaboration Direction

After conducting secondary research, the student team narrowed their project direction to develop a complete travel system, included an equipment backpack, monitoring app, and car seat insert.

Team Excellence

Concept finalization - it was during this phase, the system came together. Initially, the team planned only to develop the backpack, but as the process unfolded, it became clear that the team needed these additional, parent/caregiver, support components.



Figure 1: Explanatory sketching and results from Systematic Innovative Thinking exercise

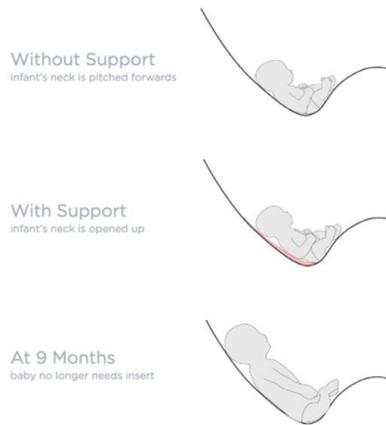
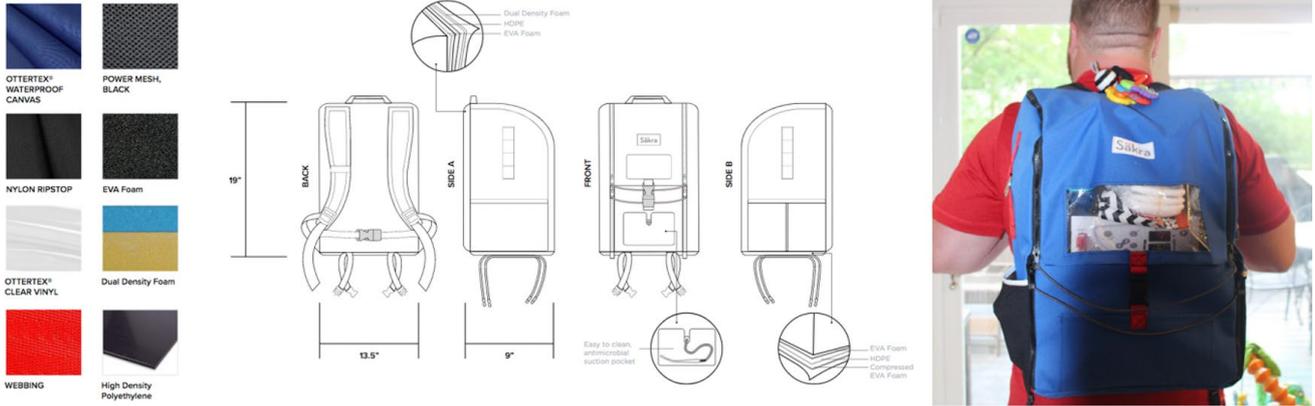
The solution

This solution consists of a transport system that includes the backpack designed to accommodate the suction machine and suction equipment, monitoring app, and premie car seat insert.



Figure 2: Example of population pyramid

The Diaper Backpack



Infant with Insert (Open)
With the insert, the preemie's lower back is pushed forward, ultimately tilting the head back and opening the baby's airway



Figure 3: Complete system; backpack, car seat insert and app

Project 2: Diabetes

Industrial Design Students: Julian Gregory
Nursing Student: Kelsey Stack

Why the product resonated

Challenges identified through research indicated that the current blood glucose monitors were not convenient to transport, they required two hands use, and it was hard to find safe lancet disposal.

Initial Sketches

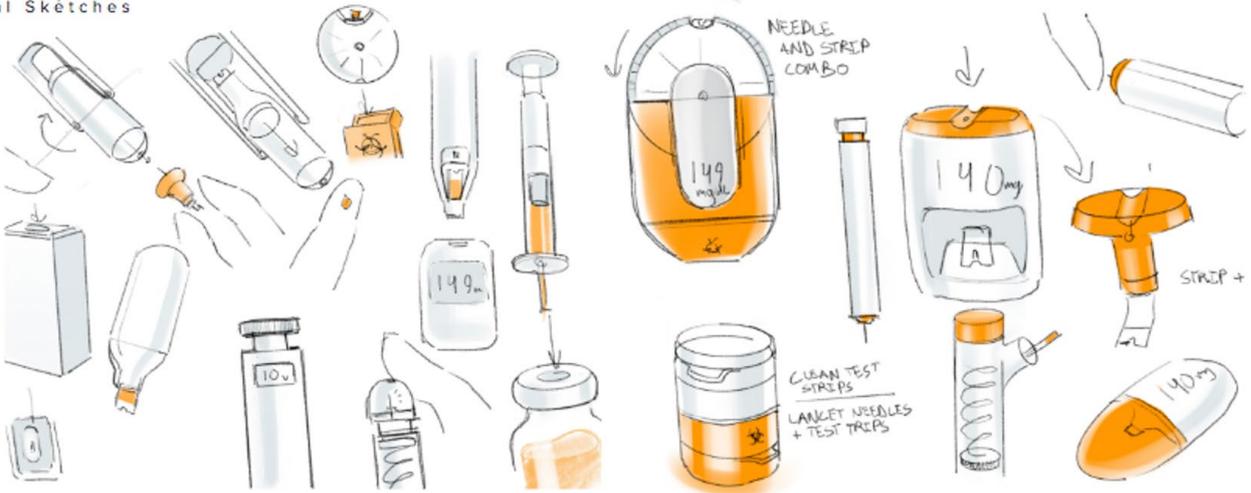


Figure 4: Initial concept sketches

Final Collaboration Direction

Students analysed feedback from initial concepts and reviewed design criteria to ensure the final solution encompassed the end-users' needs. Based on the information provided by nursing, the design student visualized the three possible options.

The final solutions were determined, and the nursing student began to develop the user manual.

Team Excellence

Concept refinement – The team excelled by conceptualizing multiple single-use lancets, test strip storage, result display, and battery into a simple pocket-sized, single-handed use device.

The Solution

Through survey results, the concept 'Palm' moved forward. It contained multiple lancets, a spring-loaded mechanism to pierce the skin, storage for test strips, an easy to read results display, battery compartment, was able to be used with one hand, and small enough to carry inside a pocket

Bold Results
One of the reasons this direction surpassed the others was its ability to display readings in a prominent way.



Figure 5: Concept Palm in normal state, extended to remove sharps, packaging, and in use

Project 3: Sleep

Industrial Design Students: Alex Vago, Josh Hollingsworth
Nursing Student: Renee Dietz

Why the product resonated:

Sleeping disorders are a significant health issue. After conducting quantitative research, the team found stakeholders currently use technology to fall asleep, and difficulties occurred in the early stages of sleep.

> Key Stakeholders



120
of our closest Instagram
friends



Ann Romaker, MD



Joshua Hagan, PhD



Jordan Hildebrandt



Dr. Sanjiv Patel

> Poll Results / n=150



What best describes your
sleep conundrum

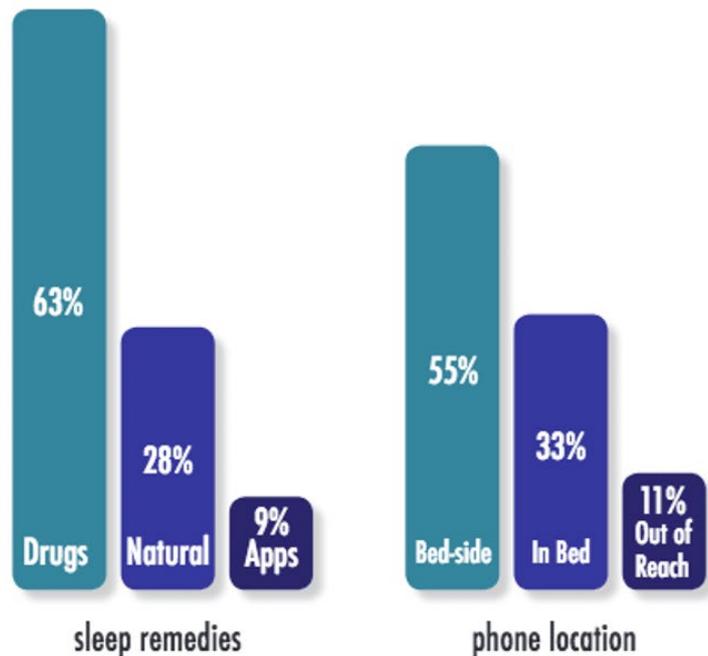


Figure 6: Team mentors and primary research examples

Final Collaboration Direction

In the clinical research, medical articles and emerging research backed up the team's theory. Simultaneously, designers explored current trends in sleep technology and found product opportunities.

Team Excellence

The team excelled at narrowing into focused directions. Additionally, the team excelled at creating a wholistic brand, Slumber.

The Solution

A sleep conducive bedroom environment was the goal of this project. The team developed two product concepts 'Sleep Pods' and 'Slumber Fan'. The 'Sleep Pods' addressed the problem of phone usage before bed. They gave optimal sleep luminance and encouraged technology disconnect. The 'Slumber Fan' promotes air circulation and white noise. The Fan obtains ideal air sleeping conditions.



Figure 7: Lighting and fan solutions provides ultimate sleep environment.

What's on the Horizon

The 'Touch and Go' Collaboration method has enabled designers and nurses to collaborate effectively. Students experience immersive collaboration, then disseminate. Students have received awards, employment, entrepreneurial funding, and top-level portfolio projects. The professors have benefited by moving projects at a faster rate by reducing the collaborative learning curve.

In the future, we will expand this opportunity to other university students. The authors are starting migrating into the university's Honors Program. To broaden the collaborations, this program will provide a diverse discipline pool and diverse knowledge base.

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INDOOR LIVING WALL: EDUCATIONAL TOOL FOR IMPROVING ECO-HEALTH AWARENESS IN PUBLIC SCHOOL

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Abstract

The increasing urbanization trend may affect negatively people's health due to the lack of natural areas. Younger generations carry out many daily activities in indoor spaces, such as schools, where the quality of indoor environment could be poor. Recent studies assert that the application of vertical greening in indoor spaces improves the quality of indoor air and provides several benefits for occupants' wellbeing. Vertical greening systems are included in the set of Urban Green Infrastructures (UGI) that apply nature-based solutions and promote an ecological approach for the improvement of built environment. They also offer the opportunity to develop educational activities focused on ecological approach in urban areas.

Urban environmental education involving green infrastructures helps to rise people's awareness regard the importance of environmental quality for their wellbeing. This paper investigates the opportunity to consider indoor living wall as complementary education tools to promote (non-) formal education and ecological literacy. It investigates how the development of green curricula activities using indoor living wall can promotes the understanding of the cross-dependence between human health and the quality of indoor environment.

Keywords: school living wall, eco-health, ecological literacy, indoor environment.



Introduction

The rapid and constantly increasing of urban population stresses the need to focus on the quality of life in big cities. In 2009, for the first time in the human history, the number of people that are living in urban areas surpassed the rural population. The United Nations (2017) estimates that 70% of global population will live in cities by 2050 and that the urbanization trend will increase especially in Asian countries. Sustainable Development Goals - SDGs (United Nations 2012), especially the SDG 11 - Cities & Communities, highlight the need to adopt effective solutions to mitigate harmful effects and to improve the quality of urban environment. The high concentration of people requires to change the structure of urban areas and these transformations cause consistent impacts on environment and on human health and wellbeing. Considering the ongoing intensification of worldwide urbanisation trend, the holistic interdependence between natural ecosystems and human health should be taken into consideration. The WHO (1948) defined human health as 'a state of physical, mental and social wellbeing and not merely the absence of disease or infirmity'. Sustainable development concept requires a more holistic understanding of environmental quality and human wellbeing. The positive effects of urban green areas on human health are recognized reducing psychophysical stress, inducing positive emotions and facilitating the renewal of cognitive resources (Figure 1) (Harting et al. 2011).



Figure 1: Royal Botanical Garden in the Central Business District of Sydney (Australia) (Authors' picture, 2019). Urban parks provide several benefits for urban population in terms of carbon sequestration, microclimate regulation, wildlife habitat provision, noise reduction, social cohesion and mental wellbeing.

Biofilia in urban context

The Biophilia Hypothesis asserts that human respond positively to natural environment (Kellert, 1995), but ordinary life in metropolitan areas has less and less direct experience with nature. Indeed, the majority of people spend 90% of daily time in indoor spaces, compromising their physical and psychological health (Liu et al. 2019). As cities are still growing, increasing attention has been given to Urban Green Infrastructure (UGI) and green spaces (Van den Bosch and Nieuwenhuijsen, 2017) as key elements to maintain human health and wellbeing and to improve a sustainable and ecological approach in planning urban areas. Loh et al. (2020) have discussed the necessity to change the common 'business as usual' approach to architecture and design and to adopt 'more-than-human' perspective, moving away from a reductionist thinking in performing built environment toward systemic one. UGIs and green areas provide regulating, supporting and provisioning ecosystem services to increase sustainability in built environment, but also cultural ones focused on science-based and nature-experience education.

Vertical greening functions in indoor environment

The biophilic design attitude applied to interiors is becoming an important strategy to improve the ecological dimension in high urbanized cities and to create healthier

spaces (Beatley 2011). Vertical vegetated surfaces, well known as green walls or living walls, are included into the strategy for greening cities providing important ecosystems services (Table 1) (Neonato et al. 2019).

Table 1. Ecosystem services provided by outdoor and indoor vertical greening systems.

Ecosystem Services	Benefits	Indoor	Outdoor	
Supporting	Habitat for insect (urban ecological corridors)		x	
	Biodiversity of plant cultivars	x	x	
	Nutrient cycle: Photosynthesis	x	x	
	Pollination		x	
Regulating	Carbon sequestration and climate regulation	x	x	
	Stormwater drainage management		x	
	Removing water pollutants	x	x	
	Improvement of air quality	x	x	
	Building energy efficiency	x	x	
	Noise reduction	x	x	
	Reduction of 'heat island effect'		x	
	Relative humidity regulation	x	x	
	Provisioning	Food production	x	x
		Medical resources	x	x
Cultural	Ornamental resources	x	x	
	Natural landscape heritage		x	
	Aesthetic purpose in interiors	x	x	
	Therapeutic or Eco-therapeutic (mental health)	x	x	
	Science and education	x	x	
	Recreational and community experience	x	x	

Living walls incorporate vegetation in their structure using different kind of substrates as growing media for plants. They can be organized in modular or continuous structure. Modular living wall systems are different typology and they differ by weight, composition and assembly (Manso and

Castro-Gomes 2015). In all cases, growing media and irrigation system are kept separate from the construction material by a water-proof membrane to ensure the integrity of the wall structure (Dunnet and Kingsbury 2008).



Figure 2: Examples of indoor and outdoor living wall systems, University of Technology Sydney (Authors' pictures, 2020).

Living wall systems in urban environments are a space-saving strategy to reintroduce natural elements, not competing for land-use because they exploit existing vertical surfaces. Recent studies assert that living wall systems are effective solutions not only for ornamental purposes, but also

for the improvement of indoor air quality (IAQ), using plants ability to reduce the concentration of airborne pollutants in interior spaces, such as carbon dioxide, benzene, formaldehyde and other organic volatile compounds (Brilli et al. 2018).

Living Wall System - Commercial Products

Continuous systems		Modular systems	
Felt pockets	Trays or Pot system	Panels or Cassettes	Flexible bags
			
© Florafelt soft pocket	© Turnesol siteworks	© Junglefy Breathing Wall	© Geolana Hemp

Figure 3: Examples of commercial products per type of living wall structure.

Children and young students usually spend many hours per week in a school environment and often they may be exposed to poor indoor air (Marchland et al. 2006). Moreover, children in deprived neighbourhood may lack access to green areas and they are forced to spend the most of their free time with indoor activities. This habit also increases the risk to develop health diseases, such as

depression, negative emotions and low cognitive attention. The application of living wall system into school mitigates effects of indoor air pollution (Tudiwer and Korjenic 2017), it gives the possibility to increase the daily nature exposure, increasing cognitive functioning and attention (Taylor et al. 2002), and to develop educational programmes focused on nature-based solutions for urban environmental quality.

The importance of Eco-Literacy to support urban ecology

The complexity of urban contexts raises problems related to public health, liveability, resources and outputs management, environmental impact and quality of services. The discipline of Urban Ecology promotes an interdisciplinary approach to investigate interactions between human living and the urban ecosystem, underlining that human wellbeing strictly depends by ecosystem health (Richter & Weiland, 2011). The World Health Organization (WHO) considers urbanisation one of the most important challenge of the 21st century (2014) associated with the increase of stress, poor mental health and respiratory disease. Urban environmental education might help to cultivate ecological attitude in citizens, and especially in young people. Environmental education through UGIs gives the opportunity to understand basic principles of ecological systems and their application into built environments. It also encourages awareness, knowledge, skill development and participation in

problem solving for environmental issues. In other words, it gives a chance to become ecoliterate. Ecoliteracy is defined as the understanding of principles of nature and the using of them to create sustainable human communities (Orr 1992; Capra and Luisi 2015). Raising citizens ecological consciousness may encourage changes in behaviour that create attention on nature-based solutions and greening strategies, involving urban communities to improve more healthy environment.

Greening school: multifunctional purpose of indoor living wall

A indoor living wall is proposed to be installed in a primary school in Mirafiori Sud district (Turin, Italy) into the wider framework of the ongoing proGReg project (2018), which has the goal to implement nature-based solutions for post-industrial urban regeneration. The proposal is considered a pilot project to improve indoor environmental quality of suburban schools and to promote civic ecology education in young students.

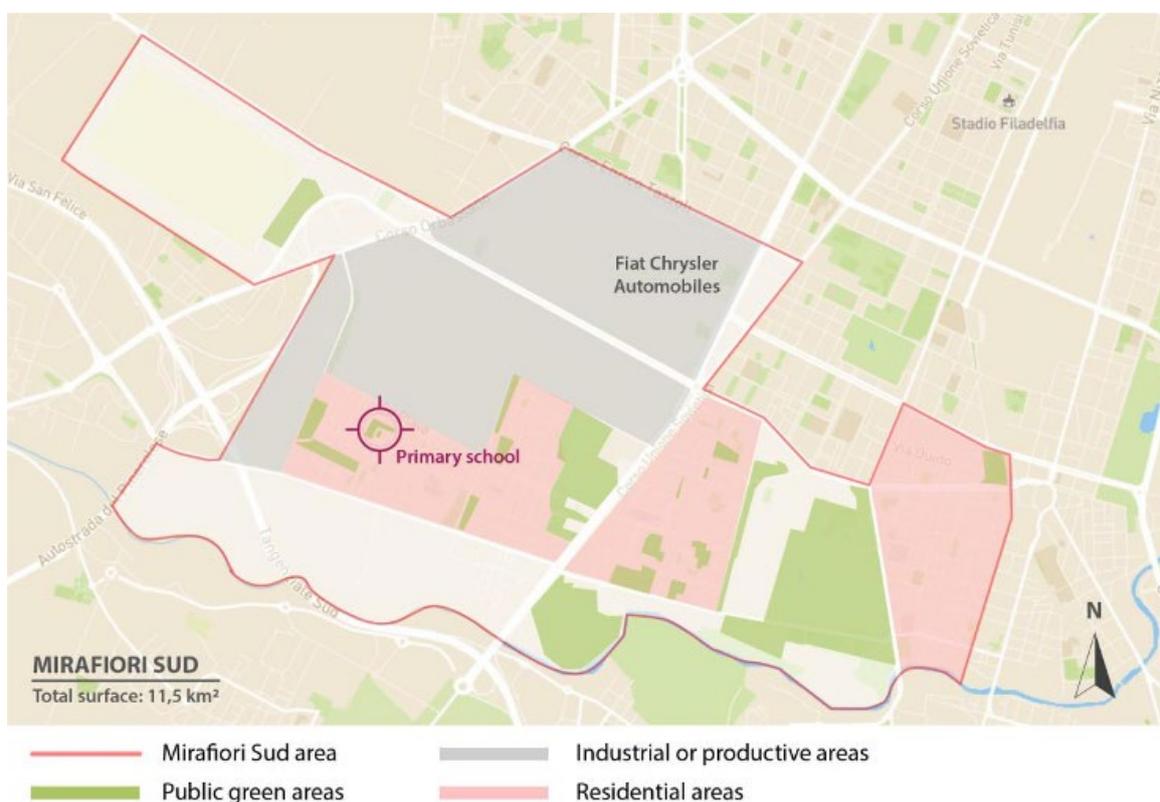


Figure 4: Map of Mirafiori Sud district and main land-use areas.

Mirafiori Sud is a working-class district in the south of Turin that has developed around the automotive industry ex-FIAT Mirafiori, nowadays known as FCA. The primary school is in the western side of the district, in a residential area rich with connecting green areas and gardens, but also really close to the industrial one. The decision to install an indoor living wall was taken to use plant-based solutions for IAQ, but also to involve students in informal learning activities based on the interaction with indoor plants. The aim is to encourage young students to develop collaborative interaction, responsibility and hands-on experience in indoor plant care and vertical gardening. A indoor corridor, used also as recreational area, has been selected to

host the indoor living wall, facilitating the access of students from classrooms. The location has been selected based on light requirements and water provision (through automatic irrigation system). Substrate-based pot-plant modular living wall (12m² of total surface area) is considered the most suitable structure to allow students interaction and reduce security hazards. Indoor ornamental plants recommended for air phytoremediation should be placed on the top part of the indoor living wall, while bottom cassettes are mainly dedicated to indoor vertical gardening (e.g. planting herbs) that requires students active involvement in planning and maintaining actions (Figure 5).

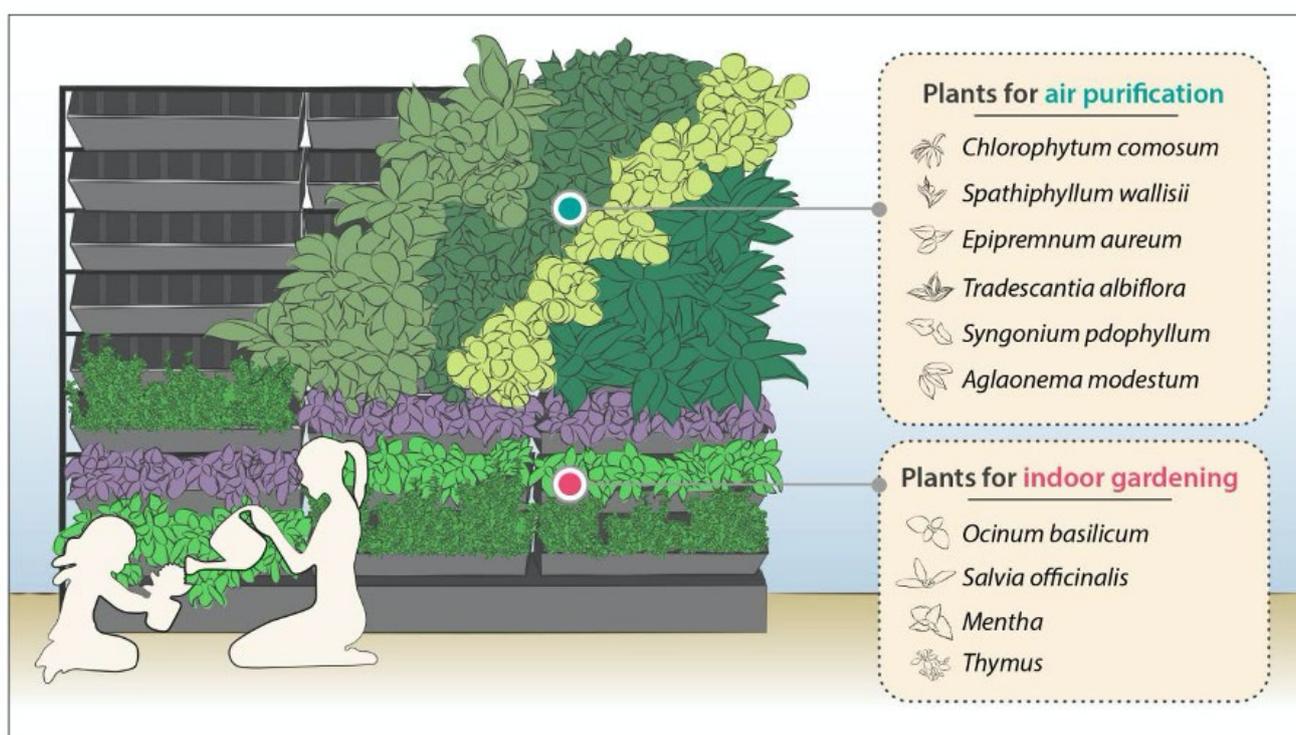


Figure 5: Indoor living wall scheme with indication of plant species.

Building civic ecology education and ecoliteracy skills

Indoor living wall in schools has the potential to inspire students in ecological thinking through the integration of project-based learning modules. They promote students interaction with indoor greening systems and create the opportunity

to implement a nature-based learning curriculum. Indoor living wall becomes an education tool for informal education activities to improve knowledge in science, technology, arts and culture. It gives the opportunity to learn about the importance of vegetation in interiors: students develop critical reflection about why and how plants can improve indoor environments

and learn practical skills to facilitate the integration of vegetation as a component of interior environments. Vertical greening is high technical solution applied to 'phytomitigate' negative effects of strong urbanization (Kennen and Kirkwood 2015). It demonstrates how technical skills can support plant growth to increase urban resilience. Students have the opportunity to learn more about plant physiology and ecology in urban environment through conversation with experts and specialists. This framework define that environmental education model can be developed in, about and for indoor living walls.

Education 'in' indoor living walls

Education in indoor living walls refers to the opportunity to organize place-based learning, hands-on and experience activities in classroom and also after-school. The school's living wall is considered as living lab to experiment vertical indoor gardening and to translate abstract ecological principles into practical ones. Place-based learning in indoor living walls helps to integrate informal education model into traditional curricula and to build sense of place using school spaces for unusual community-based activities.

Education 'about' indoor living wall

This refers to the knowledge improvement of benefits provided by indoor greening in term of IAQ and psychological benefits. Specific lessons focus on air quality, sources of indoor air pollution, human health, botanical and physical aspects of indoor plants, physiological mechanisms involved into the degradation of airborne pollutants, living wall benefits, indoor gardening and technical aspects required for vertical greening systems to create healthier indoor environment. Indoor living walls could be considered as a complementary tool for school gardening programmes that are already active in the primary school. Students could also experiment with indoor agriculture through cultivation of some

edible plants or herbs, especially during autumn and winter season. Learning plants requirements that are affordable for indoor environment fosters improved knowledge about the integration on nature in interior spaces.

Education 'for' indoor living wall

This refers to the need to provide knowledge and skills to make users able to do appropriate maintenance. Education activities should be organized to promote students participation and involvement. Information about plant care, pests, diseases, watering, lighting and fertilizers could encourage students to develop critical thinking skills to maintain ornamental and functional properties of the living wall system. Looking at other initiatives, such as the 'It's Time to Grow Up' project (2020), actions to improve the knowledge transfer about vertical greening systems in urban environment are essential for the involvement of local community and citizens groups. Informal education for indoor living wall could build cooperative social skills and promote community-based learning activities through the participation of students families and local neighbours. Community-based and project-based learning promote action skills to mitigate urban environmental problems that impact human wellbeing, considering also social and cultural aspects (Ballard and Belsky 2010).

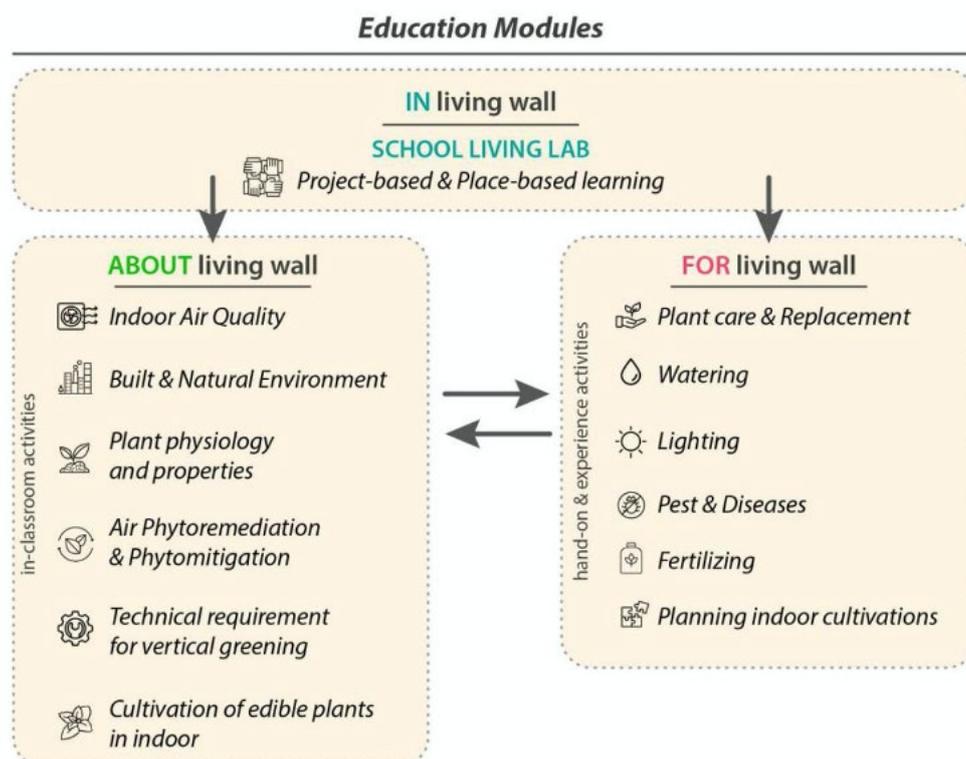


Figure 5: Indoor living wall scheme with indication of pant species.

Conclusions

Improving ecological vocabulary and knowledge to be ecoliterate

Indoor living wall provide opportunities to students to interact with an example of UGI and to reflect about their role in the improvement of ecology in, of and for the urban environment (Pickett et al. 2016). Environmental education activities based on observing, analysing and experimenting indoor living wall improve students understanding of nature-based and phytotechnology solutions benefits on human wellbeing mitigating climate at city scale. Improving young students consciousness about ecosystems services provided by UGIs could promote individual appreciation of nature and foster more positive attitude towards ecological approach in urban environment. Through practical interaction and conversation with experts, students have the opportunity to learn more about the differences between natural and built environments and about UGIs role for sustainability and resilience of cities. Informal education encourages

students to stay more in connection with living systems (plants) creating recreational moments that have positive effects on perceived stress reduction and on mental health. As well as improving air quality, indoor living wall systems contribute to teach basic information about biophilic urban strategies and ecological approach to design more sustainable interior spaces. In addition, recent global disruptions linked to the spread of Covid-19 highlight the need to re-think some informal education activities, that include community-based and project-based learning strategies, due to social distances measures. This scenario requires the use of virtual tools to improve ecological consciousness and environmental education programmes. On the other hand, restrictions on people's movement encourage them to think about the importance of nature local accessibility, such as parks, and of indoor greening.

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FACILITATING USERS AND DESIGNERS TOWARDS A SHIFT OF PERSPECTIVE FOR TRUE PARTICIPATION IN CO-CREATION IN HEALTH CARE: A HOLISTIC ACTIVITY THEORETICAL APPROACH

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Abstract

Modern healthcare is a complicated sociotechnical system where medical technology is a prerequisite for quality as well as cost-effectiveness. New and complex technologies for diagnosis and treatment are progressively developed to meet the challenge of future health care. However, this requires increasingly close cooperation by heterogeneous stakeholders with various views that must be heard and negotiated. Traditional participatory design approaches may not suffice to establish the needed close cooperation. This paper builds on the authors' research over the last decades on eliciting stakeholders needs and requirements in the development of medical products by means of participatory design processes, analysed by Activity Theory (AT). By facilitating stakeholders' interactions

with mediating tools, the rules and relationships that shape behaviours and outcomes to become visible. AT reveals and supports our understanding from a holistic perspective of the need for a shift of perspectives to form a new and shared activity system in a collaborative space that bridges the gaps between participants and thus holistically allows individuals to bring their respective knowledge, experiences, and motivations into co-creation processes. This requires a meta-shift of perspective that needs to be facilitated in the co-creation process and can only occur if and when participants are enabled to understand the process and the role(s) they have.

Keywords: activity theory, co-creation, participation, medical device



Introduction

Medical technology is a prerequisite for high quality, as well as cost-effectiveness, in modern healthcare. Recent developments have resulted in a range of new and increasingly complex technologies for improved diagnoses and advanced treatments. However, healthcare is a complicated sociotechnical system where new technical solutions must fulfil the needs and requirements of heterogeneous groups of stakeholders (e.g. patients, nurses, clinicians, physicians, etc.) situated in various use contexts which can impose significant restrictions on the set of viable solutions. These, possibly contradictory, needs and requirements must be taken into consideration throughout the development process, as failure to do so may lead to unused, unusable or, even worse, unsafe designs of medical devices.

Various more or less fruitful methods and processes have been proposed to address this complexity, including a range of participatory approaches, all with the underlying aim to involve users (primarily) but also other stakeholders in the design process. However, the degree of involvement is not always evident, and users' participation is often limited to being informants in early design phases or (even more often) as evaluators in the final stages of development. The possibility of real influence over the direction and outcome of the design is often missing (Halskov and Hansen 2015). This has led to the introduction of concepts such as 'authentic user participation' (Went, Gregor, and Ricketts 2009) or 'genuine user involvement' (Smith and Iversen 2018) to signify a design process in which users are indeed truly participating.

Furthermore, different sources refer to approaches involving users in the design process as 'participatory design' (Ehn and Kyng 1987) 'co-design' and 'co-creation' (Sanders and Stappers 2008). However, whereas participatory design most often

focuses on the involvement of users per se, Sanders and Steppers (ibid) describe a process where co-design refers to the actual activity of designing a solution to a specific problem through collective making with users, and co-creation as any collective creativity shared by two or more people – not only users, but also including stakeholders from diverse perspectives addressing complex design problems, such as the design of medical devices. Still, co-creation faces several challenges as does any design process in which different disciplines are brought together (Pirinen 2016). These challenges extend well beyond the implementation (or not) of a specific method and tool to include more fundamental issues such as differences in knowledge, language, perspectives, motivation, and power (Simonsen and Robertson 2012).

Nevertheless, to meet future challenges in healthcare, the development of medical technology will require increasingly close cooperation between different disciplines and individuals with diverse backgrounds and experiences (medical specialists, nursing staff, engineers, industrial designers as well as patients). In order to establish this close cooperation and to enable true participation between users and designers, a holistic approach to co-creation is required. Activity Theory (AT) provides us with such framework, enabling us to understand some of the challenges of involving diverse perspectives in co-creation processes.

Empirical Basis

This paper builds on the authors' collective insights of research into eliciting users' needs and requirements in the development of medical and healthcare products and users' involvement in co-design processes. The experience includes a Nordic collaboration research project with the purpose to create a centre to increase communication and collaboration between designers and users of medical and healthcare technology (Karlsson et

al. 2011). Another example involves an exploratory study over a period of nine months which aimed to develop a novel medical device for long-term monitoring of EEG for premature infants (Eriksson 2014, Eriksson, Sandsjö, and Karlsson 2018). The latest study ran over three months and focused on the development of concepts for an innovative medical device to diagnose strokes at the emergency site. Even though the projects differ in several aspects, a common denominator is that they all included a variety of stakeholders (e.g. medical specialists, nursing staff, patients, engineers and industrial designers) who respectively contributed their specific expertise and experiences in health care and a product development.

A retrospective analysis of the processes and outcomes of the respective projects have been carried out and a number of enabling factors as well as barriers for users' and designers' involvement in co-creation processes has been identified. The aim of this paper is to present and discuss our insights through the lens of Activity Theory.

Activity Theory in Brief

Activity Theory (AT) provides a framework, to understand diverse perspectives on human activity. According to AT, subjects (human beings, teams, organisations) have needs which lead them to carry out activities, i.e. interact with tools (tangible or intangible) in the world, in order to satisfy their needs. As objects motivate and direct activities an understanding of objects is necessary in order to understand human activities (Kaptelinin and Nardi 2006).

An important concept is mediation. Human activity is mediated by one or more physical and psychological tools that shape the way the human beings interact with the world and through which subjects achieve their goals. Examples of tools are language, methods and techniques, hand tools, etc. A well-working mediating tool allows the user to focus on the object of interest,

while a tool that does not work well causes breakdowns and instead draws a user's focus to the tool.

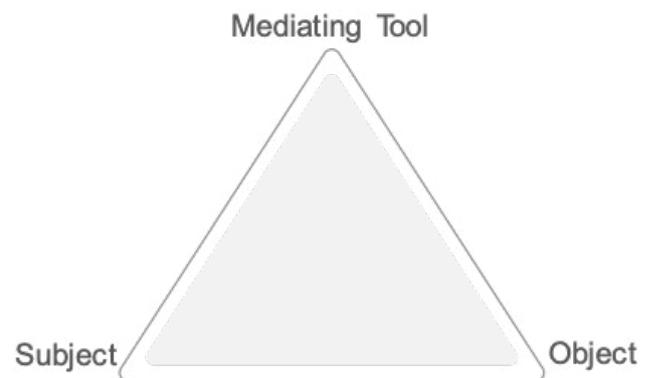


Figure 1. AT foundation unit.

Engeström (1987) expanded the unit of analysis for studying human behaviour from that of individual activity to a collective activity system. An activity system is defined as a collective, artefact-mediated, object-orientated system. To the original subject-tool-object orientation (Figure 1) three other types of mediators, community, rules, and division of labour, were added (Figure 2). In addition, Engström's model includes the outcome or result of the activity system as a whole: a transformation of the object produced by the activity into an intended result, that can be accessed and utilized by other activity systems.

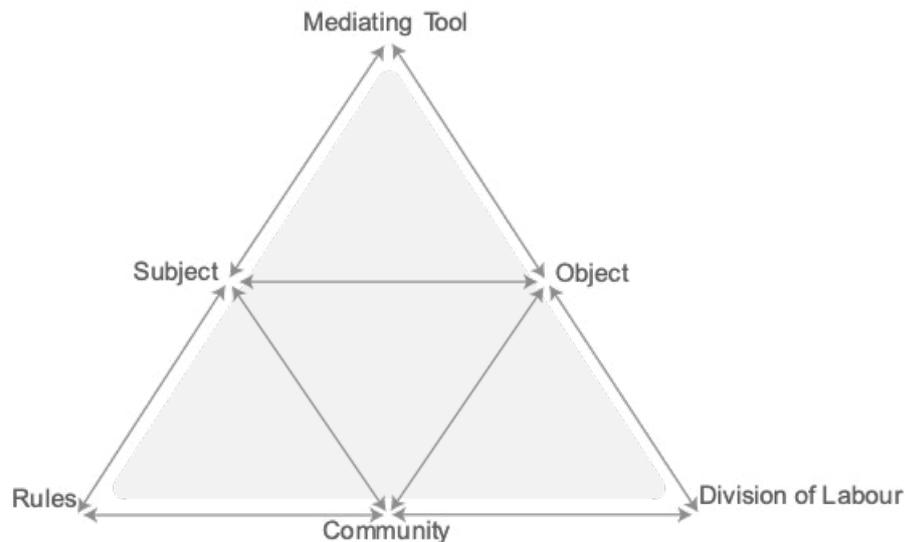


Figure 2. Engström's AT model

Activity Theory into Co-creation Practice

In line with Smith and Iversen (2018), we believe that to improve the user experience of medical devices, the challenge for the future design of such devices is not only to engage different stakeholders as designers in the design process by means of a post-it notes session or an event in collective making but rather, we need to create space for trust and commitment, fostering true participation in a continued process.

In that process, we need to elicit stakeholders' diverse experiences and knowledge, both explicit and tacit, that goes beyond the focus on the technical artefact to be designed to create prerequisites for collaborative efforts that instead support collective long-term knowledge generation that is more broadly shared and developed by the participants over time to design future products for future contexts. This requires though a shift of perspectives from the designers' and user's dichotomies towards an understanding each other's knowledge and experiences from their various disciplines' perspectives and an appreciation for what such expanded views may bring into the co-creation process and its outcomes.

In collaborative design processes, each participant brings their own thoughts, knowledge, tools, experiences, and desires towards their object, influenced by the rules and division of labour constituted in their own activity systems, into the collaborative space. Those disparities are often identified as barriers in cross disciplinary collaboration.

By identifying individuals' (e.g. professional users, patients, designers, engineers, etc.) different objects, the AT framework enables us to recognize the multifaceted character of the co-creation process, i.e. different objects for contributing and different motives for their respective activity. This means that with a system theory perspective, we can identify the gaps between the various activity systems as a vehicle for the needed shift of perspectives towards mutual knowledge generation.

If a device, for example for artificial respiration, is to be designed co-creatively, designers and users bring their own tools, i.e. knowledge and experience, into the process. A designer may bring technological knowledge of requirements for the product to be approved and sold to hospitals, but designers do not belong to, and therefore do not have, deep understanding of the use context. A nurse brings caregiving knowledge of how the device will function

in actual use-situations, including how it will interface with other devices and with the patient. A physician would probably bring tools to prescribe and adjust the rate and composition of the oxygen flow to provide the best medical care. A recovered patient will bring their own experience of being treated with a device. Thus, the users' activities, tools, and objectives, as well as the rules, roles, and community that are part of their activity system, must be made explicit for designers to comprehend them. To take advantage of their various perspectives and expertise, users must be facilitated beyond roles as informants to the traditional design team, and instead take active roles in the co-creation process. Therefore, users need to be challenged with, for instance, embodied design solutions, to enable them to comprehend designers' perspectives and thereby grasp what specific knowledge they can contribute (Figure 3).

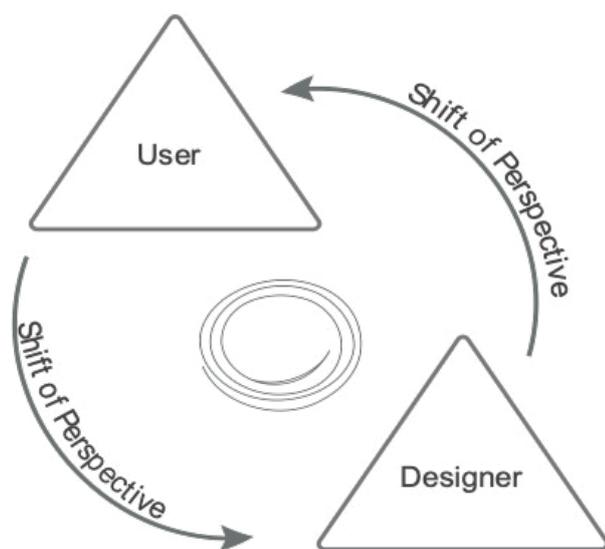


Figure 3. Shifting perspective from participants' dichotomies.

The challenge is not only broadening perspectives and bridging gaps between different activity systems, we need to create space to form a new shared activity system. Consequently, the process includes enabling the participants to expand their tools, externalize motives and objects formed in their individual activity systems and

bring those elements into the co-creation process. This will require that new shared tools and shared objects are created which in turn will lead to that new rules and new division of labour in the activity emerges.

The formation of the new shared activity system requires not only enabling the users and the designers to contribute their knowledge and perspectives to design solutions, it also necessitates something more, a meta-shift of perspectives. This includes the participants externalization, comprehension, and internalization of others' various perspectives so that an integrated perspective can be experienced and then embodied not only in currently investigated design solutions, but to support mutual knowledge generation for future designs. The meta-shift of perspective needs to be carefully facilitated as it can only occur if participants are enabled to comprehend the process and the roles they have in it. Hence, the organizers need take mediating tools, facilitator's roles, power distribution, and time into consideration – not as isolated units, but as parts that interconnect, forming a new shared activity system as a whole (Figure 4).

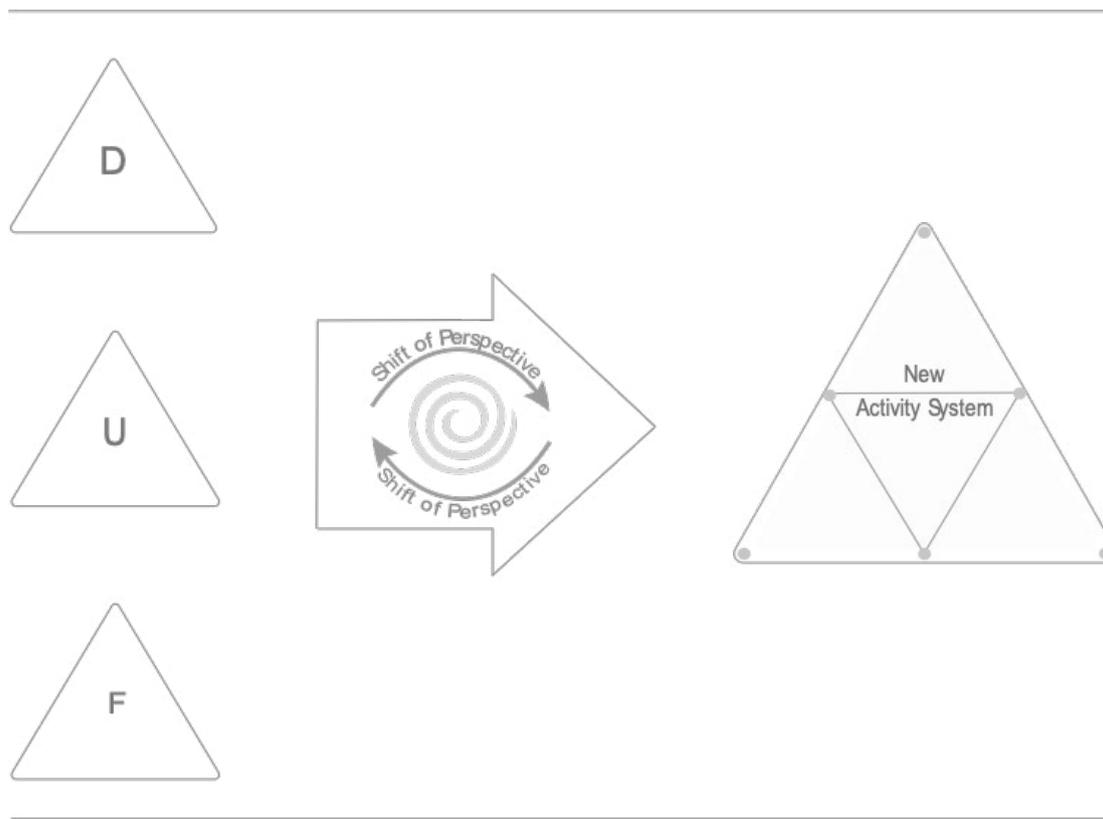


Figure 4. Process of formation of a new shared activity system from designer's, user's and facilitator's respective activity systems.

The generation of the new shared activity system requires that knowledge (explicit and tacit) is externalized from one participant and comprehended by the other, an activity of communication, knowledge sharing and knowledge generation. This is a learning process that needs to be mediated. The use of representational artefacts as mediators for embodying design solutions and manifesting design ideas to be shared among designers and users is well recognised in design research (Brandt 2007).

AT supports our understanding to recognize representational artifacts as epistemological mediating tools. Such representational artefacts, with their multimodal function, mediate communication and mutual knowledge sharing that make it possible to bridge the diverse activity systems and bring about long-term knowledge generation rather than merely focusing on the immediate design solutions. They serve as tools, mediating language and knowledge sharing among participants by

verbalizing terminologies from the different perspectives, helping to fill in when words are not understood (e.g. pointing at...), externalizing ideas by visualization, and stimulating new thoughts by confronting knowledge and experiences born from multiple subsidiary activity systems. Deeper understandings may be brought about by their tangible character, thus supporting the process of explicit externalization of a user's knowledge, experience and object and so enable designers to comprehend and internalize new understandings into their own domain's perspective (Eriksson 2014, Eriksson, Sandsjö, and Karlsson 2018).

User participation in co-creation processes is not a democratic event per se. Based on our research, we believe that trust and commitment (as vehicles for collaboration) must be facilitated by someone impartial, with skills to manage the co-creation process with a focus of empowering and voicing the participants to equally contribute their expertise and facilitate participants to embrace or

negotiate different views, yet without any commitment to the project outcome (Wastchak 2013).

Moreover, co-creation includes a change of the designer's role, from being the creative resource in the design project towards a resource that supports, e.g. users, to express and externalize their thoughts and experiences by use of their tools, e.g. design methods, if a shared activity system is to emerge. Consequently, the facilitator is recognised as a key player to ensure that the participants endorse and maintain the new rules and new divisions of labour.

Managerial support is a central prerequisite for co-creation (Pirinen 2016). Including management in the actual co-creation activity is sometimes argued to be time efficient as decisions 'on the fly' can be taken by the manager. However, in co-creation, power distribution is always skewed towards the company's favour. We found that balancing hierarchy and power distribution among the participants is of great importance if the formation of new shared activity system is to take place. Thus, management should probably not participate as an active partner in the co-creation event, so as not to jeopardize or inhibit the users' commitment to contribute.

Finally, a note on time. Most design projects face time pressures, and involving users in the development processes can be a major challenge (Karlsson et al. 2011). However, we emphasise that if true participation shall occur in co-creation projects, there has to be more than a workshop. Time facilitates pulling down well-known barriers, such as discipline disparities (language, knowledges, expectations, rules) formed in the participants own activity systems. This means that co-creation needs to be carried out in a process, including the same group of people to meet and identify needs, requirements and potential design solutions iteratively throughout the design process. Thus, time lays the ground for the participants to go beyond the technical

artefact towards the generation of new mutual knowledge that meets future challenges in medical device development. Hence, time itself becomes a mediating tool.

Conclusion

Activity theory enable us to understand influencing parameters that affects the outcome of eliciting diverse stakeholders' needs and requirements in a co-creation process of medical devices. The co-creation process aims to bridge the gap between the different activity systems of the participants, enabling users and designers to, not only bring their respective knowledge, experiences and motivations into the collaborative space, but rather create understanding and comprehension of each other's perspectives.

However, bridging the gaps between these diverse activity systems, towards the formation of a shared and common one, requires a shift of perspective which can only occur if participants are enabled to comprehend the process, and the role they have in it. Therefore, we need to support participants to go beyond users as informants to the design team, towards long-term mutual knowledge generation to meet the future challenges in health care device development. Hence, co-creation teams need to take mediating tools, facilitator's role, power distribution and time into consideration, not as isolated units, but as parts that interconnect, forming a new shared activity system as a whole, fostering true participation in co-creation processes in healthcare.

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'IT'S LIKE EACH INDIVIDUAL'S SOUL IS ON THE TABLE': USING THEMATIC CARDS AS ELICITATION TOOLS

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Abstract

The methods discussed in this paper were used within a project that explored the significance of clothing to people with dementia living in a care home. Before conducting the research, a favourable opinion was granted from an NHS Research Ethics Committee. The project consisted of three interlinked cycles of study, which were informed by the lead author's background in fashion textile design and psychology, collaborative and iterative approaches to research (e.g. co-design practices and participatory action research) and sensory ethnography. Sensory ethnographic research draws on traditional ethnographic methods, such as observations and interviews, whilst employing less conventional visual and sensory techniques, which may involve, for example, the researcher and participants designing an activity. The first cycle of study involved working with people with dementia and care home staff to explore clothing 'during wear' (i.e. sensory and embodied aspects of clothing), through a series of multisensory research encounters. Data from the encounters was analysed using reflexive thematic analysis and findings were translated into a set of thematic cards that were used as elicitation tools.

Creative practitioners (e.g. visual artist, ceramicist, illustrator), working in health and social care settings with people with dementia, were invited to engage with the thematic cards and use the cards to explore ideas regarding the design and curation of objects, images and textiles. In light of their responses, the lead author created and selected, objects, images and textiles that were used within object handling sessions with people with dementia.

Creative practitioners' engagement with the thematic cards informed not only the object handling sessions, but also suggested that thematic cards may be a powerful way in which to communicate findings with a wider non-academic audience. For example, one practitioner found the cards so evocative that they claimed it was like each individuals' soul was on the table, thus highlighting the opportunities that elicitation tools may afford in supporting the tangible and applied ways in which the findings could be envisaged.

Keywords: dementia, elicitation tools, sensory research methods



CHANGE AND NOVELTY FOR INDUSTRIAL DESIGNERS IN COMPLEX DESIGN PROJECTS FOR HEALTHCARE

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Abstract

In past decades, industrial design practice has broadened from designing (mass-)products towards the design of services, experiences and systems. With this broadening, it is questionable how models of design processes still fit today's industrial design practice. By means of process research, this study investigates new roles that designers currently take in practice. It addresses the question how ways of working change for an industrial designer dealing with an open design challenge. The context of research is a design project for a large academic hospital that is in the middle of a large-scale renovation. The project is executed by a design agency with 10+ years of experience in designing healthcare products.

However, this project concerns the improvement of service, rather than a product. The data collection (during 21 months) is based on principles of organizational ethnography, combined with interviews. The analysis is based on an events-based approach and provides understanding in how a senior designer experienced the project flow and how he adapted ways of working in eight main events of the project. The findings include strategies of a senior designer dealing with change and novelty in a complex design project in healthcare, and scaffolding concepts in the light of existing theory.

Keywords: industrial design, healthcare, hospital, ways of working, change and novelty



Introduction

Industrial Product Design involves the design of tangible objects for mass or series production, in which - in contrast to crafts work- objects are produced by other people than the designers themselves (Roozenburg and Eekels 1998). Numerous design process approaches have been developed (see e.g. Pahl and Beitz 1986, Cross 1989, and Roozenburg and Eekels 1998 on this subject) to structure the creation of such product designs, like coffee machines, cars, roadside emergency phones, mail boxes, vacuum cleaners, and umbrellas. While traditionally, the core of the industrial design practice was about devising and capturing geometry, materials and processing techniques of new products, today's industrial design practice has become more open, complex, dynamic and networked (Dorst 2015b). For example, industrial designers are nowadays often involved in designing applications for mobile devices and they create customer journeys and service blueprints, rather than creating technical drawings for products. For example, they investigate user experiences of travellers in trains, to improve the service of a public transport organization rather than solely designing the train interior. With these more open and complex design challenges, it is questionable to what extent, and how the traditional design process approaches fit today's Industrial Design practice.

This study investigates new roles that designers currently take in practice by means of a qualitative longitudinal single case study. It addresses the question how ways of working change for an industrial designer dealing with an open design challenge. It takes a process perspective, a form of research that explains how phenomena emerge, develop, change, and terminate over time (Langley 2007; Langley et al. 2013; Langley and Tsoukas 2017; Berends and Deken 2019). The phenomenon under investigation here

is 'the changing ways of working for industrial designers', who make the transfer from product design towards more open design challenges in which the output is not pre-specified. This study took a lens of organizational events and applied an events-based approach (Hussenot and Missonier 2016). Organizational events are for example project meetings (Langley et al. 2013). This study focused on project meetings in which something happened that gave direction to the further course of the project. It identified 'disruptions of flow' (Yanow and Tsoukas 2009) as experienced by a senior designer. Most learning moments about evolving design practice are likely when project meetings fail to meet designer's expectations. This study focuses on what is happening in such moments and how they give insight into change (e.g. adaptations in practice) and novelty (practices that are new for designers) in designerly ways of working. By applying an events-based approach, change and novelty are seen as part of the same act that are expressed in a present moment, the project events (Hussenot and Missonier 2016).

The empirical context of research is a Service Design project for a large academic hospital in Europe that is in the middle of a large-scale renovation. The project is conducted by a senior industrial product designer, not educated with Service Design principles, which is nowadays included in design education. Here, we do not distinguish between two different perspectives to look at service as 'products' (see e.g. Hollins 1991, and Mager 2004) or with a focus on process (see e.g. Pacenti 1998 and Han 2010). Rather, we emphasize that objectives and boundaries in Service Design projects are less clear and more open than in traditional Product Design projects, and hence it is an appropriate context to investigate change for (senior) industrial product designers who deal with more open, complex design challenges.

Method

The case and actors involved

The design brief in this case reads: Design a better, faster and cheaper solution for patients arriving at, moving during their stay in, and departing from the main building of the hospital. The academic hospital has more than 10,000 employees, and the organizational structure is complex and consists of eleven divisions, two advisory boards (for staff and frontline employees), four participation councils, seven directors, and on top a board of directors and a supervisory board. The senior designer (10+ years of experience) in the case is owner of an established design agency with a focus on strategic product design, and a product portfolio that strongly focusses on healthcare products. The agency employs about ten people, most of whom have a background in product design. The design brief asks for a 'solution' in which the kind of outcome is not pre-specified, and hence it can be seen as an open and complex design project. The designer explained that this project is of a different kind than his design agency is used to, and that he wanted to get experience in applying new methods (e.g. 'context mapping', developed by Sleeswijk Visser et al. 2005) which they usually would not apply in their product design practice.

There are eight actors involved in this case, of which the designer is main observed participant (participant 1). The other participants are a master level student with experience in context mapping and who carries out her graduation assignment in the context of this case (participant 2), a team leader of the customer service department of the hospital with a background in management and who is contact-person for the designer since the first designer-client meeting (participant 3), a specialist in measuring equipment with knowledge on electrical and electronics engineering (participant 4), and four steering group

members (participant 5-8) of an overarching European research project in which this project is a case.

Data gathering

The data gathering is based on principles of organizational ethnography (Ybema et al. 2009). The methods applied are participant observation, document analysis, and interviews. The participant observation concerned a qualitative longitudinal (21 months) collection of naturally occurring data (things observed and heard) within a single case. It includes observations of the eight participants (see 'the case and actors involved') of what they naturally did and said in 70 moments, e.g. in site-visits, meetings, informal phone calls, and e-mails. In addition, 66 project documents were collected, consisting of reports (n=6), a video-recording of a presentation (n=1), invitations-letters (n=1), presentation-slides (n=3), communication posters (n=41), personas (n=4), book chapter (n=1), stakeholder-map (1), sets of drawings (n=2), and sets of pictures that were taken within six meeting pictures. Next to the naturally occurring data collection (participant observation and document analysis), research elicited data was collected by means of 24 interviews with the participants 1-5, of which the most (n=11) were conducted in the flow of the project with the designer (participant 1).

Data analysis

We structured the data analysis following an 'inductive composition' (Berends and Deken 2019) with three components: narrative, scaffolding concepts, and theoretical explanations. First, we created a chronological narrative of almost 4000 words (component 1) and a visual representation of the timeline, which provides detailed understanding of the case. Within the data, we identified seventeen noteworthy organizational events like project meetings and defining moments. In the narrative, we searched for disruptions

of flow ‘that lies in discrepancies between actor’s expectations and experiences’ (Yanow and Tsoukas 2009, 1344). We did this by listing – for all seventeen events – the expectations that the designer explicitly made regarding the events, along with how he experienced it in practice. By doing so,

we identified eight main events that disrupt the flow of practice for the designer. Figure 1 provides insight into the flow-disruptions as experienced by the designer, in relation to the eight main events and the project timeline with seventeen organizational events.

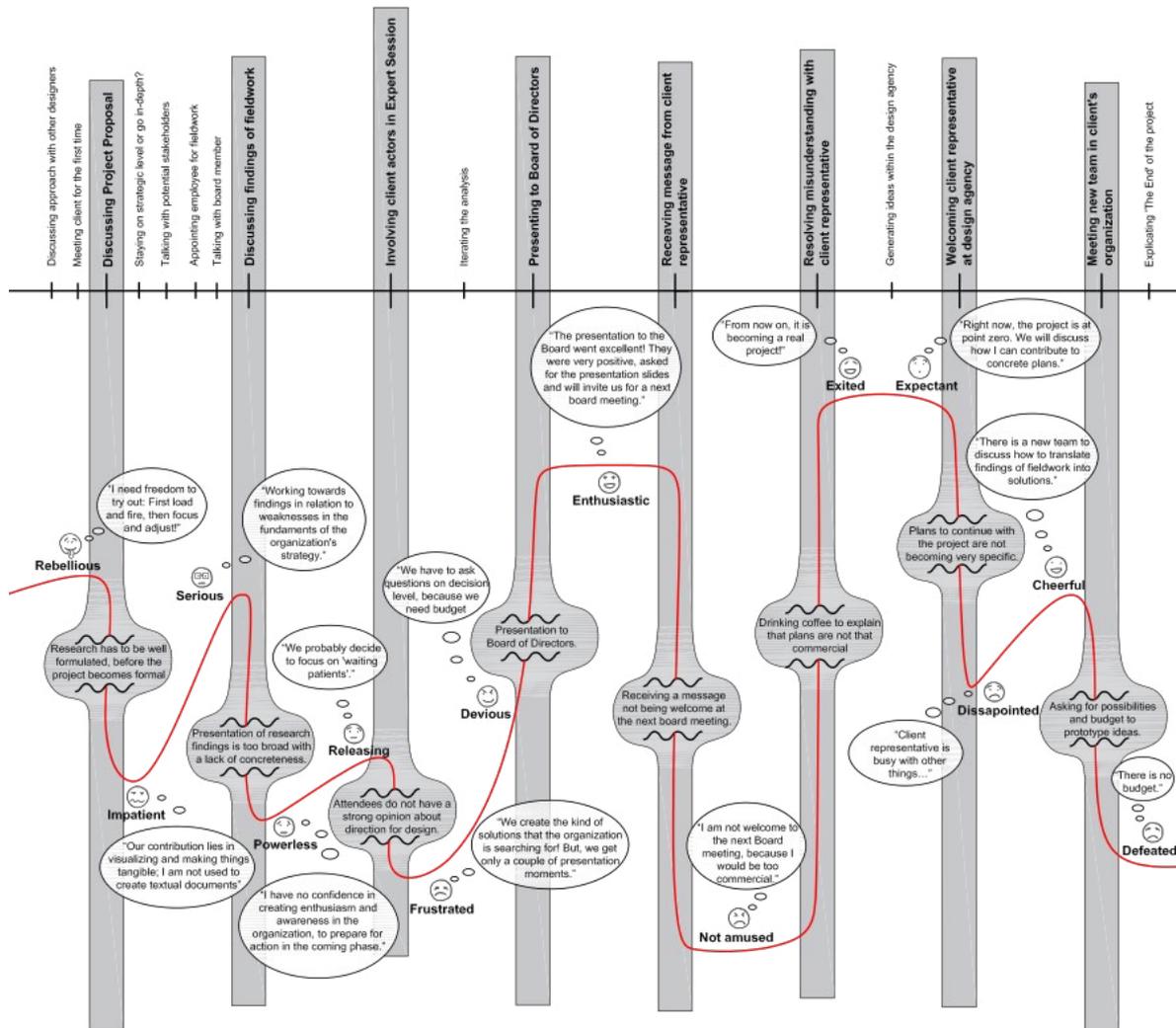


Figure 1: Disruptions in project flow as experienced by the designer

To investigate the research question, we further analyzed the eight main events, while being aware that ‘each event arises out of, and is constituted through, its relations to other events’ (Langely et al. 2013, 5). While having all data in mind, and the reconstruction of it in the narrative, we focused on details that took place in the main events. We constructed eight descriptions of what happened in the main events with regards to ‘changing ways of

working for a designer’, which was the phenomenon under investigation. As an example, one of the descriptions is given below:

‘An expert session is organized to get input and share findings of the fieldwork with eight experts from the hospital – amongst them, the team leader of the customer service department – and from an engineering consultancy. Aim of the session is to decide on, and (re)set the

project focus. The designer wants to start with creating and testing prototypes of ideas that he has in mind, but since the expert session, he realizes that there are just a couple of presentation moments that he can attend, and that's it. As a result, he changes his ways of working and plans to talk – in devious ways – with other potential stakeholders in the hospital than mainly with the team leader customer service, because she has no money to spend.'

From the eight descriptions we developed findings on organizational, process, and product level (component 2), as 'presentation of a conceptual overlay to scaffold theory development while

maintaining the underlying temporal structure of the data' (Berends and Deken 2019, 4). The descriptive findings of what happened in the eight main events with regards to 'changing ways of working for a designer' were instrumental in developing the scaffolding concept findings. The discussion-section provides theoretical explanations (component 3) for the scaffolding the concepts.

Findings

In the eight main events, we identified change, stability, and novelty in the designer's ways of working, which we visualized with text-clouds in Figure 2.

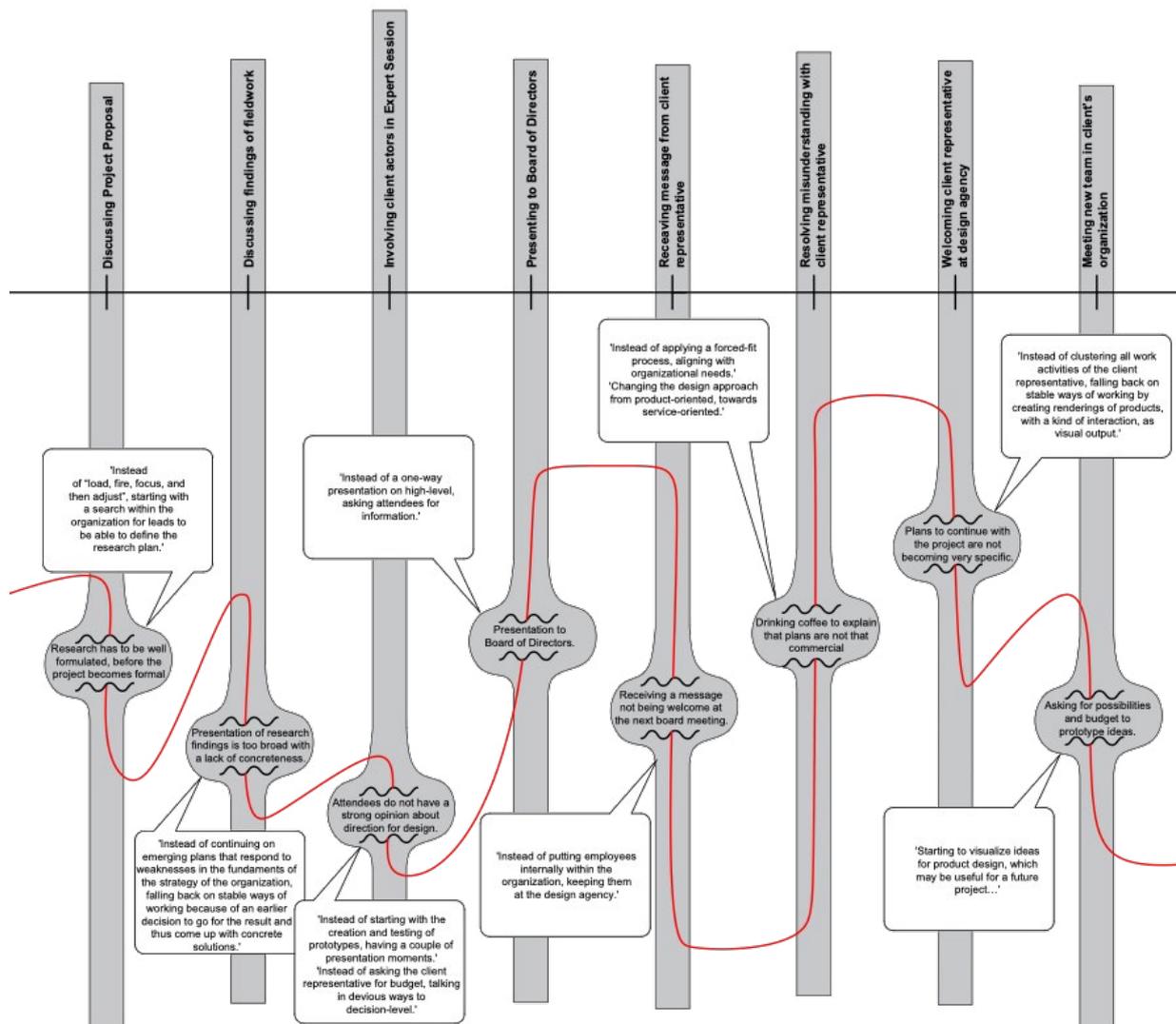


Figure 2: Change and novelty in ways of working for the industrial designer

We organized the identified change and novelty on three levels:

- On organizational level the findings show that design becomes more strategic and responds to fundamentals of the organizational strategy, in which an awareness is created that the product is developed in the organization itself, with a couple of presentation moments for the designer. The designer's strategy to deal with this change is organization-wide talking to various experts (doctors of various departments, innovation project leaders, an econometrist, customer service employees, employees of branding and relations) and on various organizational levels (with patients, operational staff, project leaders, program managers, team heads, directors of departments, staff-members, and the board of directors).
- On process level the findings show that design becomes a joint step-by-step search for added value, in which an awareness is created that it requires an open and deep investigation of organizational needs, without a demarcated timeframe. The designer's strategy to deal with this change is defining plans together with the contact person in the client's organization by clustering all her work activities around the themes of fieldwork, and further expanding on the themes by suggesting specific points of interests in ongoing projects, depending on what the contact person will bring in.
- On product level, the findings show that design becomes more process development than product development, by responding to (medium) long-term strategies of the organization, in which an awareness is created that design is not (always) about products only. The designer's strategy to deal with this change is searching for and building on knowledge and products that are already available in the organization.

For each level, we constructed a scaffolding concept on shifts in design practice, based on empirical findings and in relation to more traditional product design ways of working.

Organizational level: Focus on formulation of objectives, strategies and goals

The scaffolding concept on organizational level entails a shift in form of the designer-client collaboration: From a client-contractor relationship, in which the product is designed at the design agency with a couple of progress meetings at the client-organization, towards a strategic design project within the client-organization with many designer-expert meetings and a couple of presentation moments on decision-level. As the designer put is:

'I realize that the product or service is actually being developed in the organization itself, with a couple of presentation moments for us.'

It comprises the involvement of more professionals from different backgrounds in the front-end of design, and focus regarding the collective formulation of objectives, strategies, and goal setting.

Process level: Coupled search for focus and what to design

The scaffolding concept on process level lies in an emerging awareness that designers increasingly have to deal with the practices in the organization, in conjunction to the design practices that they are used to. The change and novelty for industrial designers entails a collaborative step-by-step search for what to design and integrating that in the context of the organization, rather than having the kind of product in mind at the start of a project. The designer gradually becomes aware that the project will have a different kind of outcome than he initially expected, as he put before talking with the client contact about the misunderstanding:

'If you give my design agency a project, you know one thing for sure, that a marketable product comes out of it! That is in our DNA! We start with a marketable end product and we work from that point backwards to what is needed.'

After this meeting he changed his perspective:

'We are not going to design anything here. We are not talking about products. This is all about process. We have to design a process out of this all.'

This search for what to design runs parallel to a deep investigation within the organization, for example to identify different perspectives, values, interests, possibilities, starting points for design, and feasibility and reliability of emerging ideas.

Product level: Anchor for work activities in relation to organizational strategy

The scaffolding concept on product level refers to a shift from focusing on the creation of tangibles towards more strategic design with a focus on interventions that build on existing knowledge in the organization. The strategic processes require to balance desirability, feasibility and viability of deliverables, rather than mainly concentrating on enhancing desirability. As the designer put it:

'I call this anchoring future work activities in the context of my work. The effect of asking questions, in relation to the strategy that we based on information that was already available in the organization, brought me to a position in which I am.'

Conclusions & Discussion

We conclude that the designer is openly exploring possibilities for change and novelty, but that he fell back on stability on decision moments that he experienced as tough. This stability prevented the designer from adapting ways of working towards

emerging insights because of agreements that he had made along the way. However, strategies that the designer in this study applies to deal with change on organization, process, and product level are respectively:

1. Organizational-wide talking to various experts and on various organizational levels, including decision level.
2. Aligning plans with the work activities of the client's contact person, coupled with suggesting specific points of interests in ongoing projects depending on what the contact person will bring in.
3. Searching for and building on knowledge and products that are already available in the organization.

Based on these findings, we constructed – in relation to more traditional product design ways of working – three scaffolding concepts that suggest that the identified change requires a shift towards 1) intensive collaboration in the front-end of the design, 2) defining plans together with the client's representative, and 3) anchoring design activities in relation to organizational strategies.

We discuss these scaffolding concepts in the light of existing theory. First, existing literature stresses a necessity for alignment across the levels of an organization (Van der Lugt and Van der Laan 2017), and that designers and clients increasingly work together on definitions of the brief in the front-end of design (Meroni 2008; Haug 2015). Secondly, existing literature stresses that designers and client actors work differently together than having a client-contractor relationship (e.g. Godfroij, Verhoeven, and Van der Lugt 2013), e.g. by together reshaping tasks (Meroni 2008; Haug 2015), and that design challenges with 'coupled knowledge flows' (Chesbrough and Bogers 2014) require collective problem-solving with a 'double creative leap' (Dorst 2015a, 25). Thirdly, existing literature stresses that design becomes more strategic (Calabretta, Gemser, and

Karpen 2017), which can be a helpful approach when building on knowledge and products that are already available in the organization. In Strategic Design, design interventions occur in the co-creation phase that should drive the project until the completed implementation of outcome (Calabretta, Gemser, and Karpen 2017). This study however, suggests that the designer aimed to move to building and testing design interventions prematurely, while the organization was not yet on the same page, and implies that 'the groundwork' in the front-end of the design process needs more attention before going to the co-creation phase.

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LIVING WITH HIP OSTEOARTHRITIS AND WAITING FOR SURGERY IN A BRAZILIAN PUBLIC HEALTH CONTEXT: A PATIENTS' PERSPECTIVE

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Abstract

This paper reports a qualitative study developed by a multidisciplinary team to collect patients' experiences of living with Hip Osteoarthritis – a prevalent, chronic, painful and limiting musculoskeletal disease – in a Brazilian public health context, where patients have to wait too long times for joint replacement surgery, the solution for the severe cases. This waiting patient commonly faces the progression of the disease and worsening symptoms in situations of helplessness and precariousness. With the goal to design new services or products addressed at this

community, Human-Centred Design approach was used. This first phase research involved semi-structured interviews followed by qualitative thematic analysis. As a result, three categories were created regarding pain, information, and expectations. Discussion relates findings with the trends about patient-centeredness, patient education materials, and shared decision-making, considering the challenge of engaging with underprivileged population.

Keywords: human centred design, hip osteoarthritis, Brazilian public health system

Introduction

Osteoarthritis (OA) of the hip is a chronic degenerative disease. In severe cases, hip OA is a painful condition that restricts mobility and interferes with quality of life. Palliative treatments can temporarily reduce pain and improve function, however, there is currently no cure. Joint replacement surgery – Total Hip Arthroplasty (THA) – is needed when the painful condition worsens (Hunter and Bierma-Zeinstra 2019).

OA affects 4% of the Brazilian population, about 8 million people, generating a huge socioeconomic burden. Brazil offers universal health care (SUS) to a population of 210 million. Due to the scarcity of financing, SUS has an enormous assistance gap in the performance of THAs in relation to the average of Europe and USA (Ferreira et al. 2018). That leads to a long waiting time for surgery, which makes people cope with pain, loss of function, anxiety, morbidity, and potentially worse results.

The complexity of the needs arising from comorbidities and socioeconomic aspects require individualized care, while also seeking to rationalize surgical and non-surgical treatment options. Prevention programs in primary and secondary care will be increasingly important to contain the burden of OA on the health system (Cross et al. 2014). Surgery should be reserved for those who do not respond adequately to less invasive methods (Hunter and Bierma-Zeinstra 2019). The Osteoarthritis Research Society recommend an exercise program combined with patient education (Bannuru et al. 2019), and there is evidence that the two combined practices may reduce or delay the need for THA surgery (Svege et al. 2015). Other studies highlight the importance of patient education, exercise program and self-care management, focus on prevention and shared decision making (Kolasinski et al. 2020).

The theme of this study points to challenges (ageing, active life); opportunities (health communication, prototyping, co-design,

evidence-based design, digital design); and emerging trends (self-management healthcare, person-centred healthcare, health promotion, preventive medicine) (Tseklevs and Cooper 2017).

The study was designed by a multidisciplinary research team from University of São Paulo and Faculty of Medical Sciences of Santa Casa de São Paulo, gathering expertise from Design, Public Health, Orthopaedics and Rehabilitation.

The Hip Surgery Clinic of the Orthopaedics Department of Santa Casa de São Paulo assists SUS patients. It has more than 500 patients waiting for THA surgery, usually for longer than 5 years. In general, these are elderly people, with low income and low education. Besides sporadic outpatient consultations, there are currently no structured non-surgical care protocols for this waiting patient, who faces the progression of the disease and worsening symptoms in situations of helplessness and precariousness.

In the Brazilian context, there has been a lack of qualitative studies on life of OA patients. This study aims to address that shortcoming by giving voice to patients' experiences. The knowledge produced during this phase will inform the development of new services or products co-designed with this audience.

This study is characterized as action research, in which empirical-based social research focuses on solving a problem, in which researchers and participants involved in the problem work cooperatively (Thiollent 2011) This action research uses a Human-Centred Design (HCD) approach (Norman 2013, Giacomini 2014) placing the needs, capacities, and behaviours of the individual as the central point of the design action. HCD seeks to ensure that the solutions correspond to the identified demands, that the products created are understandable, usable and that they promote positive and pleasant experiences (Norman 2013).

Methods

Initially, exploratory bibliographic research was carried out in databases (Google Scholar; PubMed) on hip osteoarthritis, its pathophysiology and epidemiology, symptoms, care protocols, patient education, pain management, etc. Clinical data was collected at the Hip Surgery Outpatient Clinic of Santa Casa de São Paulo Hospital through consultation in electronic health records. Kellgren and Lawrence system for classification of osteoarthritis was used to identify the severity of hip OA based on patients' radiographic exams.

Patients with hip OA were recruited by convenience on their consultation date, while also considering attaining some variation in age, gender, and disease stage. The interview script was formulated as a conversation guide, adapted from literature (Brembo et al. 2016; Nyvang, Hedström, and Gleissman 2016). During immersion in the clinic, observation and semi-structured interviews were conducted with patients and family members in a private room. The interviews were recorded and transcribed followed by thematic analysis (Patton 2002).

Results

Nine patients were interviewed. Both genders were represented (4 females and 5 males), mean age 60 years (range 36-78). The majority had severe OA according to radiographic exams. Mean time with hip-pain was 4,4 years (range 1-10). Mean time waiting for surgery was 1,3 years (range 2 months to 3 years). Five patients attended physical sessions at some point. None of them has been doing physical exercises, neither seeking more information about Hip OA outside the hospital. Most believe that THA surgery is the only solution to their problem and wish to be operated.

From content analysis, three underlying categories were created regarding pain, information and expectations. Quotes from the interviews illustrate the findings.

Pain and functional limitation

The description of how pain feels and restricts life activities is poignant, specially by those participants with severe pain and functional limitation.

'My life lost its meaning; I can do nothing by myself. I can't walk, I can't shower alone, put on clothes.'

'My life has changed 100% physically, because it is a physical pain I have 24 hours a day ... it affects your sleep, affects your diet, you get stressed by anything, because it doesn't leave your head [...] it doesn't leave your body! [...] Since I had this limitation, I have practically no social life [...] because I know what my limitation will cause if I go to the cinema I will not be able to sit in a cinema chair. If I can sit, when I get up, I cannot step on the floor ... My leg already failed, I fell at work, I fell in the middle of the street, because suddenly my leg fails, as if I did not have a leg [...]

I avoid going places because I know I won't be able to, it will hurt to take the bus, to get into a car, to sit in a chair, so I avoid it [...].'

'We even loose the will to live. I cannot walk, I walk 10 meters and I must stop because the pain is unbearable. It's like burning like fire, like someone's hammering.'

The loss of autonomy and self confidence in walking was evident. Although many are already retired, they said they would still like to be working.

Information: understanding the disease and treatments

Findings indicate participants' understanding of the disease pathophysiology, often answered dubiously:

'I understand that the disease is due to weak bones.'

'The liquid dried up, the bones started to scrape together, and that was wearing away the bone, isn't it?'

'The femoral head cartilage wears out, and ends up rubbing bone with bone what comes to hurt.'

On the other hand, when asked if they look for more information on hip OA outside the hospital (on websites, social networks), many stated that they already know enough since they are the ones experiencing it. One participant reported not searching the web to avoid being overwhelmed by too much information and fake news:

'[...] even though I have pain for 24 hours, I want to try not to be thinking about it all the time. Sometimes you research something that is a lie, it's fake news, so I prefer not to seek anything, any information because I think it will do me more harm than help me.'

The same participant reported resentment about the lack of information received by doctors regarding the progression of the disease:

'It's been about 4, 5 years I make consultations here. At the beginning it was a return every 1 year, but the problem was getting worse. Until then I had no physical limitations, it was just pain. No doctor ever came to me to say that the advanced state would be physical limitations [...].'

Although nearly half of participants attended physiotherapy sessions at some point, they reported no improvement. None of the participants was acquainted about the advantages of performing physical exercises. When asked about it, most were resistant to the mere idea of doing physical activity in this condition of pain. One participant said he wished to have been informed about physical exercises in time:

'if I had a person who knew about this disease and could guide me, before it

happened I would have done it. But I used to take medicine, then I was 2-3 days without pain, until it got to the point that I couldn't do anything else.'

Expectations: coping with the waiting-time for surgery

Surgery is seen as the only solution to their problem. Some seem desperate to operate. Almost all were optimistic about surgery outcomes and stated great confidence in the hospital quality standard. Two reported being afraid of the procedure and recovery. A general feeling of being deceived about when the surgery will take place was noticed. Two participants mentioned being worried or even hopeless about the long waiting time.

Discussion and conclusion

This paper reports a qualitative study aiming to comprehend problems and needs of hip OA patients waiting for surgery in a Brazilian Public Health system. Regarding pain, information and expectations, most of the patients had moderate to severe pain for more than 2 years, lack of understanding of the disease and its evolution, most of them do not seek information about the disease and most of them had high expectations on surgery.

Qualitative studies on OA patients have reported on a care pathway model for the hip journey (Brembo et al. 2016) and on how OA affects the whole body and self, resulting in a feeling of loss as patients are forced to change the way they lived their lives (Nyvang, Hedström, and Gleissman 2016).

Giacomin describes HCD approach today as 'the use of techniques which communicate, interact, empathize and stimulate the people involved, obtaining an understanding of their needs, desires and experiences which often transcends that which the people themselves actually realized' (Giacomin 2014). HCD has been largely

applied to health, mostly for development of software applications, websites, and other technology platforms aiming to improvement of health and behaviour change that impacts on health (Bazzano et al. 2017).

By using HCD methods such as observation and semi-structured interviews in the hospital settings, researchers gathered vivid descriptions of how pain feels, and the myriad of functional limitations and emotional states of annoyance, stress, melancholy, resignation and hopelessness that were crucial to empathize with their situation.

Findings and literature converge on the need to better inform patients about the journey through the progression of Hip OA and its management in each stage. Results imply that engaging patients that may not desire to learn more is a challenge, another one is gaining their adherence to a structured education program. The trust patients show for doctors and the institutional reputation were identified as strengths for health communications strategies, which should be especially tailored to a low education population.

Indications to THA surgery could be clarified and discussed with patients in a shared decision-making process (Harwood, Butler, and Page 2016) so that patients became active partners on their healing process, while seeking to rationalize surgical burden on healthcare system. In Brazil, there is a chronic long-term waiting list for THA. From the patients' perspective, besides the risks of poorer outcomes of a delayed surgery, staying passively on a waiting list means having no influence on their future recovery. Empowering patients to self-efficacy while on the waiting list is especially important in this scenario.

Strengths of the study were field research on hospital settings; multidisciplinary team working in collaboration since the structuring of research project, during interviews with patients when

physiotherapy and design team acted together to better conduct conversations, and during discussions over clinical records in comparison to patients' testimonials. Despite the small number of participants interviewed, they provided aspects of their experiences that increment literature on this topic while also inform next phase of co-designing solutions (creation of personas and user journey maps). Qualitative methods alongside the participatory methodology of action research, with stakeholders involved in the process, aggregated new information to quantitative data typically gathered in health sciences.

Limitations of the study were small number of participants, all experiencing advanced stages of OA, some had difficulties answering the questions, lack of previous contact with participants may have inhibited some of the conversations.

HCD methods were chosen in this context for being innovation-oriented, agile, and cost effective. However, the urge to convert observations into prototypes can make HCD too agile and too narrowed by a few end-users' perspectives, thus may have a limited impact when scaled. Furthermore, improving the life of a waiting patient might be a fair and feasible purpose, but it fails to address the deeper systemic problems in the health sector that determine the waiting line itself.

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EVALUATING THE USABILITY OF 'NMS ASSIST': A NON-MOTOR SYMPTOMS (NMS) MONITORING APP FOR PEOPLE WITH PARKINSON'S DISEASE AND THEIR CARE PARTNERS

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Abstract

Background. Non-motor symptoms such as depression, constipation, and hallucinations are a significant cause of morbidity in Parkinson's disease and have a major impact on quality of life. Reporting and monitoring of such symptoms are often overlooked by people with Parkinson's and the clinical care team. There is an urgent need to empower people with Parkinson's to report, monitor and self-manage non-motor symptoms, and provide clinicians with access to detailed clinical information.

Aim: To co-design, develop and evaluate a mobile application (NMS Assist). The app aims to enable regular home-based self-assessment of non-motor symptoms and provide animated self-help information. The aim of this project is to report on initial usability of NMS Assist.

Methods: People with Parkinson's and their care partners, alongside clinical and design teams, worked collaboratively to develop and evaluate NMS Assist. User journeys and experiences of those with and without experience of using apps were evaluated using a qualitative 'think aloud' methodology and filmed using 'Mr Tappy' technology, alongside quantitative user satisfaction and error metrics.

Results: People with Parkinson's disease (n=9) and care partners (n=4) were involved in this initial app evaluation. Usability metrics demonstrated the tested version to have favourable test and task level satisfaction (System Usability score = 80%). Error free completion rate for tasks was acceptable (median 67%) but highly variable (range 0-100). Key areas for app redesign included navigation, animated self-help content and accessibility.

Conclusions: This exciting and novel e-health project, utilises a mobile application targeting a clinical population not typically experienced in app use. Initial evaluation is favourable and indicates a NMS app has potential to provide patients with a home-based platform to self-assess and report non-motor symptoms and access self-help information. Ongoing work has linked the app to a web portal to provide clinicians live access to reported NMS data. NMS Assist (v.2) has been developed and usability evaluation is ongoing.

Keywords: Parkinson's disease, mhealth, mobile app, human centred design

Introduction

Non-Motor Symptoms

Parkinson's is the second-most common neurodegenerative disease after dementia. It is a progressive neurological condition characterised by non-motor and motor symptoms. Common NMS include anxiety, depression, confusion, constipation and urinary dysfunction, hallucinations and disturbances of sleep. If left untreated, they can result in significant health complications, hospitalisation and institutionalised care (GPDS, 2002; Martinez-Martin et al, 2011).

Despite their importance, NMS are often not reported by patients during clinic appointments, and are often not asked about by clinicians (Chaudhuri et al, 2010). This may be due to limited clinic appointment times, patient embarrassment, recall/memory issues, or lack of awareness by patients that their symptoms are related to their Parkinson's.

Self-Management

There is a clear need to inform people with Parkinson's (PwP) about simple self-management techniques to ameliorate NMS and when to trigger timely medical intervention. Patients with knowledge to manage their own health conditions experience better health outcomes, such as reduced hospital admissions, and improved quality of life (van der elk et al, 2013). Moreover, most PwP consider having knowledge about their condition very important (Riggare et al, 2019).

Mobile Technologies

The increased accessibility of smart devices, advances in mobile technology and the rapid development of mobile health technologies (mHealth) have the potential to support PwP acquire knowledge about their condition, report and record symptoms and support self-management. People with Parkinson's feel comfortable using

computers, mobile phones and the internet to obtain disease-specific knowledge (Riggare et al, 2019). High proportions have access to smart devices and would consider using an app to record and monitor symptoms (Dominey, 2019).

A co-designed approach

Here we present the co-design, development and initial usability evaluation of a mobile application (NMS Assist). Aimed at PwP and their care partners, we wanted to capture both patient and 'carer voice'. The app aims to enable regular home-based self-assessment of non-motor symptoms, perceived quality of life, and provides animated self-help information. It further allows both patient and healthcare triggered contacts should symptoms substantially deteriorate. The aim of this project is to report on initial design, development and usability of NMS Assist.

Methods

Initial Design and Development

An interdisciplinary NMS Assist project group comprising, researchers, mHealth designers, design creatives and end users (PwP, caregivers and clinicians) have been involved since inception. The wireframe and possible user journeys through the app were conceptualised following a series of design meetings. The initial wireframe design was revised through an iterative process which led to the creation of an initial prototype (Fig. 1). Design of the wireframe and prototype were based around six core app functions: log in, complete a full NMS assessment, complete a partial NMS assessment, view a symptom summary, access self-help information, and request contact from the healthcare team.

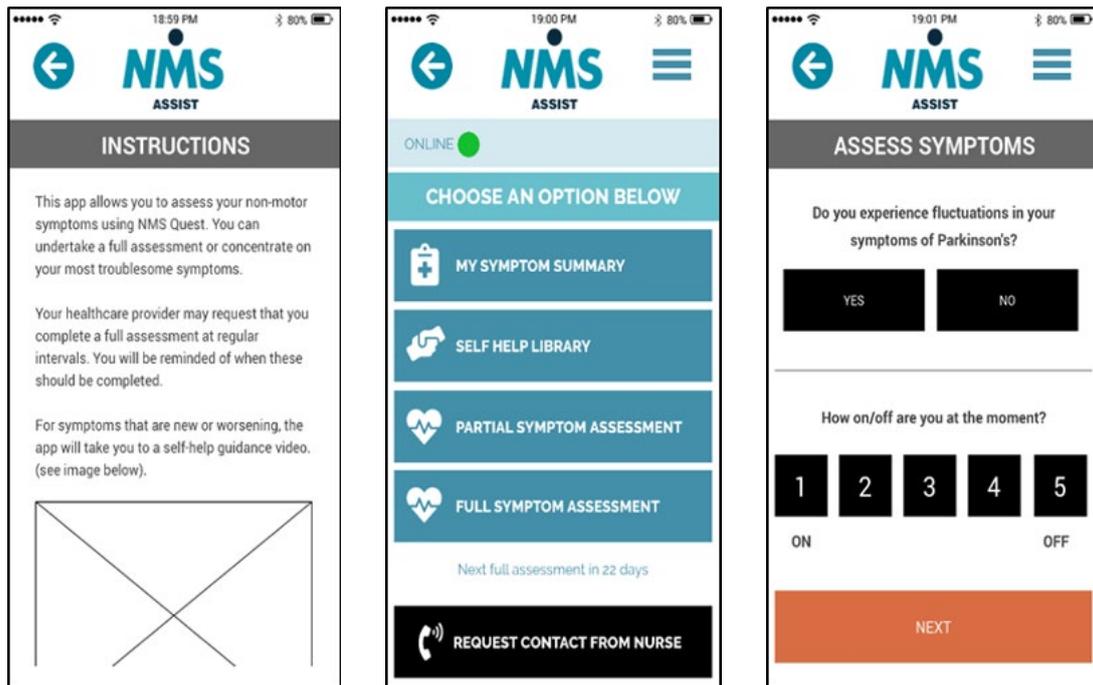


Figure 1: Screen shots of initial app design

Formative Usability testing

This study received approval from the Faculty of Health Research Ethics Committee at the University of Plymouth (FRIEC ref: 17/18-961).

Study Recruitment

Potential participants were identified via local Parkinson's UK (a UK charity) Support Group Networks across Devon & Cornwall, South West England. A purposive sampling strategy was used to allow for recruitment of users with a range of ages, disease duration, cognitive ability, and varying experience with apps. Two user groups were recruited to the study; a group consisting of PwP (PD group, n=10) and a group consisting of people who cared for/lived with a person with Parkinson's (Care Partners (CP group, n=5)). Usability testing guidelines for sample size recommend the use of 5-15 test participants (Nielsen & Landauer, 1993). Potential participants were invited to participate if they met the following inclusion criteria: Aged ≥ 40 , confirmed diagnosis of PD or Care Partner for a PwP, willing and able to give informed consent, fluent English speaker.

Procedures

A user journey was developed by the NMS Assist group in which six usability testing tasks were identified which represented the core functions of the app. Participants were given standardised instructions for each task (i.e. can you.....register your details on the app?....Can you.....access the self-help library?...Can you complete a full NMS assessment?...etc. etc.) Usability testing was performed using the experimental set up highlighted in figure 2. Qualitative and observational data were collected via the 'think aloud method' (Jaspers et al 2004), whereby participants were asked to verbalise their thoughts during interaction with the app and whilst completing all tasks. Video and audio recordings of interactions with the app were recorded using Mr Tappy Software (www.mrtappy.com). Following the completion of each task, participants were asked to complete a series of outcome measures relating to usability and user satisfaction.



Fig. 2: Experimental set up of think aloud methodology using Mr Tappy software

Data Analysis and Outcomes

Usability Issues: Each usability issue, identified from video-audio recordings, was assigned a severity of harm score by TD and prioritised according to risk to patient safety. This was calculated by multiplying Task Criticality (Impact on patient safety if task was not completed) x Frequency (frequency that the issue occurred) x Impact (Impact on the user trying to accomplish the task).

Effectiveness - Error free completion rate: The percentage of tasks successfully completed without making a critical error (i.e. an error that results in the participant not being able to successfully complete the task).

Task level user satisfaction: following completion of each task the Single Ease Question' (SEQ) (Sauro, 2016) was administered in which participants were asked: "Overall, how difficult or easy was the task complete?" Responses were given on a 7 point scale (1= very difficult and 7= very easy).SEQ

Test level user satisfaction: measured at the end of the testing session to measure users' impression of overall ease of use. The 10 item System Usability Scale (SUS) (Brooke, 2013) is a validated usability tool that uses a 5-point Likert scale to provide a quantitative measure of the usability

of a system. A value above 68 indicates good usability (ref). An overall value was calculated from the raw score to provide a score between 0 and 100.

Results

Thirteen participants participated (9 PD and 4 CP). Seven (54%) were frequent app/smartphone users (everyday use), 2 (15%) were occasional users (at least once a month use). Four participants (31%) were inexperienced users (never used a smartphone/app).

Usability Issues

Forty-six usability issues were identified via the think aloud method. Of these, eleven high severity issues were found, from which three central themes were identified: Navigation, content and accessibility. Examples of these themes include:

Navigation: Several users, in particular inexperienced users, were unable to access all of the instructions on each screen, as they did not know how to scroll down the page. For example:

'Either I'm doing it wrong or it doesn't work...there's an arrow at the top of the page (back arrow)...I could try this button (home button)...I think there's more information [on this page] but I'm not sure how to get to it.'

This finding challenged a major assumption and a key function of apps: that scrolling up/down a page is intuitive.

Content: Several users expressed confusion at what was meant by 'allow notifications' and felt unsure about security, as illustrated by one user:

'How do I know that's not a scam or something that's coming in...somehow there needs to be some reassurance to the person using it...there should be some sort of security'

Accessibility: This focused primarily around font size with many users feeling the font size was too small. A major issue that is overlooked in many apps where aesthetics over function is prioritised and the function to adjust font size is absent.

Effectiveness – Error Free Completion Rate

Across all tasks, the overall median error free completion rate was 67% (0-100) (% of tasks successfully completed without critical error) (Figure 3).

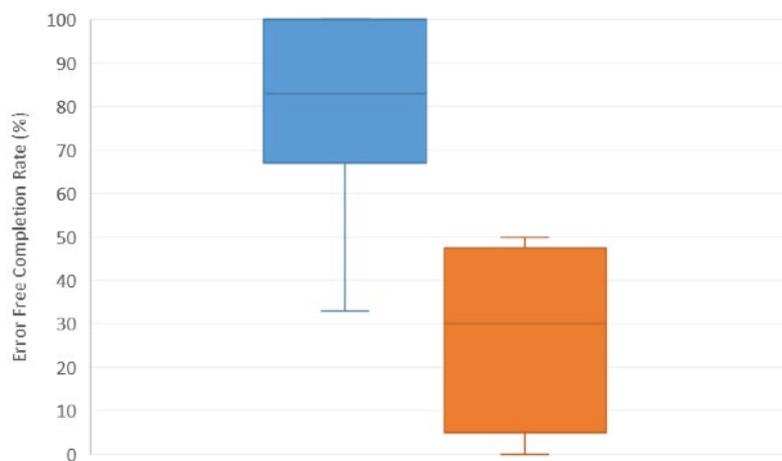


Figure 3: Error free completion rate (%) of experienced app users (n=9) (blue) and inexperienced app users (n=4) (orange). Boxplot indicates inter-quartile values, line indicates median values, with total range indicated by whiskers.

User satisfaction

A breakdown of single ease question (SEQ)

scores across the six tasks by smartphone experience is presented in Figure 4 (whereby 1= very difficult, 7= very easy).

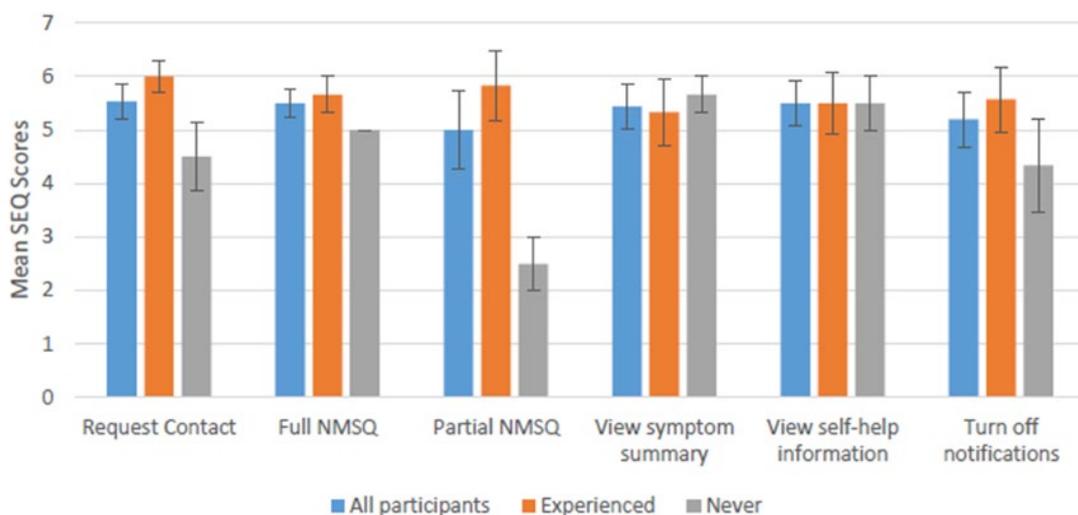


Figure 4: Mean Single Ease Question (SEQ) scores across all participants and by smartphone experience. Error bars represent standard error (SE).

The median SUS score was 80% (80/100; range 44-95), indicating very good usability. A SUS score greater than 68/100 (68%) suggests an above average usable system (Sauro, 2016). Experienced users had higher SUS scores than inexperienced users although this was not statistically significant.

Discussion

Here we have shown the value of involving intended users in the design and

development of an app, from inception to testing. Furthermore, robust and structured usability testing highlights seemingly basic, but potentially critical usability issues. Our study highlights key issues around navigation, content and accessibility which have informed the subsequent design and functionality of NMS assist (fig 5). In particular, we highlight how involving those who may have limited experience of using apps and/or mild cognitive or visual deficits is key.

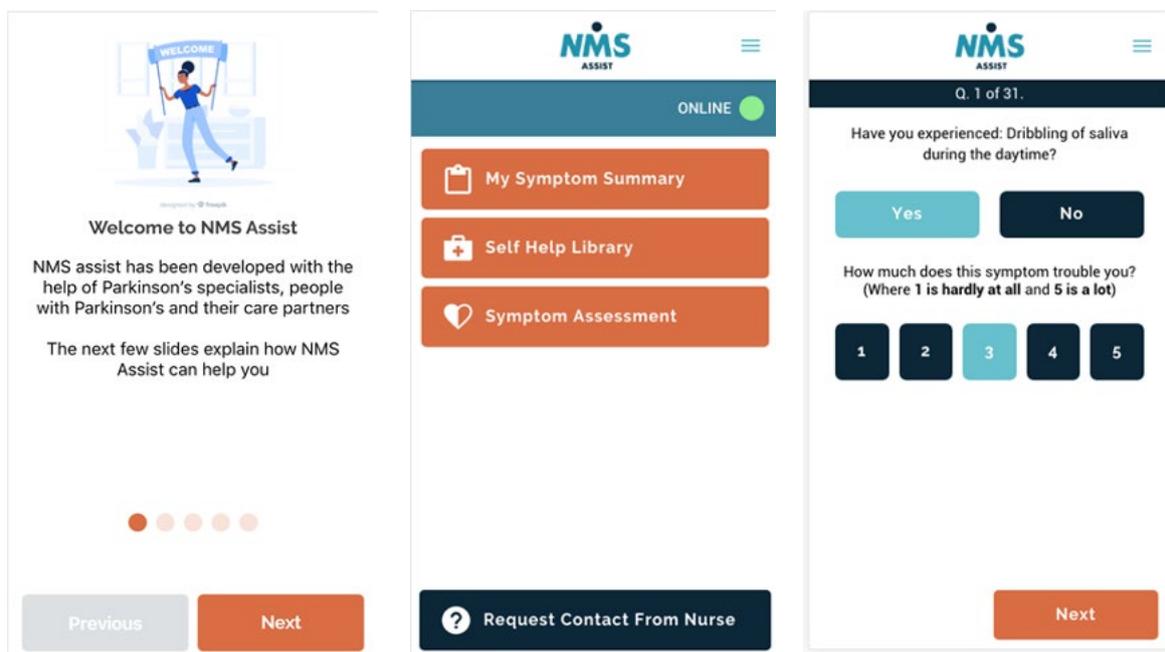


Figure 5: Screen shots of updated app design

Our study highlights that the design and function of NMS Assist be further amended to improve accessibility for users with little prior experience with apps. The inclusion of a training video on how to navigate through pages, and include clear definitions of technical vocabulary such as 'notifications'. In line with our findings, Matthew-Maich et al (2016) carried out a review of mHealth technologies, and made a number of recommendations for developers to support older adults using mHealth technologies, including minimising the number of navigation screens and minimising complexity.

Regarding navigation, inexperienced users were unable to access some of the information on the instruction page because they had no prior knowledge of how to scroll down the page. One way in which this could be overcome is by matching the length of message to the screen size where possible, which has been found to improve digestibility and readability (Nielsen & Mathiassen, 2013). It was suggested by the project group that a training video and prompts such as arrows could be put in place to educate users with low levels of digital literacy. Training tailored to meet the needs of the end-user is highly valuable, and can improve user attitudes towards

and acceptance of the use of technology (Stroulia et al, 2012).

Another issue users encountered was entering certain data due to dexterity issues, particularly in the PD group. To improve the usability of the app on a smartphone platform, an increased keyboard size will be considered, and the keyboard will be automatically in upper case. Additionally, the app has also been developed for use on multiple platforms, including web-based and tablet versions, which may be preferable for some users. Indeed, it has been suggested that tablets with touchscreens may be preferable to smartphones for users with limited dexterity, due to their bigger surface area (Huang & Hsu, 2014).

Regarding content, there was confusion surrounding certain terminology and wording. This highlights the importance of ensuring all content is comprehensible by end users. Past research has demonstrated that choosing appropriate wording and language is critical when developing a digital health intervention, and can have a significant impact on future adherence (Ludden et al, 2015).

Regarding accessibility, some users commented that the font size was too small. Visual aids such as large text and the use of bold colours have previously been identified as key requirements of smartphone apps for older adults (Gao & Koronios, 2010). Lorenz and Opperman (2008) recommend using font sizes between 36pt and 48pt for elderly users. In response, future iterations will include a feature that will allow users to increase the interface font size.

Conclusion

This innovative and clinically driven e-health project, will provide patients with a platform to self-assess and report non-motor symptoms and access self-help information. Ongoing work links the app to a clinician web portal which provides clinical access to NMS data to support clinical decision-making and inform treatments. Future work

involves further usability testing of the current beta version of NMS Assist (v.2), and feasibility trials are proposed.

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DESIGN TACTICS FOR AN URBAN-INTEGRATED DEMENTIA NEIGHBOURHOOD

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Abstract

Dementia is a degenerative disease that causes cognitive and behavioural impairments, forgetfulness, disorientation and decreased ability to fulfil autonomously day-to-day activities. When a person is diagnosed with dementia, the surrounding environment gains a crucial role for orientation, safety, comfort and well-being, as it can act as a prosthesis for lost capabilities, while enhancing the residual ones. It has been increasingly recognized that by adhering to acute care protocol, dementia care units have failed to utilize the environment to support the needs of residents with dementia. To provide a more tailored and person-centred care approach, able to resemble everyday life, a new care model emerged: dementia village. In this care model, the care institution is no longer just a building, but it becomes a confined small portion of a city, where residents with dementia live 'a normal daily life' within the safe, guarded and defined borders of the village. This paper presents

a systematic review of the main design features of the existing dementia villages. The aim of this review is to highlight the potential strengths and limits of this architectural typology and care model. Thus, based on this examination, this paper illustrates a set of design tactics elaborated for the development of a pilot-study case: PIAZZA GRACE, one of the first examples of dementia village integrated in the urban environment (within the metropolitan area of Milan). Inside this Urban-Integrated Dementia Neighbourhood, the care environment is no longer confined within a guarded perimeter, but it overlaps and merges with an existing urban environment, enabling people with dementia to live together with the so-called 'normally endowed' citizens.

Keywords: dementia; design tactics; urban environment; dementia village; systematic review

Introduction

Dementia is a degenerative disease that causes cognitive and behavioural impairments, forgetfulness, disorientation and decreased ability to fulfil autonomously day-to-day activities. In the framework of Non-Pharmacological Therapies (NPTs) for dementia, the environment gains a crucial role for orientation, safety, comfort and well-being, as it can act as a prosthesis for lost capabilities, while enhancing the residual ones (D'Onofrio et al. 2016). The importance of design for dementia, and specifically of interior design, has been suggested mainly as a means of overcoming problem behaviours in order to increase the quality of life of the person (Day, Carreon and Stump 2000). Design of the physical environment that embodies a knowledge and understanding of the condition of people with dementia, their fragilities, but also their residual capabilities, could make a difference to medical professionals and mostly patients' wellbeing (Chrysikou et al. 2018). Physical environment includes not only interiors, but also urban environments. All these preliminary considerations led us to consider Dementia Villages (DMs) as an interesting hybrid in which to experience the important role the environment plays in influencing the functional capabilities and emotional well-being of people with dementia. This consideration arises from the fact that DMs encompass in their structure not only interiors, on which extended literature has proved its beneficial capabilities in the treatment of dementia, but also outdoor and urban environments, on which similar guidance or extended research still does not exist (Mitchell et al. 2003). Thus, this paper presents a systematic review of the main design features of five existing DMs, and a set of design tactics elaborated for the development of a pilot-study case: PIAZZA GRACE.

Systematic review of Dementia Villages

During the last decades, it emerged a new care model, DMs, aimed at providing a more tailored and person-centred care approach, able to resemble everyday life. Thus, the care institution is no longer just a building, but it becomes a confined small portion of a city, where residents with dementia live 'a normal daily life' within the borders of the village. Relevant articles were identified by a systematic literature search in UCL Library Services SFX@UCL, PubMed, Academia.edu, ResearchGate, Emerald Insight, SAGE Journals, Google Scholar, Science Direct, SpringerLink, JSTOR, Ageing and Society, Routledge journals. The databases were searched using the keywords: dementia village, dementia-friendly environment, dementia architecture, dementia care village. Potentially relevant studies were assessed and summarized by the authors. We included only articles reporting specific case studies with deep analysis of architectural features and evidence of beneficial effects on well-being. As a result, we examined five DMs (case studies) in five countries: 'De Hogeweyk' (Netherlands), 'Bryghuset' (Denmark), 'The Village Langley' (Canada), 'Tönebön am See' (Germany), 'Carebright Community' (Ireland). The main design features were analysed and described according to the following four main characteristics: Living in a small-group community with the same background, urban style settings to provide a normal life, domestic characteristics and social connection.

Name	Living in small-group community with the same background	Urban style settings to provide a normal life	Domestic characteristics	Social connection
De Hogeweyk (Netherlands,2008)	152 Dementia (provide end-of-life care)	A restaurant, a café, a grocery store, a theatre, a bike repair shop and a hair salon. Various outdoor spaces.	Bedrooms and share kitchens, bathrooms and living areas. Seven lifestyle choices	Opens up restaurant to the neighbourhood Rents out its theatre for performances and conferences.
Tönebön am See (Germany, 2014)	72 Dementia (Available for couples)	Six single-storey, the sensory garden, the mini market and hair salon	Single rooms or double room and equipped with a large living and kitchen area. Seven household style	Visitors can shop in small markets during business hours. Relatives are welcome to participate in daily activities such as cooking.
Bryghuset (Denmark, 2016)	125 Dementia (all stages)	The general store, second-hand shop, restaurant, and café. Enclosed garden with a small stage, covered pavilions, raised garden beds, and a network of paths.	One-room or two-room with common kitchen, living room, disability-friendly bathroom Equipped with own furniture	Relatives are welcome to attend activities.
Carebright Community (Ireland, 2018)	20 Dementia (early-to mid-stage)	Three bungalows, a large garden, walking pathways, seated areas and sensory and remembrance gardens. A community café, hair salon, fitness centre and large community room.	Living/bedroom space, private external patio, automatic lighting in the bathrooms. Retro-styled décor	Cafe is open to everyone to enjoy our surroundings.
The Village Langley (Canada, 2019)	75 Dementia (all stages)	Six single-storey, cottage-like homes set, a general store, cafe and bistro, salon, and spa. Sensory gardens, a farmyard with vegetable patch, outdoor activity terraces, a games lawn, natural meadows and a water garden.	Private rooms surrounding an open, staffed kitchen, dining room, fireside living room with library, sunroom, and large activity room. Equipped with own furniture	Residents, family, and friends are free to wander up Main Street. Villagers can meet a friend and savour the freshly baked goods at the café or meet up with family by the fire.

Table 1 provides a short summary of the five cases, based on the four main characteristics.

Living in a small-group community with the same background

DMs, as a small-group community, have different scales. The number of residents varies from around 20 (e.g. Carebright Community) to around 150 (e.g. Hogeweyk) (Glass 2014; Høj 2019). The majority of the analysed cases welcome residents in all stages of dementia, except for Carebright Community, which accepts individuals in early-to mid-stage of dementia. Generally, all the cases welcome only people with dementia, except for Tönebön am See where couples are allowed to live together even in only one partner has dementia (Haeusermann 2017). The care approach developed in De Hogeweyk, provides the creation of small group living communities where the residents with dementia who have shared similar previous lifestyles live together to minimize their disability and maximize their quality of lives (Jenkins and Smythe 2013).

Urban style settings provide a normal life

All five DMs surveyed are composed of several building blocks built in proximity of a city neighbourhood and enclosed by gates. These building blocks form a community with several small-group accommodations and public facilities, such as restaurants, café, grocery stores, theatre, hair salon, etc. which provide residents normal daily life activities resembling life outside the village. To create an urban style, the model of DMs also incorporates outdoor spaces, such as a square, sensory gardens and outdoor rest facilities. Residents have the freedom to walk around or sit outdoors. Current DMs created a diverse urban environment by using building blocks which have different functions and outdoor space. It defines the organization of the living spaces for the residents with dementia and maximally supports a normal lifestyle.

Domestic characteristics

The homelike environment is beneficial for elderly with dementia (Day, Carreon, and Stump 2000). So, all the DMs surveyed try to provide residents a homelike environment: e.g. residents have their single rooms or double room and shared kitchens, bathrooms and living areas. In Bryghuset and Village Langley, residents can decorate their room with furniture and other personal belongings (Peoples, Pedersen, and Moestrup 2018). The Hogeweyk complex is divided into seven different lifestyles, characterising Dutch society: cultural, urban, homely, Indonesian, spiritual, rustic and upper class. The atmosphere in each interior lifestyle is different and helps mutual acceptance and recognition between residents and the environment (Jenkins and Smythe 2013). Accordingly, each household in Tönebön am See has its style such as maritime, country house, classic timeless, trendy, Mediterranean and modern (Haeusermann 2017).

Social connection

DMs offer people with dementia a safe and familiar way of living, in which social connections are recreated, even if the patients are not allowed to cross the village gates. Tönebön am See, Carebright Community and Hogeweyk are open to the surrounding neighbourhoods by offering community services, such as restaurant, markets, a theatre for performances and conferences. Some DMs (Bryghuset and The Village Langley) are always open for relatives and friends of residents, whom are welcome to wander up the street and participate in activities.

Design Tactics for an Urban-Integrated Dementia Neighbourhood Scenario

The systematic review performed brought us to consider potentialities and limits of DMs care model. Thus, based on this

examination, this paper illustrates a set of design tactics elaborated for the development of a pilot-study case: PIAZZA GRACE. PIAZZA GRACE is an Alzheimer Village built in the metropolitan area of Milan, in the historical Borgo of Figino. It includes six apartments (each able to accommodate two residents) equipped with kitchen, bathroom and a customizable sleeping area. The six apartments overlook a large common kitchen, an important space that allows the organization of social moments. These are flanked by nine other apartments that welcome elderly people in temporary shared living, and by a Daily Care Centre for Dementia. The housing mix favours relational occasions and the wellbeing of people with dementia, who can live their lives immersed in the local community. Moreover, it overlooks a square with commercial activities, surrounded by private apartments. Hereby are presented four design tactics adopted for the development of PIAZZA GRACE dementia village.

From the provision of an urban style setting to the creation of an Urban-Integrated Dementia Neighbourhood

As previously described, the establishment of a physically integrated and heterogeneous social context can contribute to a lower emphasis on the behavioural and cognitive disturbances of subjects suffering from dementia. Most of the DMs, even recently established, often appear to be isolated from a real urban social context. It occurs due to the fact that they are conceived as gated communities built in proximity of urban areas. On the contrary, PIAZZA GRACE was born as an integrated element of an already existing urban context. This has enabled the rapid integration of practices and activities, the prompt reaction of the people involved, according to the needs of each social actor, and the possibility of naturally activated virtuous social dynamics between people with dementia and citizens. Social

involvement also includes the managers of the various commercial activities, with whom a specific relationship is established, based on adequate information. In fact, they must be able to recognize any symptoms related to the cognitive disturbances of people with dementia, so that they can react adequately, in order to calm down anxiety and agitation. Thanks to the use of invisible and non-invasive technology, the guests of PIAZZA GRACE can safely enjoy the outdoor spaces and the commercial activities encompassed in the Village. With the use of small wearable devices, called TAG BLE, the village caregivers are able to know at any time the exact position of a guest, detect his or her departure from the 'safe zone' or an eventual fall. Distances and alarms are calibrated to allow a guest to be reached before approaching the alarm zone. Inside this Urban-Integrated Dementia Neighbourhood, the care environment is no longer confined within a guarded perimeter, but it overlaps and merges with an existing urban environment, enabling people with dementia to live together with the so-called 'normally endowed' citizens.

From creating a small-group community with the same background to the creation of a community that supports all fragilities

Virtuous social dynamics represent an important element within the non-pharmacological therapeutic approach. For this purpose, the distribution layout of PIAZZA GRACE is designed, so that the residences intended for guests with dementia, although protected and monitored, are located in spatial continuity with respect to the residences of the self-sufficient elderly guests. Large common areas, equipped and monitored, allow to activate moments of shared sociality between all guests, in full respect of different needs. These moments can be either coordinated by socio-health workers,

or simply monitored by them, being completely spontaneous. The spontaneity of social practices is based on the fact that these are examples of natural cohabitation or neighbourhood practices, therefore extremely effective for general daily well-being. The particular attention given to the environmental setting, with frequent references to the collective memory of domestic landscapes, are particularly effective for the creation of a sense of belonging by the guests with respect to the rooms.

Enhancing domestic characteristics through the use of archetypical elements to characterize interiors

Orientation and spatial recognition represent important features in dementia care. In PIAZZA GRACE we introduced some archetypical elements inside the interior spaces, in order to enhance orientation and spatial recognition and stimulate a sense of belonging towards the environment. In particular, the living and dining spaces, and the floors of the rooms are characterized by the presence of archetypical elements. Those elements encompass objects or pieces of furniture that characterize and identify certain domestic spaces and are commonly intended as shared symbols able to connect the conscious mind with subconscious significances. This signifies that archetypes can be perceived also on an empathic level, with strong affective implications. In fact, interior features can act as triggers for reminiscence, enabling elderly with dementia to recall past memories connected to a specific ambiance or style, or linked to specific objects found in the interior environment able to evoke personal past memories.

From social connection to interiors that enhance virtuous social dynamics

The spatial limitation of the private rooms

is aimed at encouraging the use of common spaces and promoting a virtuous social relationship between guests, as well as the use of special spaces dedicated to sensory stimulation. Social spaces are not intended as multi-purpose spaces, but as living and dining room common spaces, with domestic features. In their structure, they encompass sensory corners to stimulate spontaneous tactile and visual interaction with the environment, as well as more private corners that fulfil the need for tranquillity, without being isolated. Within a project that includes complex relational dynamics between individuals with different needs and abilities, it is very useful to guarantee sociability, as well as to safeguard moments of privacy. The main objective is in fact to achieve an optimal level of quality of one's daily life.

Conclusions

In many interviews, Ivo Cilesi, one of the medical professionals who introduced NPTs for dementia in Italy, highlights how the concept of 'living' is often associated with the one of 'home', meant as a place where an individual lives, while people with dementia usually 'stay' in protected residences, hospitals, and other types of collective structures. The big challenge that involves Design Discipline practitioners lies in the gap between 'staying' and the more common 'living': 'living' a place provides an active experience, while mere 'staying' is characterized by a state of passivity - a passivity that in fragile and compromised individuals, can only contribute to worsening his/her condition. The design community, together with medical professionals, will therefore have to face the near future with the aim of guaranteeing every human being, regardless of the level of physical and cognitive skills, a proactive experience of living in all levels of the environment, from the individual personal space to the urban dimension. The tactics described in this paper are part of this theoretical framework.

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SPARKS OF INNOVATION: TRANSFORMING CHALLENGES INTO OPPORTUNITIES

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Abstract

Mobility is one of the key criteria for older people to lead an independent life. Lack of mobility affects almost all quality indicators of life - social, health, and emotional wellbeing. An archival qualitative analysis of the Aging Concerns, Challenges, and Everyday Solution Strategies (ACCESS) database was conducted by a team of designers. ACCESS is an in-depth interview study capturing challenges faced by people aging with disabilities (i.e. mobility, vision, and hearing). In this study, we evaluated interview transcripts of older people with mobility disability sharing challenges they face in their day-to-day life, specifically focusing on transportation. Transportation has been identified as crucial to many aspects of health (e.g. getting to appointments, physical activity, social interaction, community participation). We hypothesized that ACCESS interview data may offer the design community (design researchers,

design educators, and product developers) insights that are at times overlooked in health and aging related studies. We analysed the frequency and intensity of a range of challenges faced by older adults living long-term with a mobility disability. We used these data to identify gaps from a design research perspective and possible ways to convert these gaps into opportunities for innovation. This led us to develop a framework that shows how these challenges impact the wider community, regardless of disability. We conclude by discussing health research problems that can be relatively ill-defined and would benefit from design thinking inputs at both the planning and implementation stage.

Keywords: aging; design research; transportation; mobility disability; innovation



Introduction

With the desire to age in place, aging and disability should not be perceived as a barrier to a high quality of life, independent living, or being socially engaged. What cannot be argued are the challenges that tend to accompany the aging process (e.g., impaired vision and hearing; reduced mobility) and adversely impact the activities of daily living. Opening basic food packaging can become increasingly difficult with reduced hand grip and dexterity due to muscle loss and arthritis. Planning a trip can be logistically challenging if you rely on a wheelchair or need frequent access to a restroom/toilet. For designers and design thinkers these challenges that could be perceived as barriers require a flexibility of mind to reimagine the future and consider these moments of disconnect as opportunities to enhance quality of life for others.

Designers provide the bridge between invention and the lived experience of real people. Transforming invention into innovation is critical to ensure success adoption of assistive technologies, especially for the aging population. If technologies are developed that satisfy only functional/utilitarian needs without responding to the more visceral needs (e.g., emotional, cultural, social) the technology can become abandoned, underused, or misused by users. Designers and new products developers benefit from deeper holistic awareness and understanding of elders living with long-term mobility issues that data from the Health Sciences often misses as it is not relevant to their research objectives.

Design research is a relatively new discipline alongside Industrial Design compared to more traditional areas such as economics, engineering, or the sciences. The authors were given the opportunity to conduct an archival study utilising the research findings of the Aging Challenges, Concerns, and Everyday Solution Strategies (ACCESS)

study (Koon et al. in press) to data mine for gaps in products and services that would provide sparks of innovation for designers. Utilising the voice of the elders provided insight into their lived experience and more importantly challenges that may be resolved and/or reduce design interventions (e.g., products, services, spaces).

ACCESS Study

The ACCESS study is a large-scale interview study funded by the National Institute on Disability, Independent Living, and Rehabilitation Research through the Rehabilitation Engineering Research Center on Technologies to Support Aging-in-Place for People with Long-Term Disabilities (TechSAge). This goal of this study was to uncover the disconnects of individuals (aged 60-79 years) who have been living with at least one disability (i.e., mobility, vision, hearing) for over 10 years. For each group, 60 elders were interviewed with the intention of understanding what the most challenging activities are across six different categories of everyday activities and their solution strategies to overcome those challenges. Overall, the ACCESS study focused on many facets of everyday life (e.g., health, shopping, household activities). In this paper, we focus on mobility in relation to travel from the perspective of the individual (e.g., arranging for transportation, driving). The opportunity for design researchers to access and utilise secondary user data in this way was novel to the authors, who are more accustomed to generating user-centred design primary data themselves.

Aging with mobility disability

Ambulatory difficulties (e.g. difficulty walking or climbing stairs) are the highest rated disability among people 65 and over in the U.S. Having this disability can lead to difficulties getting the transportation needed and thereby causing them to stay at home. To support older adults

transporting from one place to another, assistance from others and/or different modes of transportation can be utilized (e.g. ridesharing, buses, airplanes). There still exist barriers to public transport for individuals with disabilities, ranging from the built environment (e.g. access, ramps, lighting) (Sze and Christensen 2017) to the public's attitudes towards people with disabilities (Bezyak, Sabella, and Gattis 2017) that need to be addressed.

In general, older adults require transportation assistance for 11 years for women and 6 years for men after they lose their ability to drive (Dickerson et al. 2017). Although the gender gap may be narrowing, women are more likely than men to give-up or reduce driving earlier in the ageing process (Bauer et al. 2003). This leaves public transport as the only alternative. However, a nationwide survey showed that out of 5 modes of transportation: volunteer drivers, shuttle buses, senior-centre-based shuttle buses, prepaid taxi services, and specially coordinated bus/rail service to distant medical centres. Older adults preferred volunteer drivers alternative (Rahman et al. 2016). This option is resource intensive and not practical as most older adults live in suburban areas. This suggests a significant effort should be invested in keeping older adults driving as long as possible (Kim 2011). However, the question is will there be a point where they will stop driving and become dependent on transportation support. The move from independence to dependence could be extremely difficult. Lack of mobility is related to depression and anxiety in older population (Satariano et al. 2012) It is this transition where we see a gap that needs exploration.

'The attitudes towards AVs [autonomous vehicles] of people with disabilities differed significantly from the attitudes of the respondents without disabilities. Attitudes towards AVs among people with disabilities were significantly

influenced by their levels of interest in new technology, generalised anxiety, intensity of a person's disability, prior knowledge of AVs, locus of control and action orientation.' (Bennett, Vijaygopal, and Kottasz 2019, 1)

In this study we examined people aging with a disability as 'subject-matter experts' (SMEs) to inform the development of solutions to support an enriched quality of life. People aging with disability are coping with their condition for an extended period during which time they would have experienced/tried various strategies to address them (in this study the average duration was 55 years; (Koon et al. In press)). This experience enables them to identify both advantages and limitations of current support systems. Their current context provides a vantage point to inform designers as SMEs about the nature of the problems they are facing, limitation with current support systems, and what is needed to address them. We hypothesised that ACCESS data will provide us with this expert knowledge to identify unique problems to develop solutions with confidence.

The problem of 'identifying the problem'

Designers need more than numbers. To provide a designer with a spreadsheet of data (either statistical or textual) does not necessarily support their ability to develop a deeper understanding of their users or their needs, and therefore limits the designer's ability to develop an impactful design solution. The challenge for the design team in this instance has been to translate the data into 'lived experience'. Well-designed research meant for eliciting quantitative data to inform scale of the challenges faced by people ageing with disability. However, '... a survey may not be an accurate reflection of true thoughts, feelings, perceptions, or even behaviors' (Hanington and Martin 2012, 172). Design

insights are derived from 'lived experiences' that provide functional, cultural, emotional, and social context.

For example, in one the participant in the ACCESS study interviews, shared challenges they face when they fly which discourages them in flying altogether. This is a significant issue, however does not provide enough information to make an attempt to address it. By having the ability to dig deeper, by employing design research methods (e.g. observations, shadowing, laddering, and empathy modelling) the underlying reason for the disconnect in flying may be identified. For example, the analyses might reveal fewer tangible challenges such as do not want to be frisked by security, they are unable to use toilet (maybe using diapers), or they may be able to access the toilet without assistance. For passengers who need assistance embarking a plane, they tend to be the first passengers to board and the last to leave. When you have been travelling for a significant period of time, the need to urinate or defecate becomes extremely significant. Designers must consider not just at the scale of the problem but the intensity, which may be more important given the personal consequences. On a long-haul flight, a person sitting in his/her own diaper and urine for hours on is a demeaning experience. The identification of the issues does not mean they need new diaper, but it is having access to toilet without losing dignity.

Another consideration is gender imbalance. Female toilets are often crowded as their mode of using toilet is different from men. Toilets are designed with more men in mind in that they do not accommodate the time need for women. Men have two modes of urinating (standing and sitting), whereas women have one (sitting). Queuing to use the toilet and urinating in public can be especially stressful and time consuming in crowded environments such as airports. There needs to be more user sensitive approach. This amplifies when we are looking at people with disability and aging.

Even design or lack of it contributes to the problem.

Methodology

The research team consists of three members with design backgrounds and experience in new product development. All were practitioners of user-centred design. The team independently initially read through one interview transcript to find the coding scheme using inductive coding method. Resulting codes were compared to finalise a draft of the final coding scheme.

The overall theme of the analysis was 'transportation' with four categories, six sub-categories, and ten sub-subcategories. For this paper, we use the category 'transfer into car' sub-subcategory under 'getting a ride' category as a case study. The data were analysed using conventional content analysis method to gain insights into participants' strategies in coping with their challenges. The coding approach used is inductive, first identifying all design opportunities through open coding using NVivo, followed by abstraction and grouping under appropriate categories through axial coding. For empathic data, NVivos sentiment analysis was used to gauge the emotional impact.

Participant Sample:

Twelve interview transcripts of people with mobility disability between ages 60 to 79 years, stratified across decade and gender (3 women and 3 men for each decade), were randomly chosen from the dataset to provide a diverse sample for our in-depth analysis. A purposive sample is a recognised technique in Design Research, where deep design insight can be gained by access to a small sample of (expert) participants (Lavrakas 2008). A deep dive into the vernacular and design suggestions offered by the participants within the context of Mobility and Transportation will be done using the Direct Content Analysis.

Results and discussion

The coding structure for the transportation category transportation is presented in Table 1. The coding was used to capture obstacles and problems that impede day to day living.

Category	Sub-Category	Description	Quotes highlighting problems
Transportation by car	Using self-driven car	Using own modified car	<p>...gotten more difficult because of my ability to make a transfer- even in an out of my own car.</p> <p>I am already in the car and can't get out. I have had to kind of wait until the - if it's a spasm or whatever exactly it is - goes away and I can use my arm again to get out of the car.</p> <p>Getting myself and my chair in and out of the car.</p> <p>We didn't have to do any of that stuff (aids) ... we were strong. Um now we can't do that because we're getting weaker and now, I need all this adaptive equipment. So that's the only way I'm still able to use my own van.</p>
	Using other's car	Using car driven by an acquaintance or taxi service.	<p>...getting a ride with somebody can be very difficult.</p> <p>...getting a wheelchair and getting somebody's vehicle and going anywhere. I can't do that. So, I stay home.</p> <p>I can't get in the vehicle, ... so I reduce it and only travelling with my sister in law, because she has a van and a ramp,</p> <p>Flying is very difficult, you know, because you have to get a ride to the airport</p> <p>There are times were I just can't go where I want to because the vehicle, we are using isn't really accessible</p> <p>... taxi's very difficult because in most cases they become very inaccessible ... vehicles they bring out to you now aren't easy to get in and out of</p>

Table 1: Coding structure

The coding process assisted in identifying significant problems and the associated frequency (how often) the participants raised the problems. NVivos 'sentiment analysis' was utilised for coding the 'emotional impact' on the participant. High frequency and high impact issues are the problems that need attention. However, are these problems just symptoms of a larger systemic problem?

Framework for identifying the problem:

A problem and therefore a potential opportunity for a design intervention cannot be identified within a vacuum. It is crucial to gain the wider context of the problem, the particular task that is raising concern, and an understanding of the individual. Once a holistic viewpoint has been gained, the designer can identify 'sparks of innovation'. We view a 'spark' as a disconnect of the lived experience of the individual with the optimal experience the material landscape should offer. The 'spark' represents the moment insight offers the designer a path towards resolution/solution of the problem. As lateral thinkers, designers can gain 'sparks' from both tangible and visceral data.

Identifying a problem is a crucial stage in the design process that both inspires creative thinking and the significance of the resulting outcome. In other words, innovative problem definition will often result in innovative outcome. Designers often find the problem based on some form of ethnographic study. However, in this instance we are working with data that were collected for a different purpose. This turned the aim of this study to explore how we can use data coming from health research. Inherently many health related quantitative/qualitative research focus on problems at the micro (e.g. individual) level leading to identifying challenges at the macro (e.g. community and population) level. However, that may not be the case. On the other hand, design looks at problems at the macro level and develops design interventions at more micro levels.

The framework we are proposing uses inductive reasoning using the data available and filling the gaps with literature. As an example, if a person cannot get to the car, or cannot get in car, they cannot travel, they cannot socialise, and this leads to immediate social isolation which can lead to a sense of entrapment, anxiety, and depression (Bennett, Vijaygopal, and Kottasz 2019). Rural communities tend to experience greater challenges with public transport than urban dwellers within the US context. What this shows is that the problem of 'inability to get into a car' is a significant issue.

The framework we are proposing will help identified problems where the data are limited. In other words, problems that have potential for innovative solutions. This is a two-step process:

Step 1: Problems identified by the participants. Analysing interview data using inductive content analysis helped us identify significant problems as identified by the participants.

Frequency of the problem - how often the problem is mentioned and emotional impact: Level of Emotional impact on the user. A problem that is often faced (high frequency) and has very high emotional impact (very negative sentiment score) is a significant problem.

Step 2: Putting the problem in a broader context to see if the problem is a sub-set of a larger issue.

Meaning, for example, a person with mobility disability in a flight is bound to their seat throughout the journey. In long flight, they are forced to use adult diapers to relieve themselves. Often the problems the express is around the discomfort of wearing diapers such as getting heavier with use the once they use them and the overall experience of sitting in one's own waste is demeaning. On surface, the issue might appear to be with the design of the diaper or the seat at times. However, the problem is with the way aircraft or most of the mass transport vehicles are designed.

In short, the outcome of step 2 will result in identifying the root problem that has potential to impact larger population, or is a sub-set of a much bigger and a complex problem:

- **Scale:** who is impacted by the problem and its potential to affect larger population.
- **Systemic level:** Root cause potential for policy or system level inadequacy.
- **Significance:** Does the problem has potential to cause 'butterfly effect'. Meaning, what might appear as an

insignificant problem can result in a chain of events resulting a significantly larger issue.

- **Micro level:** Most of the problems identified in the transcripts are point observations and could be telling a story that explains lot more.
- **Macro level:** Extrapolating in the context of literature to see if micro level problems symptoms and we can do more to identify disease.

	Micro	Macro
Scale	One person	Potential to effect larger population
Systemic impact	Unable to find accessible taxi	Transportation is inaccessible, limited or non-existent
Significance	Unable to attend a family even	Risk of social isolation

Table 2: Sparks of innovation: framework for identifyin opporutnities for innovation

The outcome of this two-step analysis has resulted in identifying problems much more holistically. It showed us that it is possible to address gaps that are often found missing when designers do not have access to the research participants.

Conclusion

The aim of this study was to explore possibilities of using existing data from health sciences research to gain insights that are at times overlooked in health and aging related studies in the context of developing design interventions. The data have provided us with significant awareness of the scale of the challenges for people with mobility disabilities for elders living with long-term disabilities. However, we found that the ACCESS data, although rich, had gaps that impedes identifying significant design problems that have potential for tangible innovative outcomes from a design perspective. To address it, we developed a two-step data analysis framework that uses available

data to identify gaps from a design research perspective and possible ways to convert these gaps into opportunities for innovation.

The original intent of the ACCESS data was to gain an awareness for the problem. The research has indeed provided a clear picture of the problem areas. These data provided a solid foundation to build our 'design framework. The framework not only illustrates how these data can be used for planning design interventions but also identifies areas that need further attention. Most importantly it shows that the problems in health sciences are indeed wicked in nature and use of design thinking methodology during initial research and planning phase might result in much more actionable data for the designers.

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PROACTIVE DESIGN FOR INJURY PREVENTION OF ELITE SWIMMERS: DEVELOPMENT OF TECHNICAL TRAINING SWIMWEAR

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Abstract

The shoulder is the most common site of injury for swimmers, leading to inflammation and impingement (Richardson 1980). High training yardage and use of training equipment exacerbate shoulder pain by increasing the strain on muscles (Richardson 1980). Technical issues, such as dropping the elbow during the recovery phase of freestyle, often resulting from fatigue or poor stroke mechanics, also cause impingement syndrome (Kammer 1999). In addition, anatomical complications, such as lack of anterior flexibility or too much laxity are correlated to increased pain (Kammer 1999). Even though shoulder injuries occur as a result of overuse, training equipment, or bad posture during training, currently, research and design innovations focus on competitive racing suits which are worn for short periods of time during races. Garments that are designed to be worn during training have the potential of proactively addressing common causes for injuries and improving swimmers' health, as opposed to addressing the injuries after they take place.

The objective of this study is the development of a novel wearable product for competitive swimmers that serves as an intervention for poor technique during training and prevent potential shoulder injuries. Data are collected through fifteen interviews with elite swimmers, coaches and medical professionals to gain an in-depth understanding of specific reasons for shoulder injury, prevention and rehabilitation methods and tools used.

As supported by interview results which are coded and synthesized into design criteria, shoulder injuries are often due to lack of core engagement, leading to improper body rotation, a low body position, and an increased load on the shoulder. The product development process focused on promoting core muscle activation and raising body position in the water through buoyancy and improving shoulder posture through compression to help reduce the possibility of injury.

Keywords: swimming injuries, posture, muscle awareness, training garment design

Introduction

Competitive swimmers race in technical swimsuits, designed to maximize performance by increasing muscle function and decreasing drag resistance. Design features, such as compression, bonded seams, lightweight technical textiles, and engineered shoulder straps, are used for this purpose. However, these suits are reserved for racing because they are uncomfortable to wear for long durations, expensive, and the fabric integrity does not withstand chlorine well. Conversely, training suits are made to prioritize features such as durability and comfort, as they must withstand chlorine and sun exposure for long-term use. Swimwear companies seek credibility by focusing on innovation of technical suits worn in competition rather than training suits. Research shows that the majority of injuries take place during training, frequently from overuse, due to the repetitive nature of the strokes, technical issues, magnified by fatigue, and anatomical variants such as shoulder instability (Kammer 1999). Because training suits are worn frequently and for longer durations than technical suits, an innovative new training garment has potential for aiding the swimmer on a daily basis. A novel training garment design utilizing features to proactively address injury risk factors and common injury causes could increase the swimmers' body functions throughout training. In competition, the results are solely based on time, but in training, the swimmer improves through increasing efficiency by bettering technique and gaining power, while mitigating injury.

Studies show that shoulder injuries are the most prevalent type incurred during swimming training, and back and neck injuries are the most common resulting from weight training done as supplemental conditioning (Wolf 2009). Swimming-related shoulder injuries are often due to repetitive shoulder movements. In a study of elite swimmers, researchers found that high

training yardage and use of hand paddles to increase surface area of the hands, exacerbated shoulder pain by increasing the strain on muscles (Richardson 1980). Technical issues, such as dropping the elbow during the recovery phase of freestyle, can add stress that causes impingement syndrome (Kammer 1999). Training in a fatigued state is necessary to increase endurance and attain beneficial training volume, however the degradation of stroke technique from fatigue can cause poor posture and improper muscle engagement, leading to increased risk for injury. Swimmers often have a forward-slumped posture due to an imbalance in anterior and interior shoulder strength, which increases the load on the shoulder during swimming. Anatomical variations, such as excessive laxity and lack of anterior flexibility are correlated to a further increase in shoulder pain (Kammer 1999). Butterfly, backstroke, and freestyle swimming strokes involve similar shoulder movements, so many swimmers suffer from similar injuries despite specializing in different events (Richardson 1980). Overuse is difficult to control because it is inherent to the training regimen and the fitness demands of the sport. However, posture and body position can be manipulated through a garment, alleviating the negative effects of high-volume training demands.

This study's objective is to design a swimming training garment that addresses injury risk factors. The garment is designed through an iterative design and prototyping process, grounded in interviews and a comprehensive literature review on current related products and swimming technique. Interviews are conducted with elite swimmers, who are the targeted audience for wear, as well as coaches and physical therapists, who have direct observation over the swimmers and insight on maximizing their performance in terms of technique and speed.

Materials and Methods

Interviews

Fifteen experienced swim coaches, elite swimmers, and physical therapists were recruited in compliance with methodology that was approved by the UC Davis IRB in the exempt category. The subjects were selected through purposeful sampling technique, in which they were recruited based on experience qualifications and convenience. Each interview took approximately thirty minutes and was recorded, transcribed and coded into two design requirement frameworks to inform the iterative ideation process, prototyping and material testing.

The interviews gave insights on experiences with injuries from observational and personal perspectives. The coaches were interviewed to gain understanding on observational qualities of a swimmer's technique and modifications to training routines due to injuries. The group of five coaches interviewed had a range of experience and coached a variety of levels of competitive swimmers, from age group swimmers to professional swimmers.

Six competitive collegiate or professional swimmers, the target users of the designs, were interviewed to gain insight into personal history with injuries, such as past injuries, injury prevention recovery routines, and stroke technique understanding. The majority of swimmers interviewed have experienced multiple injuries, with varying levels of severity.

The four medical professionals interviewed do not regularly observe the swimmers' training, but they closely monitor their patients' rehabilitation progress and offer guidance throughout the process. They rehabilitate injuries through prescribing anti-inflammatories, manual work such as muscle work and release on trigger points, and exercise programs to help the patients build up strength and movement ability.

Materials and Manufacturing Techniques for Prototype Development

The findings from the interviews informed ideation as well as material and manufacturing method testing. Three different designs were prototyped and tested for fit, ease of donning and doffing, and function while swimming. Based on feedback, one prototype was selected, and the design was refined with a higher fidelity prototype.

Multiple construction techniques and materials were applied to small sample swatches and compared. Cover stitch techniques were used for creating durable, flat seams that withstand stretch and minimize drag resistance. Swimwear textiles and elastic trims with variations in thickness, elasticity and fibre content were compared for comfort and compression. Fabric panels were inserted on swatches, creating double and triple-layered areas, to achieve differing levels of tightness. This was applied to the prototype to manipulate muscle engagement by creating targeted pressure on specific muscles. Materials were also tested for possibility of applying buoyancy. Latex and silicone moulded air bladders were compared to neoprene for their ability to add floatation while maintaining durability. Neoprene, intended for raising the swimmer's body position in the water by lifting the core, was tested for thickness, buoyancy, and pliability. Auxetic cuts were applied to the neoprene for increasing flexibility and stretch so that it would not limit the mobility of the core muscles to which it was applied.

Findings and Discussion

The frameworks were divided by subject category to understand and compare different perspectives on injuries (Table 1) and on technical swimsuits (Table 2), including the personal experiences of swimmers, observation by coaches, and medical observation of physical therapists.

The topics included the impact of design features of technical suits on the swimmer, and injuries, including prevention,

treatment, and rehabilitation. These frameworks provided design criteria to develop the prototype.

	Common causes	Prevention	Managing injury	Recovery and rehabilitation
Swimmers' perspectives	<ul style="list-style-type: none"> -overuse from high-volume, freestyle training -aggravated by use of hand paddles and kickboards -weightlifting, especially overhead weights 	<ul style="list-style-type: none"> -stretching -build up training volume -lots of kicking during early season 	<ul style="list-style-type: none"> -substitute pulling with kicking -stop using hand paddles -switch to more of strokes other than freestyle 	<ul style="list-style-type: none"> -icing -applying heat -dry needling -cupping -foam rolling -sports massage -manual work by physical therapist -Kinesio taping -more warm-up, warm-down, and sleep
Coaches' perspectives	<ul style="list-style-type: none"> -technical issues such as dropped elbow, disengaged core, swimming too flat -overuse injury from inadequate aerobic base 	<ul style="list-style-type: none"> -high elbow freestyle pull -straight arm recovery freestyle -build up training volume -band work to improve shoulder strength 	<ul style="list-style-type: none"> -lower yardage -rest -cross-training to remain active -switch to kicking 	

Perspectives on Shoulder Injuries Table 1

	Changes when wearing a technical suit	Beneficial features	Issues
Swimmers' perspectives	<ul style="list-style-type: none"> -elevates hips in breaststroke -core compression -more streamlined feel -muscles fatigue slower -can hold kick longer 	<ul style="list-style-type: none"> -targeted compression panels -comfort straps 	<ul style="list-style-type: none"> -tight shoulder straps -straps in wrong place -difficult donning and doffing -compression in wrong place -material too thick or too thin -improper proportions of torso to legs
Coaches' Perspectives	<ul style="list-style-type: none"> -body position higher in water -mental benefit -improves swimmer' focus 	<ul style="list-style-type: none"> -compression to achieve a more streamlined body shape 	<ul style="list-style-type: none"> -helps certain swimmers more than others, especially females

Perspectives on Technical Swimsuits Table 2.

Due to the high percentage of shoulder injuries and importance of the core in maintaining proper posture, the novel prototype (Figures 1, 2) addresses these areas by covering the upper body from neck to waist and including sleeves that cover the shoulders and extend over the triceps. For women, this garment is worn over their training suits, and for men, it is worn in addition to their training suits, which do not extend above their waist. The garment is made from a single layer of tight-fitting polyester Lycra knit fabric to decrease drag resistance. To improve shoulder posture,

panels of thicker polyester knit fabric start at the front of the shoulder and arm and lead back to the compression panel on the back. The garment has neoprene panels around the core for increased buoyancy to counter the effect of fatigue-related issues, such as dropped hips and lack of core engagement. This garment is designed to mimic certain benefits of wearing a technical racing suit but can be worn during training. It is not feasible to wear a racing suit regularly during training due its cost, low durability, and discomfort over long periods of time.

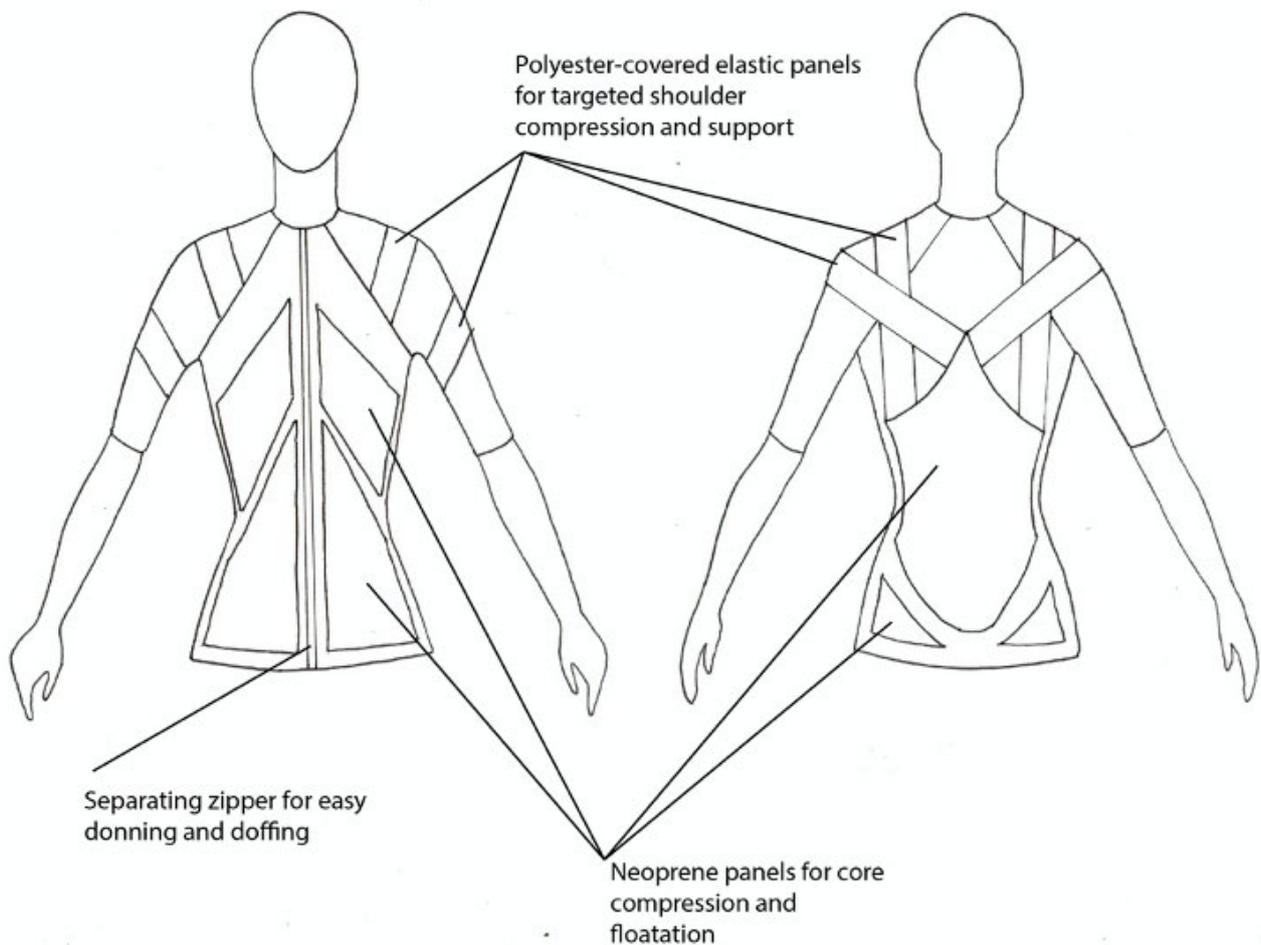


Figure 1: Technical Flat of Prototype Design, front and back views



Figure 2: Prototype Design, front and back views

The interviews offered valuable information on how to develop this design for the best health and performance possible. Coaches recognize that swimmers can get overuse shoulder injuries from the repetitive motion of swimming strokes when they have not adequately adapted to the training volume, so they address this by gradually increasing the swimmers' training. Poor technique, such as when the shoulder, elbow, or hips drop in the water, can lead to injuries, by placing additional pressure on muscles, joints, or tendons that cannot handle this weight. A design feature that supports the shoulders in a neutral position reinforces habits of proper posture, especially when fatigue increases the forward-slumping of the shoulders. This feature is achieved by adding support through compressive strips on the training garment prototype. These strips, made by wide elastic covered with 100% polyester fabric, add support by limiting the stretch in specific areas of

the garment compared to the surrounding areas, achieving selective compression to gently supporting the shoulders in a proper position. A lack of core engagement and inadequate rotation while swimming are also linked to improper use of muscles. Core compression for increased awareness of the muscles can be used to counteract this risk factor. To address both the need for compression and for keeping the hips and core elevated, the training garment prototype includes polyester-covered neoprene panels around the core to add buoyancy to the swimmer and address fatigue-related body position changes due to slowing of the kick and dropping of the hips. Additionally, the compressive nature of the neoprene panels promotes engagement of core muscles by increasing the swimmer's core awareness. This improves rotation, which lessen the load on the shoulders and increases engagement between core and kick.

The swimmer interviewees gave insight into their personal experiences with working to avoid, manage, and recover from injuries. They explained their training and racing regimens, including their warm-up and warm-down routines, recovery methods, and how these habits were altered in the event of injury. The swimmers explained that the most common injuries that they had experienced were shoulder injuries from overuse, especially from use of pulling equipment and high volumes of freestyle, characteristic of the early-season aerobic training phase. This suggests that including the shoulder area in the garment design allows for the potential to stabilize the joint to mitigate fatigue-related issues. The sleeves on the garment address the need to stabilize the shoulder. Overall, the data from the interviews supported the findings in the literature review and the interviews with the coaches.

The physical therapist interviewees discussed risk factors for certain injuries, injury prevention, and treatment methods. Poor posture, which they explained as when the ear, shoulder, and core are not lined up correctly, is a risk factor and cause of multiple injuries. They noted that many everyday activities, such as sitting at a computer or looking at a phone encourage an improper position of leaning forward, which is correlated to an imbalance in interior and anterior shoulder strength. The physical therapists stated that the shoulder is not meant to be a strength joint, but rather for controlling the hand in space. Swimmers need proper shoulder rotation because swimming too flat puts increased pressure on the shoulders, and this improper use leads to an increase in risk for injuries such as impingement or dislocation. For treatment, the physical therapists discussed that early in an injury they try to control pain, then they work to address the issue and help the patient recover. Compression is used for both support and comfort in the form of Kinesio tape (a thin, stretchy cotton tape strategically applied

on body to improve performance, mitigate pain, and add stability), braces for joints, and other compressive garments such as sleeves to help manage pain and support the body in proper positions. The prototype's shoulder compression panels are based on the method of using tape to reinforce habits of correct posture. The instability of the shoulder and the tendency for swimmers to have improper posture affirm the need for a design feature that offers support to the shoulder joint.

Swimmers credited features of technical suits such as core compression with helping them achieve a more streamlined feel and better engage their muscles, and panels for changes in thickness and tightness for allowing mobility. Manufacturing methods, such as cover stitched seams to lessen bulk, were chosen to minimize drag resistance in manufacturing the novel training garment prototype. To promote comfort, especially during donning and doffing, the prototype is made in a variation with a front zipper. The short-sleeve design eliminates the discomfort of tight straps and the possibility of straps twisting or being in the wrong place. Swimmer interviewees also shared issues about suits that compress equally all over rather than selectively in panels, causing limited mobility. Multiple swimmers noted that wearing a racing suit helps their hips feel higher in the water, which increases their kick in freestyle, backstroke, and butterfly, and aids the speed of the snapping motion of their breaststroke kick. The prototype elevates the hips, allowing the swimmers to train in a body position beneficial to performance. The data from the interviews with coaches supported the conclusions made by the swimmers, although coaches gave more credit to the mental benefit of technical suits, due to the extra rest and excitement of taper, while the swimmers focused more on the perceived physical benefits.

Overall, the data from the interviews informed design decisions. Recognizing that swimmers spend the majority of the

time swimming in training rather than competition, development of a training garment has promising potential to proactively prevent injuries. Although technical suits have regulations in material used and body area covered, designing a training suit is not limited to these restraints because it is not used for competition.

Conclusion

This study offers design criteria, including addressing shoulder instability and core muscle awareness through use of compression, for developing innovative training swimwear products to limit injuries based on in-depth analysis from interviews with coaches, swimmers, and physical therapists. This study integrates technical qualities such as targeted compression, formerly only applied to technical swimwear, into training swimwear. It additionally offers posture control and buoyancy for body position support, not available on technical suits due to regulations, to training suits. Future studies will include multiple competitive swimmers as subjects testing the prototype in active and static positions, including out-of-water posture measurements and an in-water standardized swimming routine. The garments will be judged on elements of comfort and function, and continued to be modified with improvements based on the qualitative and quantitative feedback.

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THE CONTEMPORARY HOSPITAL DESIGN: A CONTEXTUAL STUDY OF THE LIVED EXPERIENCE OF HEALTHCARE PROFESSIONALS AND QUALITY OF CARE

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Abstract

A hospital is a complex work environment that includes several users, such as healthcare professionals (HP), patients and their families. HP often encounter stress in their work environment. This paper focuses on the lived experience of HP in one new hospital in Canada to understand how the design of this contemporary hospital affects quality of health care as perceived by HP. This hospital is one of the new university hospital centres (CHU) constructed in Canada during the last decade. Its physical environment integrates new design approaches to alleviate users stress and ensure their well-being, using the patient centred design approach in which the main focus is on the patient and his well-being in hospital. Within this context, little is known about how the physical environment effects the experiences of HP. This is especially pertinent given that prior scientific literature has placed less emphasis on the HP interactions within the physical work environment.

Using a constructivist approach, observations of physical setting and

HP' behaviour, and semi structured interviews were used to collect data. Data were collected from 44 HP on two care units in this CHU during 3 months from August 1st, 2018 to November 1st, 2018. Thematic analysis and triangulation of the data set were conducted.

Results indicated that HP evaluated their work environment as supportive. HP evoke few negative attributes related to the physical environment, organizational elements and socialization between HP in the physical environment. However, HP perceived some attributes of the physical environment in this hospital as an irritant or stressor. The tasks of HP when they are compromised by these physical environmental irritants may consequently affect the quality of care provided to patients. This research highlights that quality of care can be improved by designing a facilitating work environment for HP.

Keywords: design for health, physical environment, healthcare professionals, lived experience, quality of health care

Introduction

Stress experienced by health professionals (HP) is associated with low job satisfaction (Koinis et al. 2015), poor quality of work (Shinde and Anjum 2014), organizational inefficiency, high staff turnover (Shinde and Anjum, 2014), and even absenteeism (Ulrich et al. 2008) due to illness and rising health care costs. However, Soliman et al. (2016) demonstrated that stress has a moderate effect on nurse turnover and overall health but has no effect on patient satisfaction with nursing care. It is inferred that there is no consensus on the manifestations of stress among HP on quality of care. This is what prompts us to verify in our empirical study of various HP how physical environment stressors have an impact on perceived quality of care.

The physical environment of healthcare settings plays an essential role in supporting care services and social interaction between various users. However, it is difficult to clearly identify the benefits to quality of care resulting from aspects of the physical environment (Zhang et al 2019).

Based on evidence and scientific literature, design for health largely focuses on patient wellbeing and user-centred design, but there is a small body of research centred on HP and their lived experiences (Zhang et al. 2019). While patient well-being is essential, it is equally vital to understand the realities of HP who work and care for patients within this physical environment. Evidence suggests that physical environment has a positive or negative impact on individuals which explains why some companies are interested in well-being within work environments. It is within this context that this exploratory study arises.

Context Setting and Aims of the study

In recent years, new university hospitals (CHU) have been built in Canada as a result of the development of medical technologies and with the objective of improving quality of care. New design approaches are integrated, and the physical environment is planned to reduce stress for users and ensure their well-being including the patient-centred design approach. Although attention is focused on users seeking care services, less is known about how this physical environment is experienced by HP (Huisman et al. 2012). This research examines the issues related to the daily stress of professionals providing care in hospitals. The goal of this study is to explore the lived experiences of HP to understand how the design of the contemporary hospital affects quality of healthcare as perceived by HP. We centred our study on the care unit in one newly built CHU in Canada, in which several innovative and technological elements have been introduced to better provide advanced care, such as a new smart computer system to ensure continuity in supplies in the utility rooms of care units, telecommunications infrastructure, the on-call system used in patient rooms and all clinical environments, and a pneumatic transport.

This new CHU, opened in September 2017 in the downtown region of a large metropolitan city in Canada. Composed of several buildings connected between them by corridors or footbridges, this large hospital includes care units from the 8th to 20th floor in the hospitalization building. Between the 9th and 20th floor, there are two care units connected by circulation spaces such as elevators, staircases and two family' lounges with bathroom.

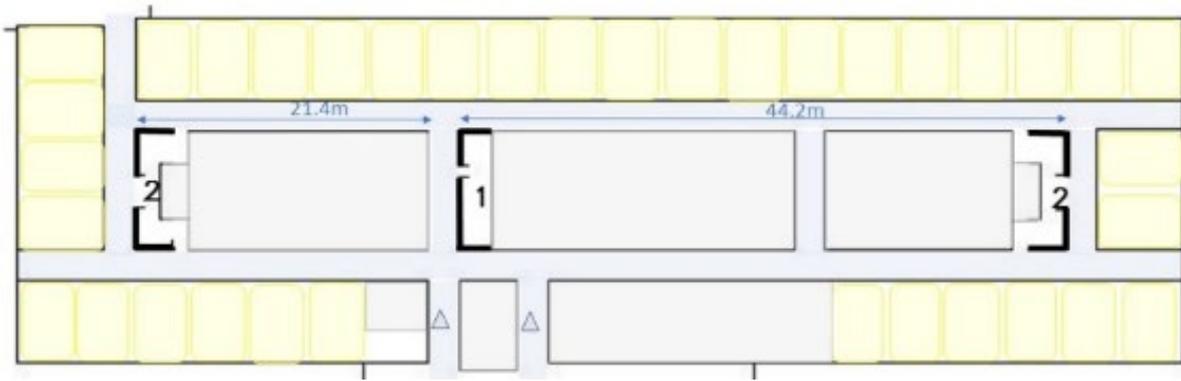


Figure 1: Linear spatial configuration of care unit with decentralized workstations. 1: central workstation, 2: secondary workstations. Peripheral location of the 36 spacious single patient rooms.

Each unit consists of a peripheral strip of 36 single patient rooms with an area that exceeds 20 square meters, with big windows allowing daylight and views to the downtown and natural landscape, a warm ambience equipped with furniture, space

for patients and their family members, and additional facilities for HP such as the patient lift fixed above the patient's bed and a private bathroom with accessible shower (figure 2).

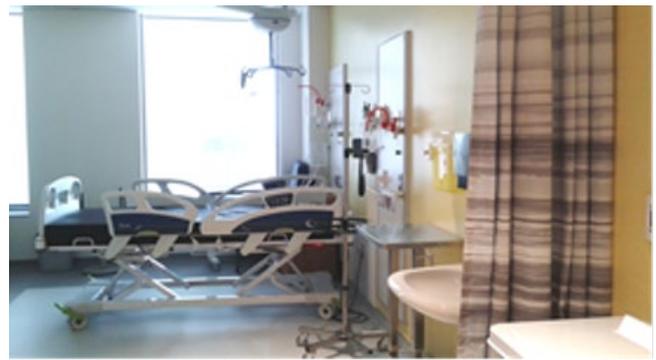


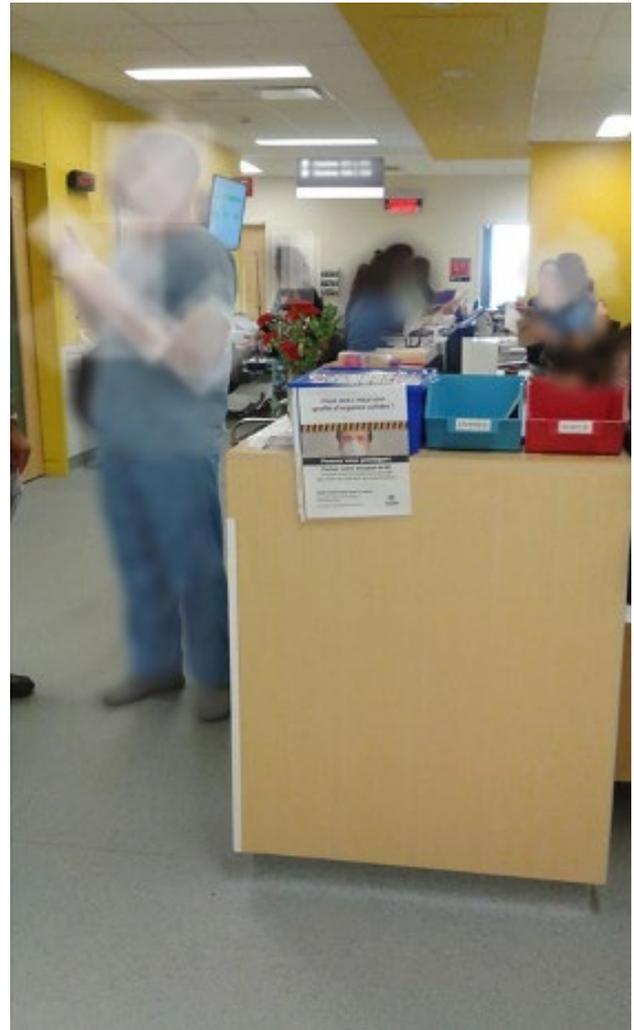
Figure 2: Examples of ambience rooms, furniture and commodities within the single patient room

A central band in the care unit contains the workspace for HP and support and maintenance staff (Figure 1). Two long corridors (north and south) run along the care unit and are devoted to HP spaces and rooms. The length of these corridors varies between 79 and 90 meters (Figures 1 and

3). Four corridors perpendicular to the two long corridors cross the care unit, and three of them serve the nursing workstations. They provide a link between the northern corridor and the southern corridor in the same care unit.



A



B

Figure 2: Examples of ambience rooms, furniture and commodities within the single patient room

Methods

We limited the study to 2 care units due to time constraints and research feasibility. However, in the two units studied, there are differences in spatial configuration, including the colour/light ambience but also in medical specialization. We proceeded in stages. First, we observed the physical setting and analysed the existing environment. Second, we observed HP in their work environment to understand their spatial behaviour within this environment in relation to the environmental attributes that existed during different work shifts. We conducted 8 weeks of observation of the space behaviour of HP (2 weeks per care unit during the day shift, and 2 weeks per care unit in the evening and

night shifts), for a total of approximately 270 hours of observations. We conducted a detailed analysis of the movement of HP within the physical environment and quantified the movements of 6 HP observed in the two care units studied, where we used two pedometers and followed their movements in the care unit until the HP entered the patient's room during all their work shift. Within an inductive and iterative methodology approach this measure of distances was done to obtain an objective distance walked by the HP during their work shift in the care unit and compare it with the subjective interview results for this attribute that emerged from the beginning of the interviews with the HP.

In the two care units, we conducted 44 semi-structured interviews which were completed using a mental map, where we asked HP to draw the attributes of the environment, and whether they feel important as supportive or negative for their work or their well-being in the care unit or the whole hospital. The selection of these care units was based on the head-unit managers who expressed a willingness to participate and who agreed to collaborate by informing the HP affiliated with their care units about our study. Analysis methods are based on a comparative and interpretive approach, for a thorough description of the essence of the lived experience of HP. We conducted a thematic analysis to reveal the hidden meanings of the description of the experience lived by HP at the new CHU. We essentially followed an inductive and synthetic approach. However, we highlighted categories of themes that were subsequently compared with existing data in the scientific literature (Huisman et al. 2012; Zhang et al. 2019).

Study Sample

All HP working in the two care units more than 2 months were invited to participate in the study. Before data collection, descriptions of the study and data collection dates were sent by email and presented to the two charge nurses of the two care units who informed all HP affiliated with their units. Data were collected over a period of 3 months and cover 3 shifts in each of the two care units from 1st August 2018 to 1st November 2018. Day shift started at 8:00 a.m. and concluded at 4:00 p.m., evening shift started at 4:00 p.m. to 12:00 a.m. and the night shift from 12:00 a.m. to 8:00 a.m. The sample of participants interviewed consists of 44 participants with 5 physicians, 2 pharmacists, 3 physiotherapists, 1 occupational therapist, 3 nutritionists, 23 nurses and 5 beneficiary attendants among these professionals (see table 1).

Demographic groups	number of participants
Age	
25 and less	5
26-35	10
36-45	10
46 - 55	15
56 and more	4
Gender	
Female	27
Male	17
Work experience (in years)	
2 and less	6
3 - 5	6
6 -10	9
11-15	3
15 and more	20
Work experience in this new hospital (in months)	
2 - 5	4
6 and more	20
Type of professionals	
Physician	5
Medicine resident, intern	2
Pharmacist	2
Nutritionist, nutritionist technician	3
Physiotherapist	3
occupational therapist	1
Head nurse, assistant to the head nurse	5
Nurse with rotatory role of assistant to the head nurse, nurse, trainee nurse.	15
Nurse assistant	3
Beneficiary attendants	5
Work shift	
Day	23
Evening	7
Night	4
Rotatory shift (day/evening, day /night, evening/night)	10

Table 1. Demographic characteristics of participants

Results and discussion

This study revealed different opinions of HP on their work environment within the hospital. HP consider this work environment to be favourable, but most of them (90%) are less satisfied and evaluated the physical environment less favourably than other characteristics of the environment. These results are in line with previous research findings (Sadatsafavi et al. 2015). Innovations and changes in the practice of care is a permanent installation in this contemporary hospital. HP, in particular nurses and beneficiary attendants have difficulty keeping up with these permanent changes (Hammouni 2020).

Results show that some attributes of this hospital physical environment are perceived by HP as an irritant or stressor. This irritant, or even stressor, acts contrary to the well-being that allows HP to be socially well surrounded, supported in their work and efficient in their tasks and positively stimulated by their environment as noted in the scientific literature (Dijkstra and Pieters 2011; Ulrich et al. 2008). From this perspective, the tasks of HP when they are compromised by these physical environmental irritants consequently affect the quality of care provided to patients.

Quality of care is positively affected by the quality of the physical environment of the patient single with, natural light, and space for families. This physical environment enhances the quality of interaction between HP and patients and family. However, quality of care is negatively affected by the distancing of decentralised workstations, particularly in terms of support and assistance to junior HP. The linear configuration of the care unit combined with these decentralised workstations contributes to a perceived negative impact on quality of care by participating HP. These HP pointed out noise as irritant in the central workstation that can negatively affect the quality of care because of the loss of time due to difficulty in concentrating

during shift changeover. They link the evaluation of some environmental attributes to their perceived inefficiency and poor quality of care to the patient. These results are aligned with previous studies that have shown a link between job satisfaction, performance and quality of care (Lundstrom 2002; Dijkstra and Pieters 2011).

This perception of the efficiency and quality of care is related to the time allocated to patient care and socialization, the time of response to the patient's request when using the wall-phone call system, and the most appropriate timely care estimated by these professionals. These professionals are essentially other professionals than physicians who link their poor assessment of some environmental attributes to this type of perception of quality of care.

However, quality of care is also perceived positively by HP in terms of the professional-patient relationship and communication. The single-patient room environment in this new hospital promotes the quality of the relationship between the professional and the patient. The natural light, the views to the outside (Ulrich 1984), the size of the room with a surface area of more than 20 square meters excluding the private bathroom space. The soft colours and the furniture, the social support of the patient due to the arrangement in the room which allows the patient to be accompanied by family are all elements that improve quality of care by enhancing the professional-patient relationship.

The results of this study are in line with previous studies which have highlighted that job satisfaction of HP is associated with work performance and quality of health care (Lundstrom 2002; Dijkstra and Pieters 2011).

Limitations of the study

This research is limited to 2 health care units in one hospital. Despite its size and the large number of HP, the number of participants may be considered as

a limitation. However, the sample is representative because of the diverse types of HP recruited. The results of this research can be verified in others care units of this new hospital to see if other results emerge regarding the physical environment attributes as experienced by other HP. Future research should focus on the impact of the physical environment on perceived quality of care by HP and others within the new CHU in Canada, in order to obtain a more comprehensive overview of attributes of the physical environment which may impact quality of care.

Conclusion

This study reveals a mixed opinion of HP on their working environment in this hospital. Some attributes of the physical environment of this new hospital are perceived by HP as an irritant or stressor. This stressor acts contrary to the well-being that allows health professionals to be socially well surrounded, supported in their work and efficient in their tasks, but also positively stimulated by their environment. The tasks of HP when they are compromised by these physical environmental irritants consequently affect the quality of care provided by these HP to the patient.

This research highlights that perceived efficiency and quality of care are linked to certain environmental attributes such as a linear spatial configuration of care unit with decentralized workstations, long corridors, decentralized care preparation rooms and equipment storage rooms, and the spacious single patient room. Quality of care can be improved by designing a facilitating work environment for HP.

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AN INTERNATIONAL PARALLEL DESIGN STUDIO ABOUT DESIGNING FOR WELL-BEING IN COHOUSING FOR OLDER PEOPLE: CHANGING PERCEPTIONS THROUGH SOCIAL ENGAGEMENT IN THE CITY

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Abstract

This paper presents the activities and results of an innovative parallel design studio held simultaneously in two interior design programs in Montreal, Canada and Diepenbeek, Belgium. Students designed solutions for new ways of living and leisure experiences for older people, in the context of well-being in the city. In various countries over the globe, people are generally living longer and are healthier. New modes of co-housing support aging well, while stimulating residents to engage in social activities. Designing for well-being offers new opportunities for housing, and designers can innovate with new ways of designing beyond existing institutional solutions. In the concerned design studios, students take these types of housing into consideration within scenarios of real urban contexts that generate new ideas of living. This parallel studio included activities stemming from a common interest and shared project location. The activities unfolded over the first semester in the two locations, under supervision of two design studio professors and two PhD Candidates. The

first studio (Belgium) explored co-housing and the second one (Canada) explored activities within the social spaces of the same co-housing complex, with doors open to the city centre. First, students in both institutions learned by investigating real needs, complex contexts of designing for wellbeing in housing and studying what stimulates social engagement for older people. Second, students developed various scenarios exploring how subjective well-being is a fundamental human right/ need and how design action is a vehicle to promote this idea. The results demonstrate how the design studio activities proposed both social connectedness and intergenerational activities which can be used to connect older persons with the neighborhood. This inter-university collaboration provides a valuable platform for knowledge exchange and knowledge transfer.

Keywords: aging well, design for well-being, older people, parallel design studio, international inter-disciplinary perspectives.



Introduction

According to Fernandez Arrigoitia et al. (2018) 'aging well at home, whether in independent co-housing or within institutions for older people, is very important for residents' well-being'. Consequently, different ways of living for older people exist and include innovative modes of co-housing. Contemporary lifestyles include keeping active, engaging different types of social activities and other activities to remain vital. Design and health thus offer opportunities for well-being (Petermans and Cain 2019), and designers can innovate with new and different ways of designing for housing of older people beyond existing institutional solutions. New modes of co-housing support aging well in place, while stimulating residents to engage in social activities. Cohousing generally supports social interaction and informal mutual support, by allowing for a lifestyle that can enhance health and well-being of residents. The physical and mental well-being for older people can be improved through social activities in co-housing initiatives (Fernandez Arrigoitia et al. 2018). It is within these perspectives that this paper presents the results of design studio activities in two different interior architecture/design training programs in Europe and North America where students explore subjective well-being in the context of ageing well within an innovative co-housing environment.

Quality of life is enhanced for people who are aging, when they enjoy a sense of community and place attachment and when residential satisfaction is also a factor that is taken into account (Evans et al. 2002). The students in the Canadian design studio were asked to consider how and what to design for people to engage in social activities within co-housing complexes, while the students in the Belgian design studio focused on the design of co-housing units themselves.

We first elaborate about the context, set-up and approaches of both design studios. Next, we discuss a selection of studio results, demonstrating the value of students' work in showcasing how interior architecture can add to knowledge regarding subjective wellbeing of older people in a co-housing project.

Parallel studio: Context and project educational activities

The interest of the partnership between European and Canadian universities is to forge interdisciplinary links through design thinking that would focus on the specific needs of older people and their choices of ageing well in place through the development of the concept of cohousing. There was an interest to hone the ways that research informs practices, with the activities informed by the research of doctoral candidates teaching in the design studio and sharing their experiences.

There is a growing recognition for the need to take aspects regarding people's subjective well-being (SWB) into account in design in general (Petermans and Cain 2019) and regarding social connectedness (Poldma 2019). The greying of the population brings about various challenges, and these are interesting to explore, for both Belgian and Canadian students.

The activities of this parallel design studio were divided in two different studios in training programs of interior architecture. At Hasselt University, these studios are supervised by trained architects, interior architects and academics, while at Université de Montréal the design teachers are from backgrounds in interior design and architecture/medicine. The design studio at Hasselt University usually introduces a 'real life case' within the studio, in collaboration with social / societal stakeholders and academic researchers.

This collaboration was originally initiated by the request of a Belgian non-profit

organization (BNPO) wanting to offer an innovative cohousing solution for people aged fifty and over and provide a new environment for collective living, while preserving the building using sustainable methods.

The design studio at Université de Montréal, Canada, ran from mid-September 2019 to the end of semester, mid-December 2019. The design studio at Hasselt University, Belgium, ran from the end of September 2019 to the midst of January 2020. The studios were enriched with intercultural exchanges and worked in parallel, supported by PhD assistants, staff and student mobility programs.

The project site and location

The monastery, situated in the city of Ghent, Belgium, includes a closed building complex with a high private wall and a door to the street from which one enters the public spaces and the chapel, some of the rooms and a courtyard garden. An arched gallery leads to the entrance of the private space composed of two floors with a square courtyard. There are various common areas such as a large kitchen, a chapter house, a refectory, a recreation room, storerooms, a laundry, and a large garden with a private courtyard. Because of the monastery's typology, the building was able to host the cohousing project place. Both design studios focused on the same site but on different parts of the site. In the design studio in Belgium, students explored cohousing opportunities at the monastic site in general, while the design studio in Canada explored social activities within the social spaces on the monastic site, with doors open to the city centre. In this way, needs and wishes of the neighborhood, the client and the future residents could be translated in a spatial way.

Approach of design studio at Hasselt University

A group of seven students reflected on cohousing solutions and accessible living

units in the private parts of the building. Special attention was paid to older people's well-being and physical health in the perspective of aging well in place. Overall, students were asked to:

- Visit the site, analyze the surrounding area, and make a 1/50 scale model to get acquainted with the main elements of the building and the site.
- Propose a master plan for the distribution of living units in the building, while integrating the relationships between interior and exterior places, common and private spaces and general circulation.
- After study and reflection, develop individually the interior design of a living unit, from the general concept (scale 1/50) to the details of realization and furniture (scale 1/10), and create this interior design according to a 'Persona' by imagining a future user (as formulated by the BNPO), aiming to understanding specific needs and wishes of older people to be integrated into their projects. The designs were translated into plans, sections, 3D illustrations and concrete models.

Approach of design studio at Université de Montréal

A group of 11 students was asked to propose a program to support social activities and improve people's well-being and physical health from the perspective of aging well. This included working on the public social spaces of the building in the chapel, sacristy and other spaces of the convent's public areas. Students were asked to:

- Document specific needs analysis using a problem-oriented approach to research and understand issues of older people, reuse of former convents, and what specific activities and spaces are required.
- Research well-being and relevant case studies.
- Develop a reflection-oriented/project-based approach, based on design thinking

practices, and considering research and issues about behavior and social practices, and how spaces might support these issues.

- Propose both planning and three-dimensional interior solutions in the form of visual tools, with aesthetic solutions aligning with the functioning of this environment, integrating technologies with the needs of stakeholders and their functioning in these indoor environments.

These students were in continuous communication with the BNPO and Hasselt colleagues, in order to understand the project's context, as the building was in Belgium. A virtual visit was offered to the students and videoconference sessions, videos, and many photos were exchanged, allowing the students to make analyses, formulate specific issues to establish a programming, and ultimately, coming up with final design concepts.

Results of the two design studio activities

In what follows, we present the results obtained in the Hasselt and Montreal design studios. Via examples of student projects, we explain the functions and themes identified to promote the well-being of future inhabitants. Four main types of spaces emerged (Figure 1). We therefore develop the results below from private living units and shared circulation (UHasselt), to common spaces for residents and spaces open to the public (UMontréal).

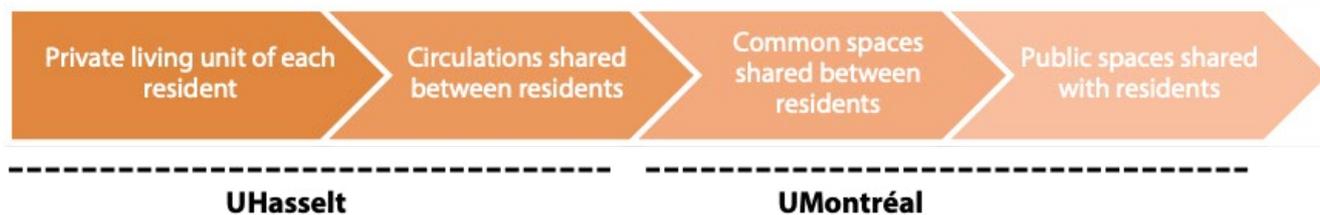


Figure 1: Distribution of intervention zones, from the most private to the most public spaces.

Hasselt University's results

The seven students proposed living unit and shared circulation designs based on the specific needs of their Personas as well as on a long-term vision of the needs of older users.

Private living unit

Given the importance of the meaning of home for older people and links between home and people's personal aspirations, the use of a Persona seemed highly valuable to the supervising teaching team. The solutions developed by the students in the private units focus on specific needs of the users, such as hobbies (e.g. dancing, cooking, yoga) or personal ambitions and lifestyles (e.g. ecology, art, 'Zen' spirit).

Some projects also focused on the mobility of people, especially those with reduced mobility.

However, beyond the inhabitants themselves, the private living units were designed with the social aim of being able to welcome family and close friends. Several solutions were explored: a guest room, extra beds for grandchildren or children coming back for weekends, a table that can accommodate a larger number of people, a guest living unit shared between residents for their relatives; each one specific to the client situation.



Figure 2: Example of a private living unit (focus on social relationships with extra beds, guest spaces and visual contact with the circulations). Jill Van Doninck 2020. Design studio Hasselt.

Circulation between residents

The students reflected on circulation pathways, as these are near to the private living units, that encourage social relations and contacts between residents. These circulations include functions that stimulate exchanges, such as tables and seats for sitting and talking, common laundry facilities, or small common kitchens. Students also reflected on several architectural solutions with interesting atmospheres for triggering social relations between private housing and circulation and thus leading to indirect contacts (e.g. second glass façade, change of material on the floor, interior garden).

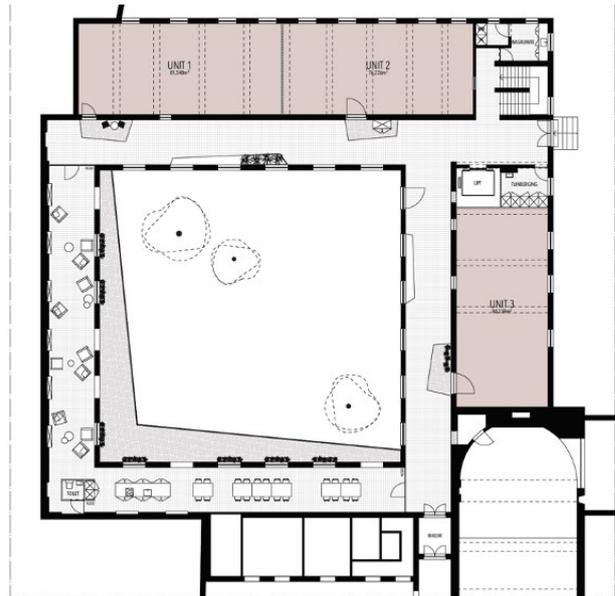


Figure 3: Common sitting, cooking and reading areas in residents shared circulations. Ella Mertens and Steffi Pinxten 2020. Design studio Has'selt.

Université de Montréal's results

All 11 students proposed opening the convent to the city and share some spaces and activities between older residents and neighborhood. They proposed complex programs where common activities and public ones are related to the analysis of the entire project and its context. We present below a stronger example of this process and a program (figure 4), wherein the idea of 'positive design' links well-being and social aspects of the neighborhood together, in terms of both 'objective' and 'subjective' well-being.

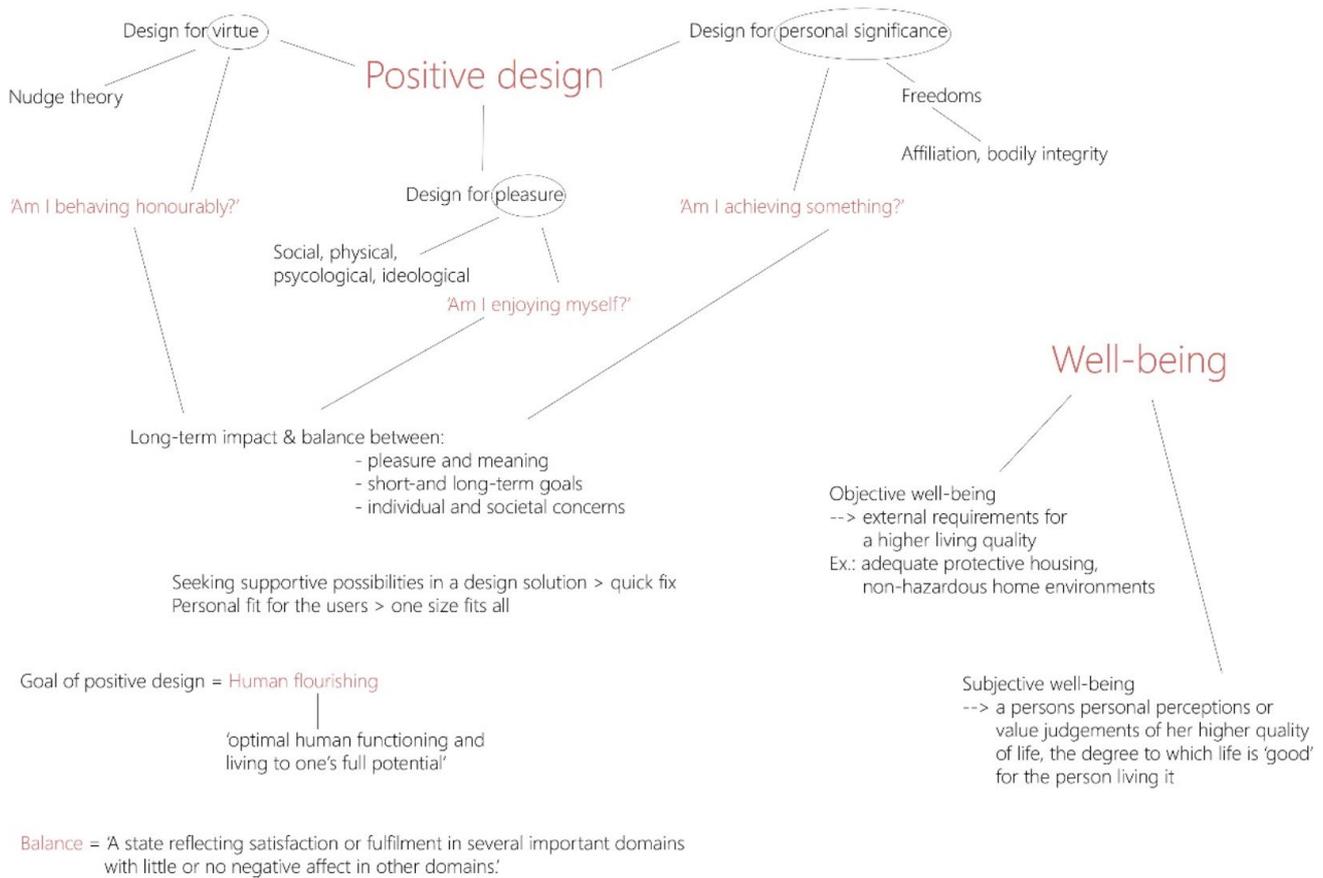


Figure 4: Analysis' example and a complex program for social activities. Silke Kerkhofs 2019. Design Studio Canada

All students' design solutions for the social activities evoked well-being. Social spaces were both external to the community and private and shared by the residents. Several concepts of design were developed to create a symbiotic environment promoting well-being, with open, unifying, interactive, flexible and accessible characteristics. The solutions were sustainable and brought the outside in with visual openings, vegetation and public activities. These various strategies help the residents stay close to the neighborhood and socialize with various people. External social spaces shared with the community included pet centres, common eating spaces, cafés, a library and other social spaces that encourage social interactions.

Common spaces

Common spaces proposed to only the convent's residents encourage social interaction. As we see in Figure 5 students provided communal dining spaces and social spaces as part of the solution.

Communal dining



Communal creative room



Figure 5: Example of design for social activities: communal dining room, communal cooking and communal creative room. Silke Kerkhofs 2019, Design studio Canada

Public spaces

These spaces are common and frequented by residents and the community (Figure 6). Dynamic spaces such as a play area, café/bar, multi-purpose room, gymnasium and art studio were proposed to be adjacent and accessible to each other or to the outside. Relaxed spaces such as a bookshop

and relaxation room were designed to be isolated from the noisier spaces and spaces for gardening and outdoor activities were directly located in the garden. Also, a community space where residents and young children can live together while learning from each other was proposed in the perspective of multi-generational inclusion.



Figure 6: Example of design for public activities in the chapel: ceramic bar with space, tennis table within a warm environment. Left: ©Tomy Angekenia Horacius, Right: ©Mary Fawzy, bar and library. 2019, Design studio Canada

Discussion

As a first experience, this parallel design studio was enriching on several levels. First, both studios profited from the rich site location, with each studio adapting to their project, co-housing in Belgium and social activity spaces in Canada. Second, the

emergent themes and details explored by students were very in-depth and enriching. Third, the integration of doctoral assistants in both studios was enriching, as both studios profited from the expertise shared. Fourth, students needed to understand a population and location which were not common for them, and various initiatives

provided added context that helped demystify the issues for the students as part of their learning activities.

The pedagogical value for the project included the capacity to explore a theme in two different institutions and with the perspective of reflection through research of the interdisciplinary subject, and then application within a specific site context applied into learning activities of two different studios. While each institution provided different locations within the same site, both differences and common ground occurred in the learning activities. First, research informed students' design thinking, in that doctoral assistants provided rich information to students at both locations to support information gathering. Supporting design activities with research informing understanding by students, provided for more in-depth considerations in the programming stage, as demonstrated in different Figures above. Second, both institutions received and shared all relevant data about the site in Ghent. Third, the choice to have both institutions work on different aspects on site was a good way to bring together two, often disparate aspects of cohousing complexes. Finally, the student projects were largely enriched by the experiences and variety of exchanges that occurred. Although vary enriching for all involved, there were challenges, generally as the two studios being literally 'apart' in different countries.

Conclusion

This collaboration provides a valuable platform for knowledge exchange, comparison and collaboration. The interdisciplinary nature of the experience also was enriching, as were the interactions with both professionals and doctoral students. Showcasing experiences from international perspectives allows for different interior design solutions on how to consider subjective well-being as a fundamental human right and how design is a vehicle to promote this idea. It is hoped

that future parallel studios will be created. However, issues include considering the distance to a site for students who were in Canada, not being able to visit the site situated in Belgium. Further connections would also be encouraged between the studios at strategic times, to share information and ideas. Overall the design studio activities contributed to changing perceptions and training of these students as future designers about what constitutes aging well in co-housing, and how social connectedness and intergenerational activities can be used to connect older persons with the larger social environment of the city.

Acknowledgements

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INFORMING HIV SOCIAL CARE SERVICE DESIGN THROUGH PARTICIPATORY ZINE MAKING

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Abstract

Visual communication materials relating to HIV have long included activist, community-based design practices such as zine making. Arguably, a need for new graphic materials has arisen in the wake of medical advancement, to accurately reflect contemporaneous experiences of living with HIV. As HIV discourse pursues 'future-oriented' narratives (Namiba et al. 2016) in order to move past cyclical descriptions of HIV stigma, it is crucial to generate new materials from which to draw upon. This is especially true for underrepresented groups, such as women living with HIV, for whom there is little historical visual documentation. We utilised participatory design methods to investigate how a group of women living with HIV in the UK conceptualised and visually expressed their experiences of peer support services through zine making. Weekly workshops were conducted over five weeks with nine members of a peer support group in the North East of England, hosted by a local charity. The workshops were facilitated by

two staff members of the charity and led by a designer-researcher (the first author). Using a method informed by Wizinsky's translational model of design research (2019) and the participatory empirical graphic design approach of Bennett et al (2006), the workshops resulted in the production of a 24-page zine, and themes associated with strengths gained through peer support.

We make two contributions to Design4Health. Firstly, we illustrate the experiences of the 'time' theme using language, visual metaphors, and narrative structures. Secondly, from a methodological perspective, we explore the role of the designer-researcher at various stages to inform our understanding of meaningful participant involvement. We present zine making as a novel visual participatory method, informing service design through community-based means.

Keywords: HIV, women, participatory research, service design, zines

Introduction

Visual communications relating to HIV/AIDS have historically included activist, community-based design practices, such as zine making. Zines are self-published documents, usually with a limited print run, where the maker(s) control the content, production process(es), and distribution of the publication. In the 1980s, zine making was adopted by some living with HIV/AIDS as a means for self-expression, community building, and information exchange between those who felt unrepresented, ignored, or hidden from mainstream representation or activism (Long, 2000).

In recent years, the zine format has been appropriated as a means for academic HIV research dissemination for underrepresented groups. Examples such as the 'The Criminalization of HIV in Canada: Experiences of People Living with HIV' zine, which facilitated self-publishing of academic research reports (McClelland 2019), utilise zines to provide a medium for HIV information dissemination and advocacy rather than a participatory method. Considering zine-making as a participatory method requires a definition of 'participation' that includes how contributors become meaningfully involved.

The importance of critical engagement with participatory visual methods (PVMs) was raised by Switzer (2018), pointing to a lack of clarity between PVMs and their methodological foundations. Switzer highlights that 'participatory initiatives can often put the burden of responsibility back onto individuals and communities and take attention away from the importance of larger state responses to inequity', arguing that greater criticality should be applied to the power relationships connected to choosing and using PVMs (2018, 199). Boydell et al. (2012) explicated ethical challenges within arts-based health research (ABHR) specifically, outlining a need for further methodological development.

Meaningful involvement of participants (MIPA) has been advocated for within HIV discourse, promoting participatory research approaches and pursuing 'future-oriented' narratives to move past cyclical descriptions of HIV stigma (Nambia et al. 2016). Design-led interdisciplinary collaborations in participatory HIV research have led to insight about PVMs and design methodologies through the collaboration of expertise, referred to by Wizinsky (2019) as a translational model of design research. Equally, the necessity to coordinate multiple diverse stakeholders, often inherent within HIV design research, has led to new transnational design methods, such as Bennett and colleagues' use of an empirical approach to graphic design (2006). These works highlight the generative and editorial efficacy of using PVMs within HIV-specific visual communication research and have contributed methodological insight through their practices and analyses.

Informed by these works and critical PVM/ABHR discourse, we designed a series of zine-making workshops, resulting in a zine to be used within the hosting organisation's initial meetings with potential clients. Our inquiry focused on (1) how experiences are conceptualised, and what language, visual metaphors, and narrative structures were expressed; and (2) in methodological terms, how much influence participants desired from a professional designer at various stages of the zine design and production process.

In this case study account, we present zine-making as a participatory visual method to inform the design of future-orientated HIV social care services. Additionally, we offer new empirical insights on how women living with HIV conceptualise and visually communicate the tacit value of peer support services. We then contribute a critically informed participatory visual method for conducting arts-based health research.

Study Design

A workshop series was devised to run across weekly peer support group meetings for women living with HIV (see Figure 1). Nine women were recruited to participate via the hosting organisation, Blue Sky Trust [BST], and two staff members supported workshop activities.

The topic of 'strengths developed through peer support services' was chosen through conversations with BST for two reasons: (1) this topic had been raised within peer group activities running at that time; and (2)

'strengths' would support a 'future-focused' dialogue and avoid raising trauma among participants.

The study protocol was discussed with staff prior to commencement. Ethical approval was granted by Northumbria University, and informed consent granted by participants. Workshops were scheduled within existing sessions and communication materials simplified, to prevent unintentional disclosure. Participants were remunerated with a £10 voucher and copy of the zine.

Study Procedure

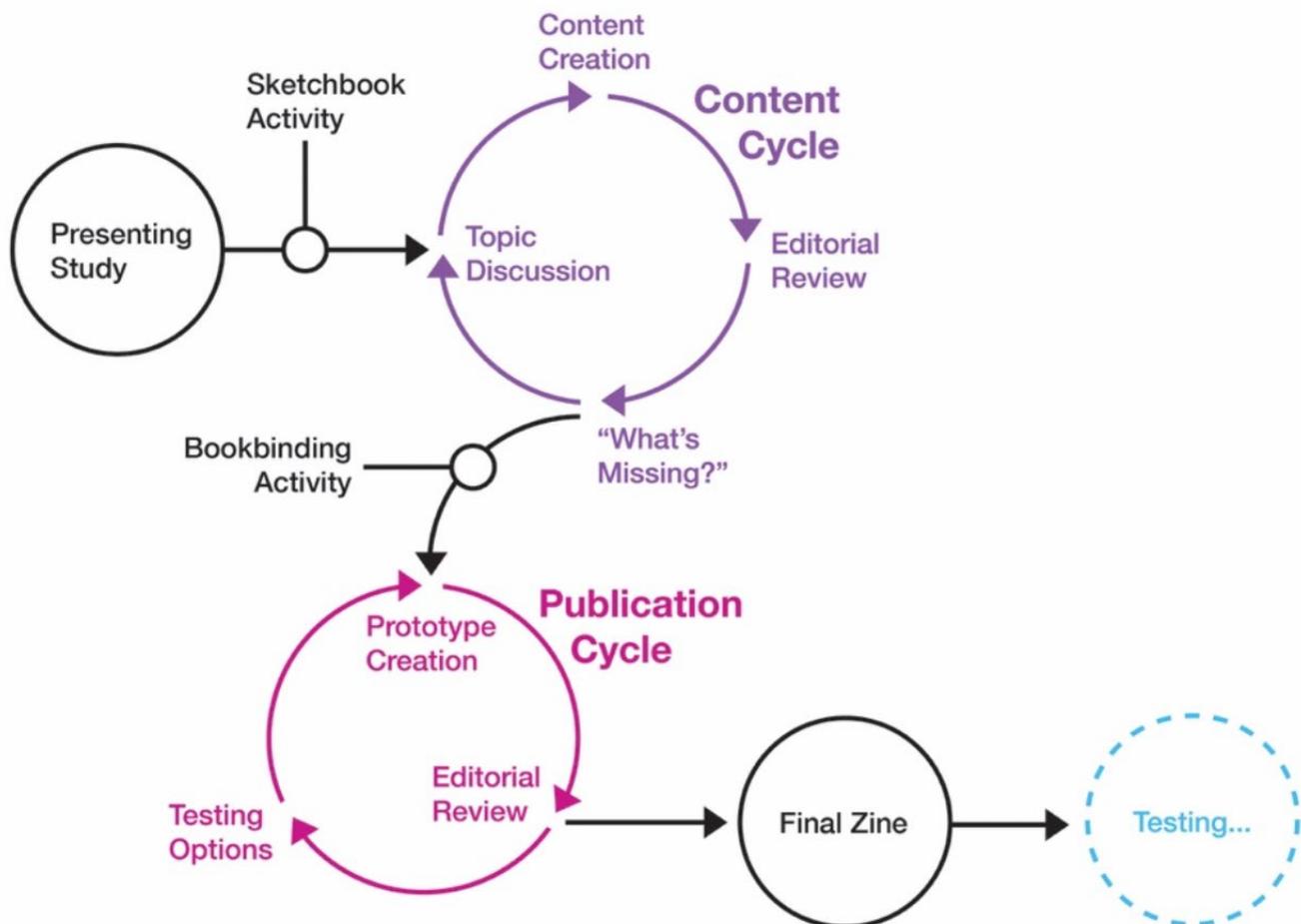


Figure 1: Zine-Making Process

Prior to workshops, an informal presentation on the aims, structure, and ethical consent processes was given. Those consenting to participate were given a small sketchbook, with a prompt to reflect on what 'strengths' they had developed through their peer support journey, and a zine introducing zine making. The series consisted of five workshops, with informal post-workshop visits for production updates. Workshop tasks covered the basic workflow of zine production: topic discussion; creating content; deciding an editorial order and layout; and producing the zine. These tasks were divided into two iterative cycles: content production and publication production.

To create content, participants were given blank page templates with three design prompts on which to create zine pages (see Figure 2). Several media options were given to participants for creating zine pages, including printing personal photos, drawing, painting, and writing; however, collage-making was predominantly chosen.

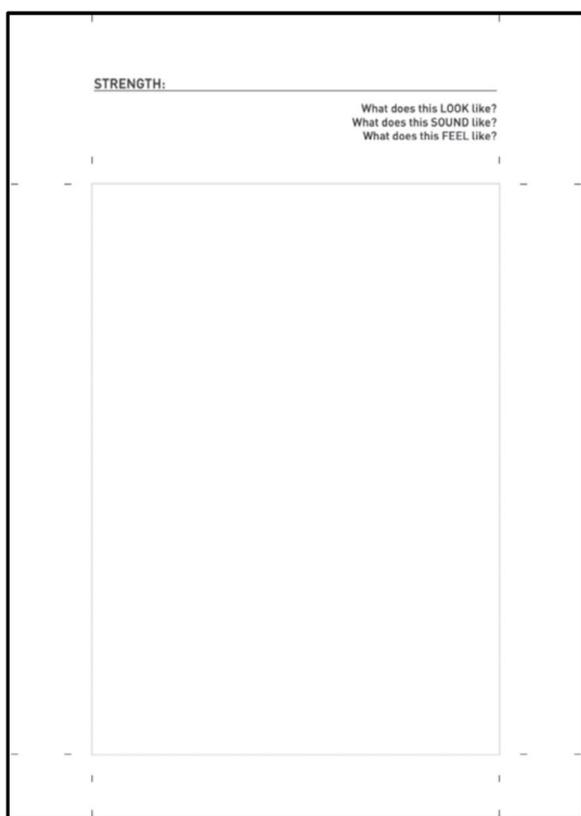


Figure 2: Zine Page Template

Collage-making provides a generative method in which 'the creator seeks the fragments and glues them together to express a feeling or sense of an experience or phenomena rather than a particular idea' (Butler-Kisber 2010, 104); and facilitates reflection as 'the joining of disparate fragments can produce associations and connections that bring unconscious thoughts to the surface' (ibid., 105). In this way, collage-making supported our research goals of exploring the experiences of women living with HIV, and supported discussion and reflection on how the metaphors and narratives were explained and expressed.

Once initial pages were created, an editorial workshop was conducted. Each participant presented their pages to the group before the group agreed on an editorial ordering of pages, layout design, and identified gaps to fill. Cyclical content creation and editorial stages then continued until a final version was agreed upon.

Analysis

An audio recording of the content editorial session was transcribed, anonymised, then used in conjunction with author field notes and visuals made by participants. In a visual analytic process informed by interpretive phenomenology (Smith, Flowers, and Larkin 2009) and visual anthropology (Collier 2004), materials were contextually clustered and coded to illuminate themes conveying interpretations of intended meanings of the generated images, metaphors, and narratives.

Research Insights

We investigated how women living with HIV in the UK visually expressed their experiences of peer support services through zine making. Here we present selected pages from the final zine and describe 'Time', one of the themes identified, and key methodological insights.

The theme of time was represented through different media: clock faces (image), time (metaphor), and change (narrative). Two participants used clock faces in their page designs (Figure 3 and 4).



Figure 3: Pages by [P1]



Figure 4: Pages by [P2]

In presenting their collages, both participants explained that the clock was a metaphor, representing the concept of time passing, and expressed the significance of this in their lives. For P1, this related to her late diagnosis of HIV and initial prognosis of only two weeks remaining to live:

P1: And that [pointing to watch face] is time. I have a thing about time. [pause] I collect watches now. I'm obsessed with time. I think it's because they only gave me two weeks to live, and... it's just... [Staff: precious?] Yeah in my head now, about time... Yeah—I have to do

[participants: certain things], yeah on the go, on the wheel all the time now; I can't stop, [P3: like a hamster] I can't stop; yeah. If I sit—if I sit down, I lose time... time is very important to me.

Time was something to be valued, and utilised to its maximum potential. As living with HIV had meant an extreme personal reflection on the time available, P1 expressed time as an obsession; something important that should not be wasted. While P2 also highly valued time, strength was identified and represented by having patience:

P2: Time for me is so... a big word, 'time', time... losing time; smart time; no time, to do the things... more time, to go... to go to that place, with the other[s]; n—no timetables. And... the... quiet-ful-ness that we have, in this place [peer support group]. We need quiet. We need quiet moments. In our busy lives... being patient. Is a gift. Yes it is. And very hard to obtain. To be a patient person. [Pause] You must waaait, a looooot of time for this, for that, for anything... [pause] to know how patient, how patient [you] will be. Like waiting in a hospital... like waiting for the time [to] pass or, any reason or... That's it; all about patience and time.

Unlike P1 wanting to be 'on the wheel', P2 found patience with time brought peace and strength to her experience of living with HIV. Patience was a difficult skill to master and particularly important in settings one could not control, such as waiting in a hospital. P2 expressed that 'quiet moments', peaceful moments away from everyday bustle, were a respite of value and importance that the service provider facilitated.

While both expressions of time present interesting implications for service design, the construction of a shared narrative around time presented another concept for consideration: temporality. While the metaphor of time differed in both P1 and

P2's works, through conversations about time participants discussed how time related to a larger narrative of temporality in their lives; as stated by P1, 'time rules our lives'. When considering how time 'ruled' their lives, P1 raised the added value of the time spent within the peer support group as a time to heal, building on P2's valued 'quiet moments' - enjoyment of the present time with the group:

P2: Take advantage, the time that is near us now; this moment. So good.

P1: Our healing time.

Within this utterance, the value of peer support services is remarked upon as something important in the care of these participants: a space and time to heal and enjoy. Beyond service provision, this foregrounds the importance of supportive services for retaining a temporal healing space and time in the participant's life.

Methodological Reflections

The desire for creative involvement from the designer-researcher varied through different elements of the zine, highlighting the need for flexibility. While participants wished for no visual changes to be made to their individual collages, small adjustments (e.g. colour correction) by the designer-researcher were permitted to improve legibility and print quality. Providing multiple examples of work-in-progress was also well received by participants, and supported the voicing of layout preferences and other design decisions by them in conversation with the designer-researcher.

By example, Figure 3 and 4 depict two-page spreads, with the left page showing a written phrase inside a coloured border, and the right a collage. These layouts were devised through conversations during an editorial session. Recommending a repeating element to visually link pages together, the designer-researcher presented various examples with colourful shapes and backgrounds. The participants unanimously

chose the border, with P1 explaining '[it] looks nice... makes the page stand out'. The designer-researcher selected initial border colours, which were later approved by participants.

Overall, participants preferred to maintain control over the main zine content; and maintain some control (choice) over supporting visual elements (e.g. colours); and leave publication-related aspects (e.g. image print quality) to the designer-researcher.

Discussion

Through zine-making and subsequent publication, individual experiences were expressed through image and text. In making and presenting collaged pages, participants engaged in a reflexive creative practice, and group discussion provided further insight into their experiences and values. Through discussion and editorial work, participants and the designer-researcher developed a shared understanding of the use of visual metaphors, retaining multi-voicedness whilst building a shared narrative. Through the generative and collaborative activities of zine-making participants were provided with a means to express themselves both as individuals and as a collective.

As a participatory method, participants preferred varying levels of creative input from the designer-researcher. While creative and thematic elements were mainly directed by participants, areas that required publication expertise were delegated to the designer-researcher. Through iterative editorial conversations, participants could decide on the aspects they wanted to lead and direct the researcher to provide support in other areas. In this way, the designer-researcher supported project facilitation—'clearing the path' of technical issues and offering examples for unfamiliar aspects of production.

Additionally, through participatory publication design, participants were given editorial control over the presentation of the final output. This output became an active component in service delivery for new referrals to the organisation, providing a valued contribution to future users of the peer support group they are part of. Through the collaborative creation of this final output and its distribution, zine-making facilitated a PVM that supported meaningful participation, which provided validation that participants' experiences and expressions were valued and worthy of an audience.

This co-creation of a useful resource for the peer support group connects this method to its historical intentions: supporting community-building and advocating the importance of marginalised experiences by the marginalised. Women living with HIV are an underrepresented demographic within HIV discourse, uniquely affected by issues such as late diagnosis. Communicating individual and shared insights into how these experiences are conceptualised can arguably aid the design of supportive services to meet unmet needs, and in itself become a supportive exercise for participants.

It is crucial to state however that these two elements are intertwined: in order for solicited expressions of marginalised experiences to be impactful, they must be purposefully heard. As Switzer states, 'issues [of PVMs] are not just aesthetic: they are ethical and political' (2018, 201). While PVMs may be perceived as 'fun' means for engagement, they should only be enacted with ethical and political considerations. We have endeavoured to address these considerations with our novel method, through: (1) ongoing discussions of participatory work delegation with participants; and (2) establishing the intended purpose of the final output, as a resource for newly referred clients, prior to study commencement.

Conclusion

We report on a co-creative participatory zine-making method, applied within an existing peer support group for women living with HIV in the UK. We argue that our study presents a basis for zine-making to be considered as a critically informed participatory visual method. While the final zine from our study is currently being evaluated as an artefact within social service provision, the process of zine-making has facilitated MIPA, via practice and impactful application of the output. Zine-making should be further explored as a PVM within ABHR for research pursuing critical inquiry with marginalised populations and engaging with ethical and political considerations.

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EXPLORING DIGITAL SOVEREIGNTY: OPEN QUESTIONS FOR DESIGN IN DIGITAL HEALTHCARE

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Abstract

Driven by a culture of ‘data fundamentalism’, datafication is being increasingly introduced in health services, sometimes with little transparency and patient engagement. This paper draws on research from the UK in order to critically reflect on the wider impact of health digitalization and issues of digital rights and data justice, which are sometimes overlooked in this field. The case from the UK deals with the effects of datafication in community health services - and more broadly welfare services - within the field of mental health. People with experience of mental health service using digital health services are in fact made visible,

represented and treated differently as a result of their digital activities and records. Theoretically the paper will frame these issues and case studies within the available literature on Digital Sovereignty. The question of digital sovereignty is understood by the authors as central to deal with issues of independence, control and autonomy over the digital self. It raises issues of transparency and accountability on several levels, from the Government’s purchasing of digital tools, to potential impact on health worker and algorithmicization decision making process.

Keywords: data justice, design for the digital self, digital sovereignty



Introduction: Design in Healthcare

The use of design approaches in healthcare can currently be considered as an established feature in many national health systems across the world. It was in 2005 that the English National Health Service (from now onwards also NHS) started experimenting with design in order to respond to the consistent challenges for improving quality of care, while also delivering more patient-centred and/or patient-led services (Donetto et al. 2015). Initially conceived as a promising approach for healthcare quality improvement, the application of design theory and practice in health has extensively expanded to the new elements of digital healthcare. The digitalization of healthcare service provision has profoundly changed the healthcare system (EU Commission 2019) and this has been happening also as result of the work of designers, employed in higher numbers to develop better digital interfaces, data collection processes and information design. Initially involved in the re-design of the healthcare experience in order to improve its quality within a relational and participatory framework, the design work in digital healthcare seems to have gradually shifted away from the initial focus on the patient experience and turned towards questions of usability, access and interfaces, as designers are involved in the difficult task of mediating between patients' needs, systems' processes and the work of IT engineers and programmers. Dealing with the design of technologies in fact is not something that can be deployed simplistically, as during the technological development phase ethical issues are translated into context specific and actionable practices through design choices (Peters et al. 2020).

The Digitalization of Mental Healthcare in the UK

We use the term 'digital health' to designate

the wider field which involves the use of technologies and digital platforms in healthcare. In this article, we only refer to the use of technologies in the interaction with patients, although we are aware of the impact that digital technologies have on healthcare staff and within the healthcare system more broadly (Djellal and Gallouj 2005).

The case from the UK is in this respect particularly interesting, both for the ambition of the digitalization plan and for its pace. It was 2014 when the NHS England published the NHS Five Year Forward plan, including an ambition to 'exploit the information revolution' and already in 2016 the digitalization also expanded to mental health services, as the adoption of information technology in acute, community and mental health services was considered by the NHS to lag behind.

If it is true that healthcare is a quite different sector compared to other public service sectors, for its 'sheer scale, variety and complexity, as well as the (often) fragility, vulnerability and dependency of its clients.' (Robert and Alastair 2017), then we could say that mental health is a different field than many other healthcare fields, on one hand because mental health services cover a huge spectrum of healthcare provision (from wellbeing services to community mental health, up to acute mental health services), and on the other hand because mental health is considered to affect globally 1 in 4 people in society (WHO 2001). If we follow the World Health Organisation statistics, that says that 'One in four people in the world will be affected by mental or neurological disorders at some point in their lives.' (WHO 2001), we also start framing mental health not as a permanent status affecting a limited number of people but as a transient one, which could potentially affect anybody at any specific point in time. In this way, the uniqueness of mental health services, compared to other health services, becomes clearer.

The use of digital technology and artificial intelligence in the field of mental health is currently widespread: from wellbeing and meditation apps, to digital talking therapies and counselling services (the use of which for instance is currently spreading, due to the increased anxiety generated by the Coronavirus pandemic). 'Digital psychiatry' is now commonly used to describe technologies that use artificial intelligence 'to infer, with varying degrees of reliability and validity, whether an individual is suffering from depression, anxiety, autism spectrum disorder, post-traumatic stress disorder, and suicidal ideation.' (Burr et al. 2020).

Similar to other fields of public service delivery, in healthcare data have acquired a prominent position through what Stevens et al. (2018) call the 'semantic reality' built through the dissemination of positive discourses around the AI, always depicted as key to ensure better, faster and more efficient delivery. But critical accounts regarding the use of data also started emerging through the work of scholars mainly coming from Science and Technology Studies. These accounts, acknowledging the complexity of data security and data justice, denounce the potential risks of introducing AI in public services and particularly in healthcare services. As the UK House of Lords Select Committee document on the use of Artificial intelligence reminds us 'The NHS holds data on nearly everyone in the UK; some of it going back decades.' (2017). Not much needs to be added to give us an impression of the scale of the risks the system is facing.

Issues with the datafication of mental health service through digital health are varied and all linked to the broader discourses on data justice (Taylor 2017), which highlight the risks of digital tools used in public services, as citizens using these services are made visible, represented and treated differently as a result of their digital activities and records. We could mention the issue of intelligibility, as decision-making processes

through algorithms can be very opaque (both in the way these are designed and in the way they are actually implemented and they take decisions in practice); but also the question of stigma, as data inform how people with mental health are seen and described through the process of labelling them for the purpose of creating digital categories. The question of stigma and discrimination has been traditionally central in UK mental health services, where community-based mental health provision was introduced with the wider ambition and mission – together with providing services in the community – of fighting stigma and discrimination and promoting broader societal change to ensure mental health is viewed, talked and treated differently in the wider society (Sangiorgi et al. 2019). This mission risks not only being lost in translation through the digitalization process but being exacerbated if AI and predictive analytics in digital health care are not deployed carefully. Finally, a data-based approach to mental health services risks to undermine the holistic and systemic approach that is very much needed in this area of healthcare (Sangiorgi et al. 2019), as a single app or digital platform becomes the only point of reference to infer from existing data the diagnosis and the possible treatment.

'Practicing' Digital Sovereignty

Understanding digital sovereignty from a democratic self-determination point of view (according to categorizations by Thiel 2019) means looking at the concept/term as a citizen's right to be claimed and a process constantly in the making, as a condition of the ability to critically partake in the digital transformation. The latter requires profound and well-informed public conversations and debates around the main three pillars of digital sovereignty technology, regulation and digital literacy, as they have been proposed by the German Consumer Affairs Council (2017). Hereby, one main fields of design practice related to mental healthcare

is to foster discussion and negotiation about the ways in which digital technologies reconfigure our daily lives as well as health services – in order to achieve a balanced view of the effects of digitalization in healthcare, as also required by the Expert Panel on effective ways of investing in Health (EU Commission 2019, 8). Especially in line with the systemic approach that is very much needed in the area of mental healthcare, as mentioned above, informed and broader conversations, public negotiations and deliberation processes that include actors beyond those being explicitly involved in the field of mental healthcare are a key factor for democratic self-determination and empowerment within this area. Countering a deterministic technology-driven perspective on digital health, the practice of digital sovereignty as a design practice should take into account the rights as well as skillsets people need to understand and control their data, as a main aspect of their digital literacy. The underlying understanding of this political design practice is deeply rooted in Dewey's political philosophy and his concept of democracy: *'Democracy is a way of personal life controlled not merely by faith in human nature in general but by faith in the capacity of human beings for intelligent judgment and action if proper conditions are furnished'* (Dewey 1939, 2). In order to be understood and lived, according to Dewey democratic values have to be experienced, by individuals and collectives alike. Furthermore, practicing sovereignty relates to the capability approach as pioneered by Amartya Sen in the 1980s, where the focus is on what people are effectively able to do, as an expression of their freedom and agency. How we understand and frame freedom and *'the set of valuable functionings that a person has to possess which represents the effective freedom of an individual to choose between different functionings and combinations'* (Saigaran et al. 2015, 191) shape the kinds of policies that are made and the reality in which we live.

Against this backdrop, we understand digital literacy as one that not only stresses competent navigation through the digital world but embraces the dimension of steering and designing processes of digitalization – as a form of critical, socio-political embedded digital literacy, that might also counter the risks and the challenges individuals face when coping with the digital realm. Especially with regard to digital inequalities, a critical digital literacy is needed to adequately address key issues of participation and to address the growing digital divide at all levels, as summarized by Massimo Ragnedda (2018). While the first and second level of digital divide address inequalities in access and use of the Internet, the third level of digital divide (van Deursen and Helsper 2015) refers to the tangible outcomes generated online that are also of social value (Ragnedda 2018, 2366). As a way to analyse the phenomenon of digital divide, Ragnedda correlates digital inequalities to the digital capital and its interrelations with 'social, economic, personal, political and cultural capitals', defining the digital capital as 'the accumulation of digital competencies (information, communication, safety, content-creation and problem-solving), and digital technology' (Ragnedda 2018, 2367). At the basis of this analysis lies the insight that social inequalities influence the increase of digital inequalities (Helsper and Eynon 2013). Ragnedda's analysis shows that skills and knowledge as well as the socio-cultural and socio-political backgrounds determine the way individuals are able to transform their digital experience into social outcome:

'It is not only knowledge, digital skills and motivation, but also the capacities and possibilities to use the digital capital as a currency to obtain other resources that can improve individual's life chances. In a digitally-enabled society it becomes crucial to be able not only to physically access, but also to move confidently in the digital arena and get the most out of it.' (2018, 2373)

In order to improve digital literacies as one of the main pillars of digital sovereignty, broader analyses of the impact of informed and confident usage of ICT within the healthcare sector and the interrelations between the new digital capital and the outcomes for individuals involved in mental care are needed – not only from a data collection and data security perspective, but from a democratic self-determination point of view.

Open questions for Design in Digital Healthcare

In this paper we wanted to open a series of ethical questions that we believe design should address when it is deployed in the field of digital healthcare. Once we frame the question of digital health as a question of practicing digital sovereignty, as this paper is suggesting, a new role for design emerges which aims to support democratic self-determination and empowerment, whilst countering a deterministic technology-driven perspective. Practicing design as a way of practicing digital sovereignty also means taking into account the skill-sets people need to understand and control their data, as a main aspect of their digital literacy.

As the healthcare sector is characterized by a multiplicity of players with varying interests (from healthcare providers, patients and families, insurers and researchers who are directly involved in clinical practice), designing transparent digital systems that are less vulnerable for discrimination and misuse of data becomes a key concern for designers. On the other hand, ways of designing for digital participation and inclusion are also needed, as digital sovereignty requires a constant deliberative process which involves re-negotiation of rights, assessments of risks, opportunities and capabilities. The value of looking at design in digital healthcare through a digital sovereignty lens therefore includes moving at the forefront of design's

concerns ethical issues of data justice, digital literacy and digital inequalities.

In sharing our open questions on the role of design in digital healthcare, we could not avoid considering some new reflections based on what has been happening in different countries as a result of the Coronavirus pandemic, and the role that data and digital devices have played in this context as we write. These times of emergency have in fact brought many governments in Europe to re-think the use of personal digital data for the purpose of better monitoring and controlling the population, and consequently the spread of the virus. We believe even in these times of emergency, the question should not be posed in dichotomic terms, like citizens had to make a choice between the right to privacy and informational self-determination on one hand, or the efficiency of public health on the other. Both could (and should) in fact be cared for without the need of giving up our digital sovereignty. But of course the COVID19 emergency has affected the debate on digital sovereignty in interesting and profound ways: it has increased the public awareness and participation on this topic; it has moved us to rethink the debate beyond easy ideological standpoints; it has also demonstrated at the same time the fragility and the strategic importance of our digital infrastructures. Finally, as nurses and doctors are celebrated as heroes around the world, the current emergency has reminded us all of the importance of investing in a strong healthcare system and its analogic components. Digital healthcare developments – like for instance the massive introduction of AI – are high-resources investments, which require funding to be diverted from the State and distributed among private contractors that design and develop the digital infrastructures that the welfare and healthcare system use. In the current times, perhaps a new awareness is taking shape which rethinks and acknowledges the

positive role of the state (Mazzucato 2013) as well as the importance of those front-line services and staff, which have proved to be so crucial right now.

Even if it might be too early to advance any conclusion on how issues of digital sovereignty will be affected by the present crisis, what is for sure is that concerns around digital ethics are growing both in the academic and practice field (Peters et al. 2020) and that designers will have to decide what role to play in translating the ethical theory and principles into context specific and ethical digital practices and devices.

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ARE AGILE DESIGN APPROACHES USEFUL IN DESIGNING FOR HEALTH? A CASE STUDY

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Abstract

When designing interventions for health, multidisciplinary teams increasingly work according to an 'agile' process. Potential benefits of this approach are better knowledge transfer, stakeholder inclusion, and removal of barriers to interactions. Unfortunately, the question whether agile approaches are useful in designing health interventions remains as yet unanswered. To contribute to current knowledge, we analysed the process and results of a large multidisciplinary project with an agile approach. Our case study shows such an approach may indeed be a feasible method for the development of health interventions.

The process allowed for a high pace, and good stakeholder inclusion. Some limitations also occurred. The agile approach favours speed over rigour, which hinders integration of user research and scientific evidence in the development process. Multidisciplinary cooperation remains difficult because of the limited availability of experts and stakeholders. Finally, the difficulties in documenting the process and results of the agile approach limit its use in scientific projects.

Keywords: intervention development, agile, design methods, case study



Introduction

The development of (digital) interventions for behaviour change is increasingly a multidisciplinary process, in which design (thinking) plays a significant role (Ferreira et al., 2015; Bazzano et al., 2017). Essential for successful collaboration between creatives (design[research]ers, human-computer interaction specialists), (para) medical and behavioural scientists, health care professionals, and patients, is a shared vision of what constitutes value, expressed in a shared methodology for intervention development (Hermsen, Renes, Mulder, and Van der Lugt, 2016). Unfortunately, medical and behavioural scientists on the one hand, and design and HCI researchers and professionals on the other, more often than not use fundamentally different methodologies (Mann, Kuppin Chokshi, and Kushniruk, 2018). The former generally use linear, theory-driven approaches (e.g. intervention mapping; Bartholomew, Parcel, and Kok, 1998, Behaviour Change Wheel; Michie, Van Straalen, and West, 2011), which rely on well-defined processes, evidence-based tools, rigorous documentation, and pre-set rules and plans. The latter increasingly use agile approaches (Beck et al., 2001) such as Kanban, Scrum, Google Design Sprint, Xtreme Programming, etc. Agile approaches favour individuals and interactions over processes and tools, working interventions over comprehensive documentation, stakeholder participation over clear rules, and responsiveness over pre-contemplated plans (ibidem).

Health intervention development could very well benefit from incorporating agile principles (Hekler et al., 2016). Unfortunately, the question whether agile approaches are useful in the development of health interventions remains as yet mostly unanswered; what literature exists from adjacent fields shows potential benefits, but also limitations of agile approaches. Potential advantages are horizontal – rather than hierarchical

– knowledge transfer, inclusion of all stakeholders in the development process and removal of barriers to interactions (Beck et al., 2001). Potential disadvantages are problems in integrating user research and scientific theory and evidence in the development process (Ten Klooster, Noordzij and Kelders, 2020, Ploos van Amstel et al., 2017); limitations in reaching shared understanding (Ten Klooster, Noordzij and Kelders, 2020; Ploos van Amstel et al., 2017); no possibilities for testing assumptions because of high pace (Peters, 2019); and a lack of transfer of knowledge through limited documentation (Salah, Paige, and Cairns, 2011).

More knowledge of the efficacy of agile approaches for designing health interventions can help researchers and practitioners from different fields develop a shared methodology and avoid potential pitfalls. Building this knowledge starts with explorative research such as case studies, from which experimental hypotheses can be derived. The current paper provides one such case study; it describes and analyses the process and results of a large project aimed at developing interventions for paediatric physiotherapists (PPTs) to support children with physical disabilities in active play and sports participation. In this case study, we test the hypotheses that 1) an agile approach leads to useful and usable prototypes, based on insights from evidence and user research; 2) the agile approach helps include all stakeholders and fosters good interactions between them; 3) the agile approach benefits multidisciplinary cooperation, and leads to good knowledge transfer between participating disciplines.

Method

To shed light on whether using agile approaches had a beneficial effect on the development of interventions for PPTs to support children with physical disabilities in active play and sports participation, the authors of this paper collected and analysed the available data from the project:

sprint reports, reflective journals (Thorpe, 2004) in which the sprint team collected their experiences and thoughts on the development process, and photos and film clips of sprint activities. All authors took part in a triangulation session with available members of the sprint team, in which we shared our findings and elaborated on them.

The case study

In this case study, a multidisciplinary team developed a toolkit for paediatric physical therapists (PPTs) to stimulate physical activity in everyday life settings of 6–12yo children with physical disabilities. The team consisted of behavioural scientists, health scientists, paediatric physiotherapists, designers from a design agency, and design researchers, with regular input from parents and children in the design process. The core sprint team contained two PPTs, two behavioural scientists, two designers, a design researcher, and a social worker.

The development process consisted of four one-week periods ('sprints'), following the rules and set-up of the Google Design Sprint (Sari and Tedjasaputra, 2017) approach: a five-day process for answering critical development questions through design, prototyping, and testing ideas with stakeholders. The goal of each sprint was to quickly develop feasible prototypes based on insights from evidence and user testing, with maximum attention to stakeholder participation. In the first two sprints, the team designed practical tools for use in physiotherapeutic practice; in the third and fourth sprint, the team designed a concept for a digital solution that enables PPTs to connect with social workers for sports participation.

Each sprint was preceded by a preparatory phase in which the team collected insights from literature and practice to inform the design sprint. Based on these insights, they prepared a start-up co-creation session. This session took place directly before the sprint and relevant stakeholders such as

parents, PPTs and others took part. During the cocreation-sessions, the sprint team evaluated whether insights from literature and previous user research resonated with the available stakeholders: did they agree with the insights? Could they relate these to their own (professional) experience? What wishes, dreams and barriers for potential intervention themes transpired?

Working from these results, the design team then started the sprint week proper. On the first sprint day, the team went through a divergent phase in which they collected and mapped all available knowledge in mapping sessions, user journeys and personas, and reformulated the initial research questions into sub-questions based on the mapped knowledge. If necessary, the team performed further user research on this day, for instance by performing in-depth interviews with experts and stakeholders. The second sprint day focused on converging activities, by selecting emergent themes from the data gathered on day one. On the third sprint day, the team worked on turning these themes into intervention prototypes, by generating ideas using brainstorming techniques, and further elaborating on the ideas using guiding principles and tools to incorporate insights from the behavioural sciences in the design process. On day 4, the designers in the core team developed the prototypes proposed on day 3. Each sprint finished on day 5, with a demonstration lunch in which the sprint team presented the prototypes to all available stakeholders, and a reflective session in which the core sprint team and other project members evaluated the sprint week. Appendix 1 provides a complete overview of the first sprint week as an example.



Figure 1: Showing connections: start-up activity for a co-creating session at the beginning of a design sprint week

Results and Discussion

The design team in this case study managed to end each one-week sprint with prototypes that received positive evaluations from stakeholders. This provides a first indication of proof for the hypothesis that agile approaches are useful in designing health interventions: they lead to useful and usable prototypes which can then serve as materials for testing the underlying change mechanisms in experimental or real-life settings.

The high pace and restricted time frame of a one-week sprint leave no room for this testing of assumed change mechanisms, nor of intervention feasibility or intervention efficacy. In this project, therefore, feasibility and efficacy testing took place after finishing the agile project, in a field lab setting which informs further iterations of the prototypes. This combination of

agile development and field lab-based testing proved fruitful in maintaining a balance between speed and rigour, one of the known pitfalls of agile approaches. An example is the development of the Photoframe tool (see figure 2), meant as a probe to see what happens when children take a picture of their abilities in therapy settings and show them to their PE teachers (who are often unwilling to let children with disabilities participate). Positive response led to its addition to the toolkit without further iterations. Pilot testing then showed that this intervention was in fact impractical because of its size and vulnerability. In later versions of the toolkit, a film clapboard will replace the Photoframe – as it is more practical, and it also invites making short films instead of static photos. These later versions of the toolkit will, once again, be tested for efficacy in field lab-settings.



Figure 2: Photoframe prototype. PPTs can use this to inform other physical activity professionals such as PE teachers of children's new skills

The second part of the first hypothesis states that agile approaches are useful in using insights from evidence and user research to build prototypes. In this project, the design team attempted to safeguard the integration of behavioural scientific and systemic insights by having experts from these fields on the team and by using design tools specifically aimed at integrating these insights into design processes. This went well as long as three conditions were fulfilled: the availability of the experts, the availability of well-developed and usable design tools, and (adherence to) a well-defined approach for integrating the insights in the development process. Experts need to be approached long before the sprint starts, but the unpredictable nature of sprints makes it difficult to know when experts are needed. In the case study,

this sometimes resulted in experts being available when there were no questions for them to answer, and vice versa. Design tools need to be available and the sprint team needs to familiarize themselves with working with them before the sprint starts (cf. Van Essen et al., 2020 for an evaluation of the use of design tools in this case study). To make the best use of both experts and tools, a pre-defined structured overview of sprint activities is necessary. The challenge then lies in keeping a balance between adhering to this pre-set schedule and remaining flexible.

Our second hypothesis states that the agile approach helps include all stakeholders and fosters good interactions between them. This case study shows once again that one of agile's strong points is stakeholder inclusion. The co-creation sessions, in which the sprint team tested important insights from literature and user research with stakeholders proved especially powerful in that respect. They delivered rich knowledge to inform the development of the intervention prototypes.

The third hypothesis states that the agile approach benefits multidisciplinary cooperation and leads to good knowledge transfer between participating disciplines. This multidisciplinary cooperation, however, remained an issue throughout the project. Non-academic designers in the team, used to full-time one-week sprints, had difficulty coming to terms with the realities of Dutch academic life and working in the health sector. Neither academics (design researchers, behavioural scientists) nor health professionals (physiotherapists) were available for a full five days at any moment, no matter how careful the planning process. The Dutch practice of working part-time was one of the reasons, and also the immensely busy schedule of many of the researchers and health professionals, which did not allow taking an entire week off other responsibilities. This, combined with the aforementioned unpredictability of the sprint process, forced the team to

change from the initial plan of having a multidisciplinary team with all specialities aboard, to a more traditional setup in which a core design team of designers and design researchers worked continuously, bringing in experts when they were needed. But even that proved hard from time to time; the sprint team attempted to solve this by leaving out Mondays and have only the core team designers and design researchers work on Friday. This hindered project continuity and shared understanding, two of the alleged strong points of the agile approach. A solution may lie in slowing down the pace of the sprints.

Finally, the design team found that challenges occurred in documenting the proceedings of the sprints. Even though the sprint team had planned to keep detailed reflective journals, time pressure proved this to be difficult. This lack of documentation threatens transferability of insights in any project but is especially problematic in using agile approaches in scientific research, where rigorous reporting is essential. A solution may lie in appointing a team member with the sole task of collecting data, reporting, and planning ample time for joint reporting and reflection.

Conclusion

The current paper reports a case study in which a multidisciplinary team used an agile approach to develop a toolkit for paediatric physical therapists (PPTs) to stimulate physical activity in everyday life settings of children with physical disabilities. The study shows that an agile approach is successful in delivering a range of prototypes for interventions. Furthermore, the approach helped in bringing on board all stakeholders.

However, some limitations of the approach transpired. Firstly, it is important to keep in mind that verifying feasibility and efficacy is not possible within the boundaries of the sprints. This may be solved by combining sprints with periods of real-life testing in field labs. Secondly, the case study

showed that it is important to strike a balance between speed and rigour; high pace may especially hinder the integration of user research and scientific evidence in the development process. Thirdly, multidisciplinary cooperation remains difficult because of the limited availability of experts and stakeholders. This hinders both continuity and shared understanding. Finally, if not dealt with, the difficulties in documenting the process and results of the agile approach limit its use in scientific projects.

All in all, this case study gives reason to hypothesise that agile approaches are useful in designing interventions for health, as long as the above-mentioned known limitations are taken into account. This can be done by combining agile (sprint) approaches for development with non-agile experimental or real-life testing of assumptions, feasibility, and efficacy; safeguarding the integration of insights and evidence from science and user testing by including experts on the team, using well-developed and well-known design tools, and adhering to a predefined development process; slowing down the pace of the sprint to generate a workload that fits the schedule of team members from non-design disciplines; and making sure there is ample time for reflection and documenting. Further (experimental) research can test this hypothesis.

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MAPPING EMOTIONS THROUGH PHYSICAL ACTIVITY: CREATING A NEW DESIGN FRAMEWORK

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Abstract

The field of Emotional Design helps us create products that influence people's behaviour and, in some cases, help consumers implement positive behaviour change. Within the field of Sports Psychology, there is a growing field of recent research focussing on understanding the emotions experienced through sport and the effects this has on our health and wellbeing. By combining the methods of Emotional Design with these emotion based insights from Sports Psychology, we have an opportunity to build new tools and methods that could help designers create new interventions to promote positive behaviour change in the form of physical activity uptake. This paper proposes a set of comprehensive maps that further explore and uncover the complex relationship between human emotions and physical activity. To identify the emotions felt in relation to physical activity, the existing literature was reviewed to understand the emotions elicited

or suppressed by physical activity behaviour, the way in which different people are effected by different emotions and physical activity types and the effect different sports have on our emotional relationship with physical activity. To fill gaps in the literature, a study was conducted to explore further the emotions felt before, during and after physical activity as well as how intensely each emotion is felt. Finally, the insights were combined into a series of comprehensive maps that give an overview of how emotions impact physical activity behaviours across a range of factors. These maps form the foundations of a new design framework that can be used to develop new products and services that focus on not only improving the uptake of physical activity but also helping people sustain this behaviour.

Keywords: Emotions, Physical Activity, Design, Framework, Emotional Design, Sports Psychology



Introduction

Emotions and Physical Activity are integral parts of our everyday life. They influence one another and have a significant impact on both our physical and mental health. Within Sports Psychology, researchers are investigating how our Physical Activity (PA) behaviour effects our emotions and, in some cases, how our emotions effect our PA behaviour. Current research focusses investigation of this relationship in three key areas; the positive link between PA and reductions in negative emotions like anxiety and depression (Clarke, et al. 2018); how anticipating emotions like regret can influence partaking in PA (Rhodes and Mistry 2016); the negative effect emotions like embarrassment and shame have on PA uptake (Rogers and Ebbeck 2016). However, not addressed adequately in the literature as yet is the range of emotions that can and do effect our PA behaviour. The field of Emotional Design explores the vast spectrum of human emotions. Designers study how experiences elicit emotional responses, to create products that influence people's behaviour (Desmet, Porcelijn and Dijk 2007). We understand that our emotions affect how we feel, think and behave (Norman 2004). Combining the emotion based insights from Sports Psychology and the integral methods of Emotional Design, Physical Inactivity can be tackled using a new multidisciplinary approach.

This paper deepens the understanding of the emotional experience of PA through a new approach inspired by Emotional Design. To explain, Emotional Design acknowledges three levels at which human beings process all types of information: visceral, behavioural and reflective (Norman 2004). The visceral level concerns initial reactions and appearances, the behavioural level concerns performance and function and the reflective level concerns personal feelings and self-image. The insights taken from Sports Psychology can be related to each of these levels. Visceral: initial emotions

before PA. Behavioural: emotions felt during PA. Reflective: emotions felt throughout the entire PA experience; before, during and after. No past or current research, to our knowledge, explores the emotions felt before, during and after PA in the same study.

The approach we have used in this paper aims to uncover a complete set of emotions associated with each stage (before, during and after) of the physical activity experience. The findings are shown in a series of comprehensive maps that give an overview of how emotions impact physical activity behaviours across a range of factors. These maps form the foundations of a new framework which can be used to design more successful interventions that help people to not only become more active initially but implement long term changes to ensure they stay active.

Method

The aim of this study was to introduce a new and complete set of emotions to PA research in order to fully understand the emotional experience of PA and create the foundations of a new design framework.

A paper search was conducted online identifying all papers within the last 10 years that explore, in some way, the relationship between emotions/feelings/mood and PA. The search found 63 relevant papers which were then analysed. Studies used a range of methods including literature reviews, exercise interventions, surveys (Teixeira, Silva and Palmeira 2018) and interviews. For the purpose of vast data collection, a survey method was selected. At the time of collection for this write up, 144 responses had been collected. The responses included 88 females and 56 males with an age range of 16 to 77 (average of 26.92). Participant recruitment was carried out online via various social media channels and e-mail lists ensuring a wide range of participant background and PA experience.

The survey was split into two sections; general information and emotions felt in relation to exercise. To understand the full emotional experience of PA, each participant was given, at random, one of three scenarios; about to take part in PA (before), taking part in PA (during), and just finished taking part in PA (after). The scenarios were split evenly amongst participants.

To combat lack of emotions found within current Sports Psychology research and address the vast spectrum of human emotions found with Emotional Design, a complete set of emotions was selected from the field of Psychology – a research field which lies in between these two, providing a set of foundational insights into human behaviour which can be used to bridge the gap. Cowan and Keltner (2017) found that there are 27 distinct varieties of emotional experience. However, before factor loading, they found a slightly larger total of 34 which included emotions commonly associated with PA including triumph, pride, guilt and disappointment. For this reason, it was decided to use the expanded version of 34 varieties for this study.

After being given their scenario, participants were asked to select a PA type of their choice (e.g. football, yoga, weightlifting...) and select all emotions that they felt. They were then asked what intensity they felt each of their emotions at on a scale of 1 to 5. Additionally, we also collected information on other factors which can have an effect on our emotional relationship to PA including; current activity level, level of athlete (beginner, casual, competitive or elite) and number of people taking part in PA with the participant (individual, pair or group).

The results of the study were then analysed within Tableau software.

Results

Figure 1 shows an overview of the collected data. There are 36 lines on the graph, 1 for each of the emotions listed on the right. The journey of each line shows the average intensity felt of each emotion before, during and after activity (left to right). There are clearly 8 lines that sit higher than the majority, representing that these emotions are felt, on average, at greater intensity than the rest. The emotions, with average intensity scoring for all 144 participants for all three scenarios of before, during and after, are; satisfaction (2.51), excitement (2.18), joy (2.17), pride (1.56), calmness (1.52), interest (1.41), triumph (1.29) and relief (1.20). Horror was the only emotion not to be selected at all.

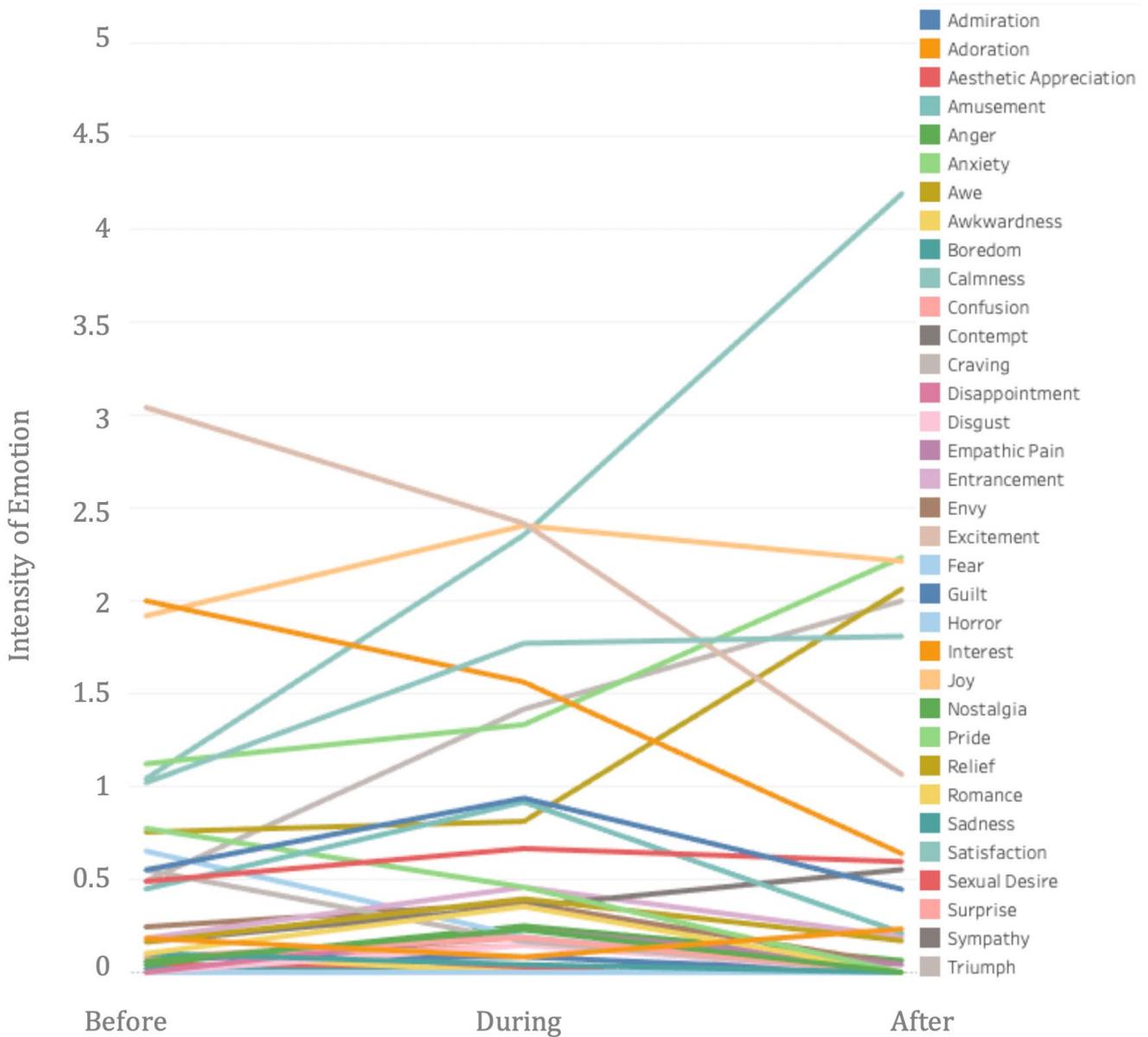


Figure 1: Emotions v Scenario (Before/During/After) & Emotion Colour Key

Using the same colour/emotion key as above, Figure 2 shows the same information split into male and female participants. Calculating the average total intensity of each of the emotions still leaves us with the same top 8 however, when split by sex, the paths of each emotion across before, during and after start to differ. One significant finding is the difference of joy for male v female participants, illustrated by the light orange line near the top of both graphs. For women, intensity of joy is felt fairly similarly, with a very slight decrease, through each

stage of PA (before: 2.55, during: 2.42, after: 2.28) whereas for men, there is a sharp increase in joy between the first two stages of PA and a slight decrease between the last two (before: 1.00, during: 2.38, after: 2.07).

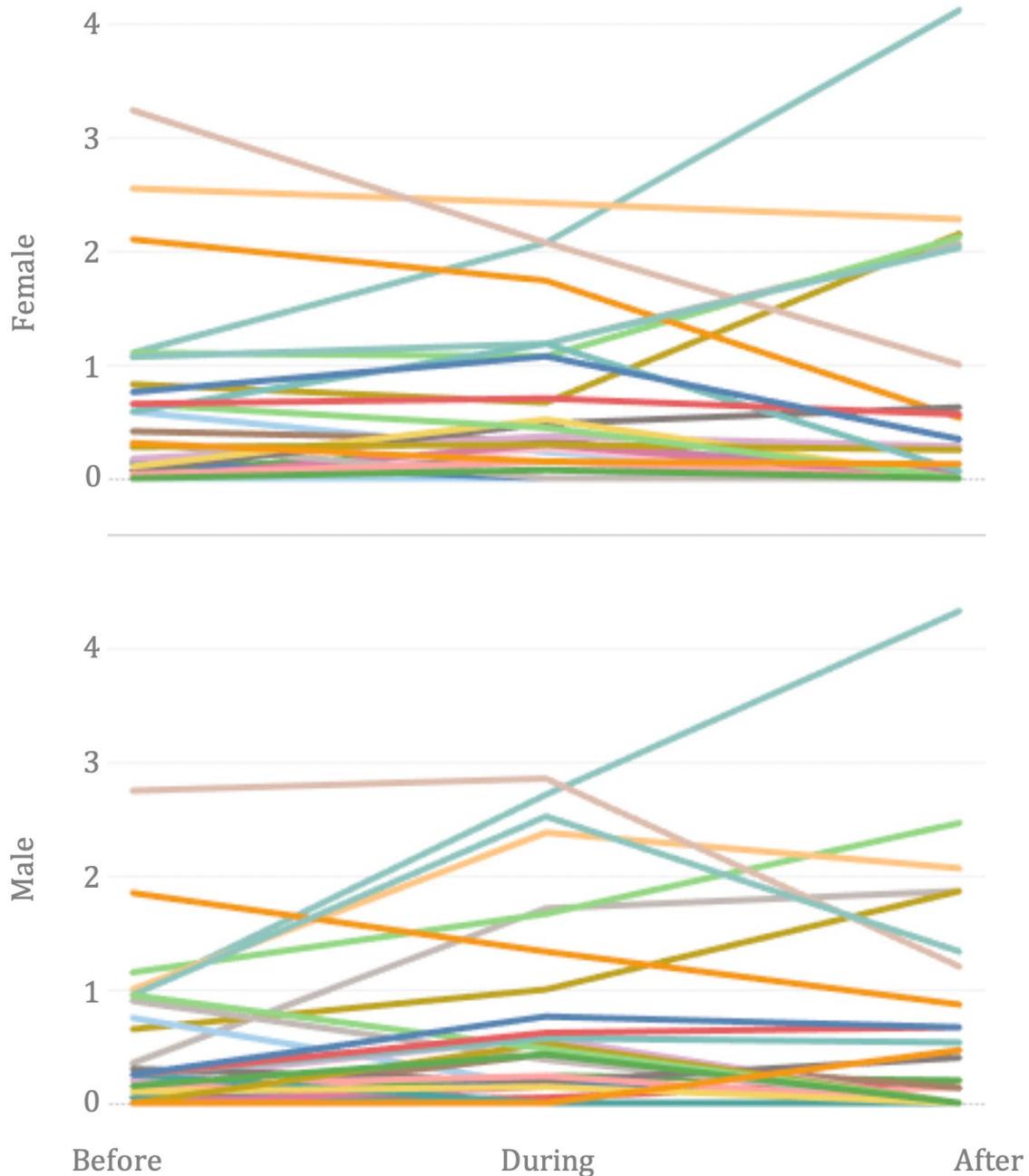


Figure 2: Emotions v Scenario (Before/During/After) : Male v Female
 Number Scale = Intensity of Emotion

Another way to view the data is by splitting it into number of people exercising with the participant; individual (themselves), pair (themselves +1) or group (themselves +2 or more). The results of this are shown in Figure 3. Expectedly, the most prominent emotions from Figure 1 are the same for Figure 3, however, 7 of them (excluding Triumph) have varying paths depending on the number of people taking part in the PA. Calmness, for example, follows a constant increase through the stages of PA when the participant is taking part as an

individual (before: 1.19, during: 1.95, after: 2.50). This is in contrast to calmness felt through each stage of PA as a pair with a much higher average intensity before (3.00), with a steep drop during (1.75) and a slight increase after (2.33). Interestingly, the path of calmness varies again when taking part in PA as a group with low scores before (0.73) and after (1.00) with an increase during (1.63) PA. Interestingly, romance was only recorded to be felt in one scenario: before (1.67) PA as a pair.

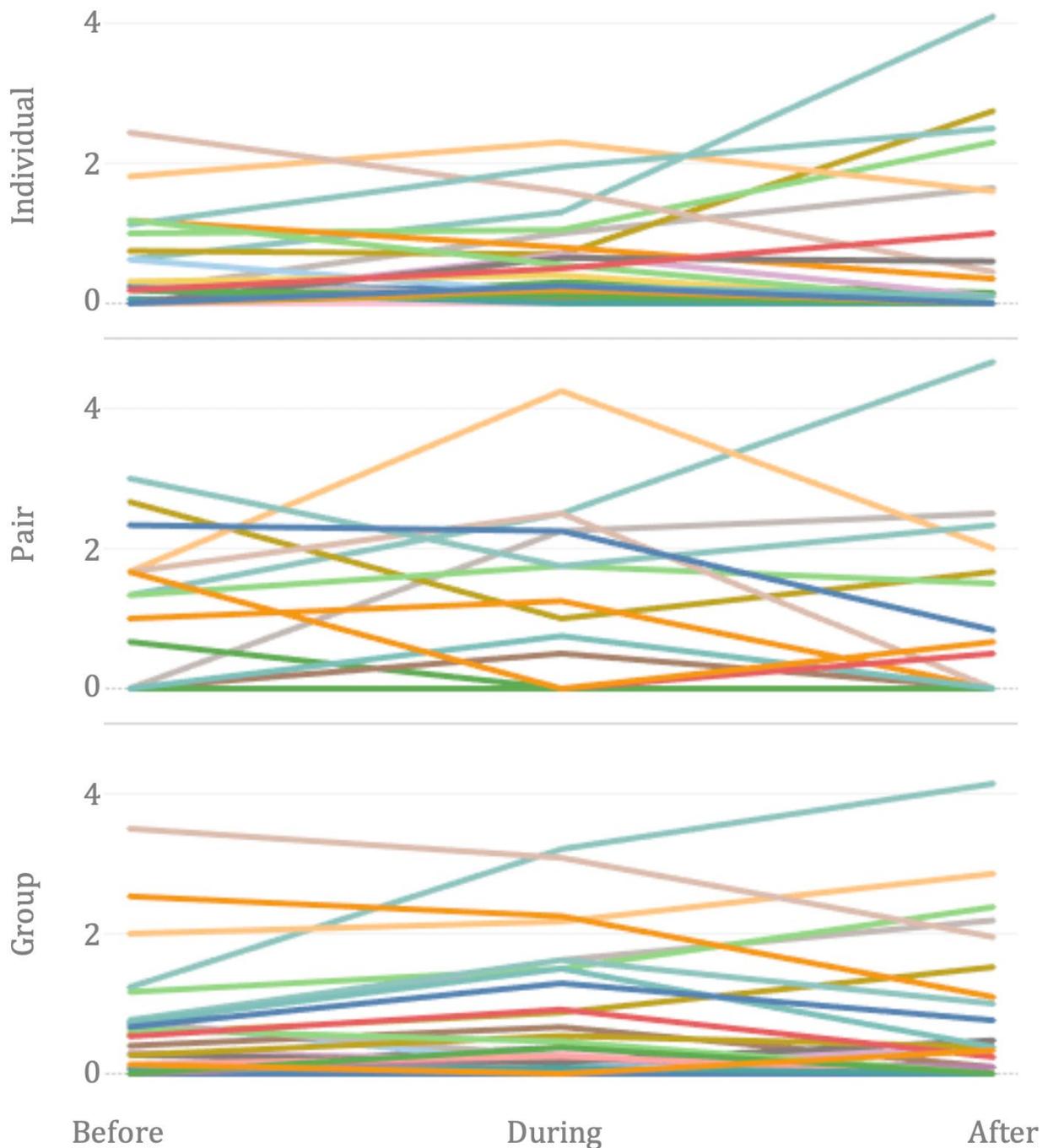


Figure 3: Emotions v Scenario (Before/During/After) : Individual v Pair v Group
 Number Scale = Intensity of Emotion

A third way the data can be split is by level of PA experience; casual, competitive or elite. For the purpose of recording and reporting these results, participants were asked to identify as either beginner, casual, competitive or elite level athlete. There were not enough beginner level (new to PA) participants to include them in the breakdown shown in Figure 4. Looking at Figure 4, it is obvious that emotions felt at each stage of PA vary depending on PA

experience. By splitting the data this way we encounter our first average intensity of 5.00 for an emotion – joy in elite level athletes during PA. Fascinatingly, it is also the exact same scenario (elite, during) where we find anger as a significant emotion with an average intensity recorded at 4. Similarly to Figure 1, Figure 2 and Figure 3, satisfaction is the most intensely felt emotion after PA for all three scenarios of athlete experience.

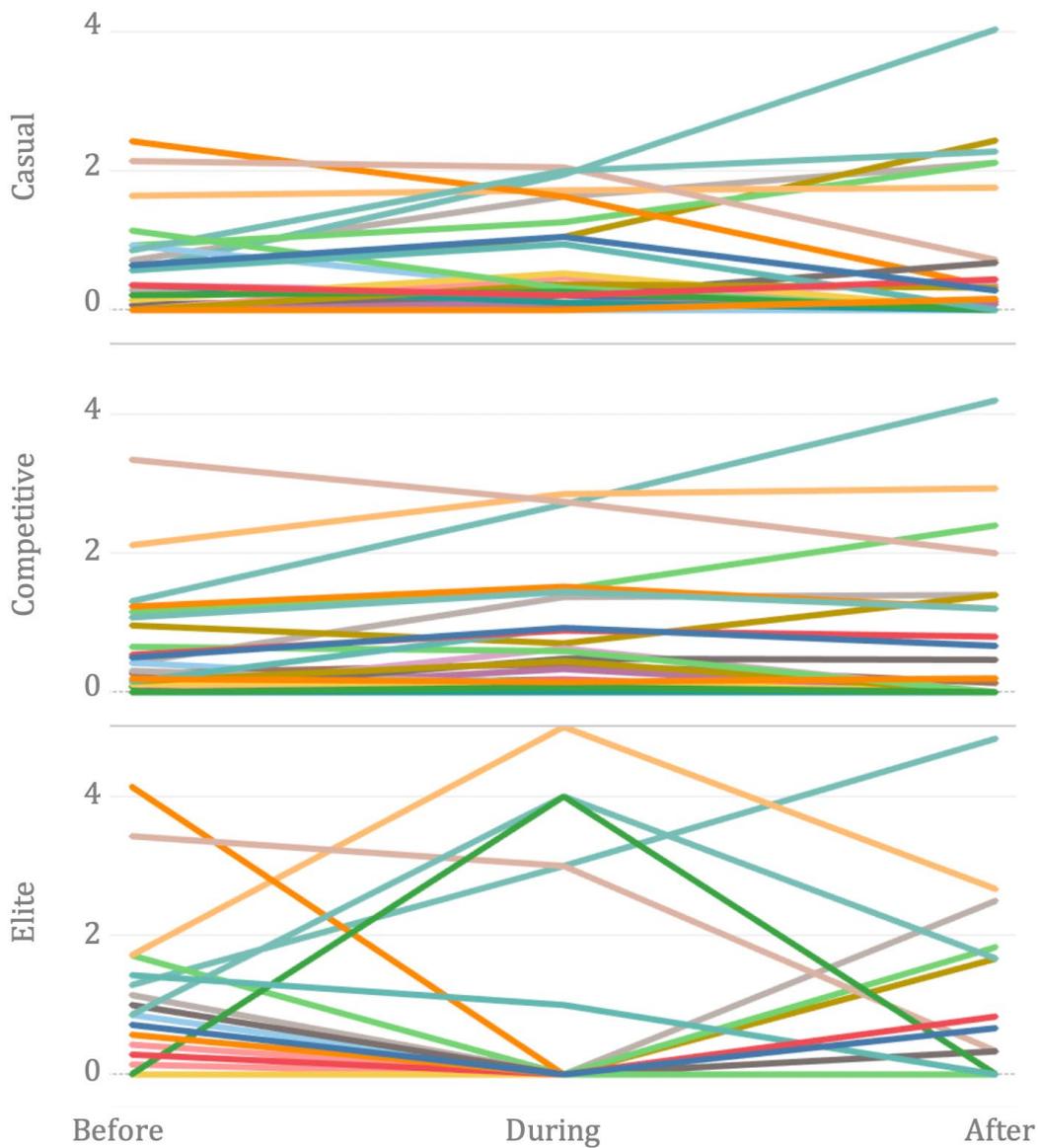


Figure 4: Emotions v Scenario (Before/During/After) : Casual v Competitive v Elite
 Number Scale = Intensity of Emotion

Following initial analysis of the results, we began to create maps. The first map (Figure 5) explores group physical activity amongst female participants, mapping four different variables; casual level, competitive level, running and CrossFit. The graph concerning casual level athletes running, stands out significantly from the other graphs in this map. This top left map has four emotions with an average intensity rating of 5.00 before PA; amusement, calmness, entrancement and excitement. Satisfaction also has an interesting path on this graph with a dip in intensity during activity with high averages before and after. This is in contrast to the other three graphs which

show satisfaction to follow an increasing path across the three stages of before, during and after PA. Interestingly, the two right hand graphs of the map show very similar graphs for competitive level females taking part in group PA of the two contrasting sports. Whereas, in contrast, the left hand graphs showing the same for casual level females appear to differ drastically. One of the significant emotional differences between running and CrossFit for casual female athletes is the stage of PA at which pride is felt: for running it is most commonly felt after PA, whereas for CrossFit it is most commonly found before PA.

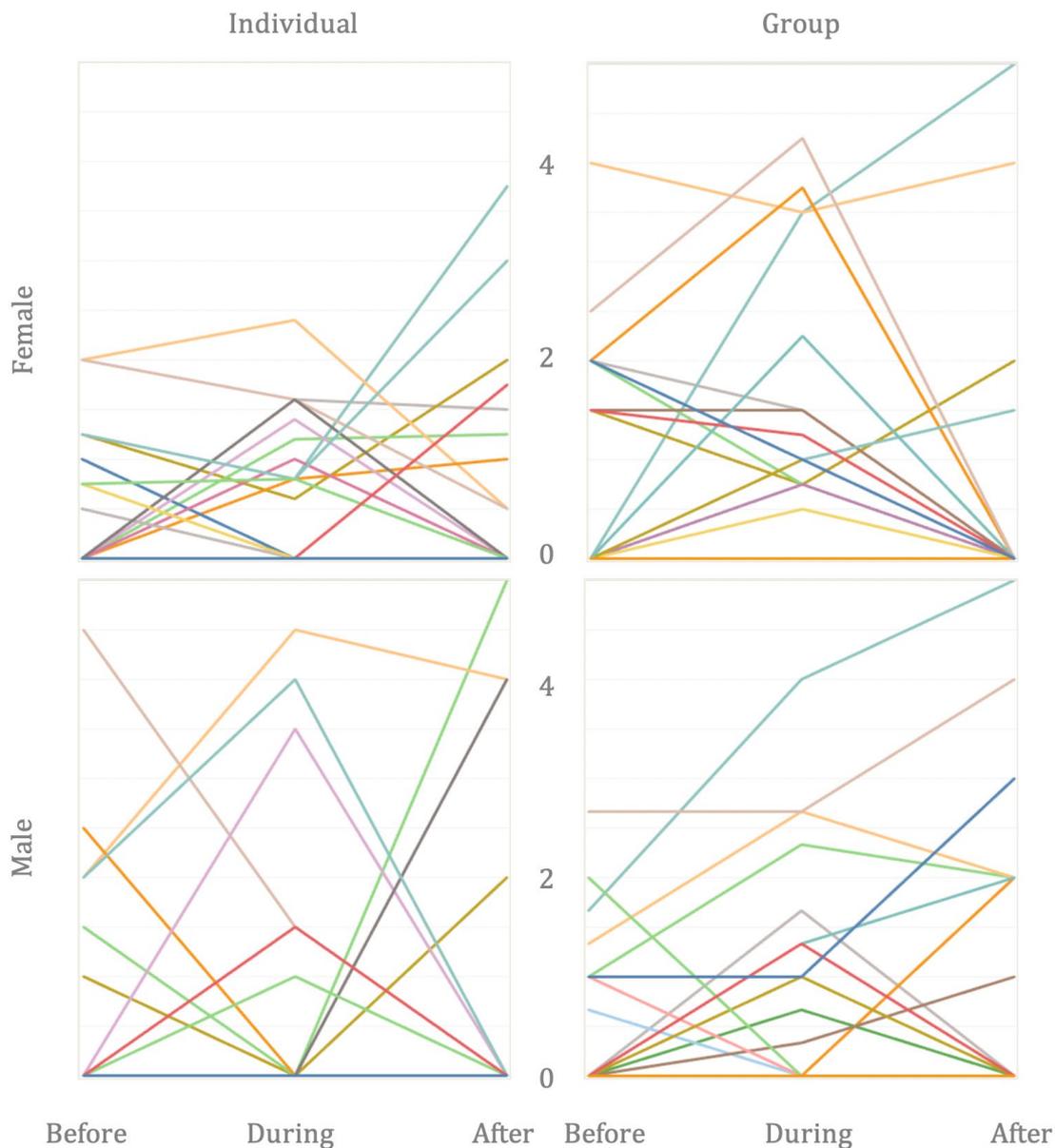


Figure 5: Map 1 : Group Physical Activity concerning Females : Emotions v Scenario (Before/During/After) : Casual v Competitive : Running v CrossFit
 Number Scale = Intensity of Emotion

The second map (Figure 6) explores running at competitive level, mapping four different variables; males, females, individually taking part in PA and taking part in PA as a group. There are a lot of differences amongst the four graphs in this mapping with the most prominent being how suppressed emotions are for females taking part individually versus the other three scenarios. Some contrasting findings in this mapping surround the emotions of entrancement, aesthetic appreciation and calmness. Entrancement follows the same path on both individual graphs of a spike during PA but shows it

felt at a much higher intensity for males than females, whereas it doesn't appear at all during the group PA graphs. Aesthetic appreciation follows the same path on both male scenarios on the map, where there is a spike during activity, but differs for the female scenarios, where it spikes after individual PA but gradually decreases throughout the stages of group activity. Calmness is different for all four graphs on this mapping and with future research advancing this work to create comprehensive interactive maps, the user could highlight calmness on this map as shown in Figure 7.

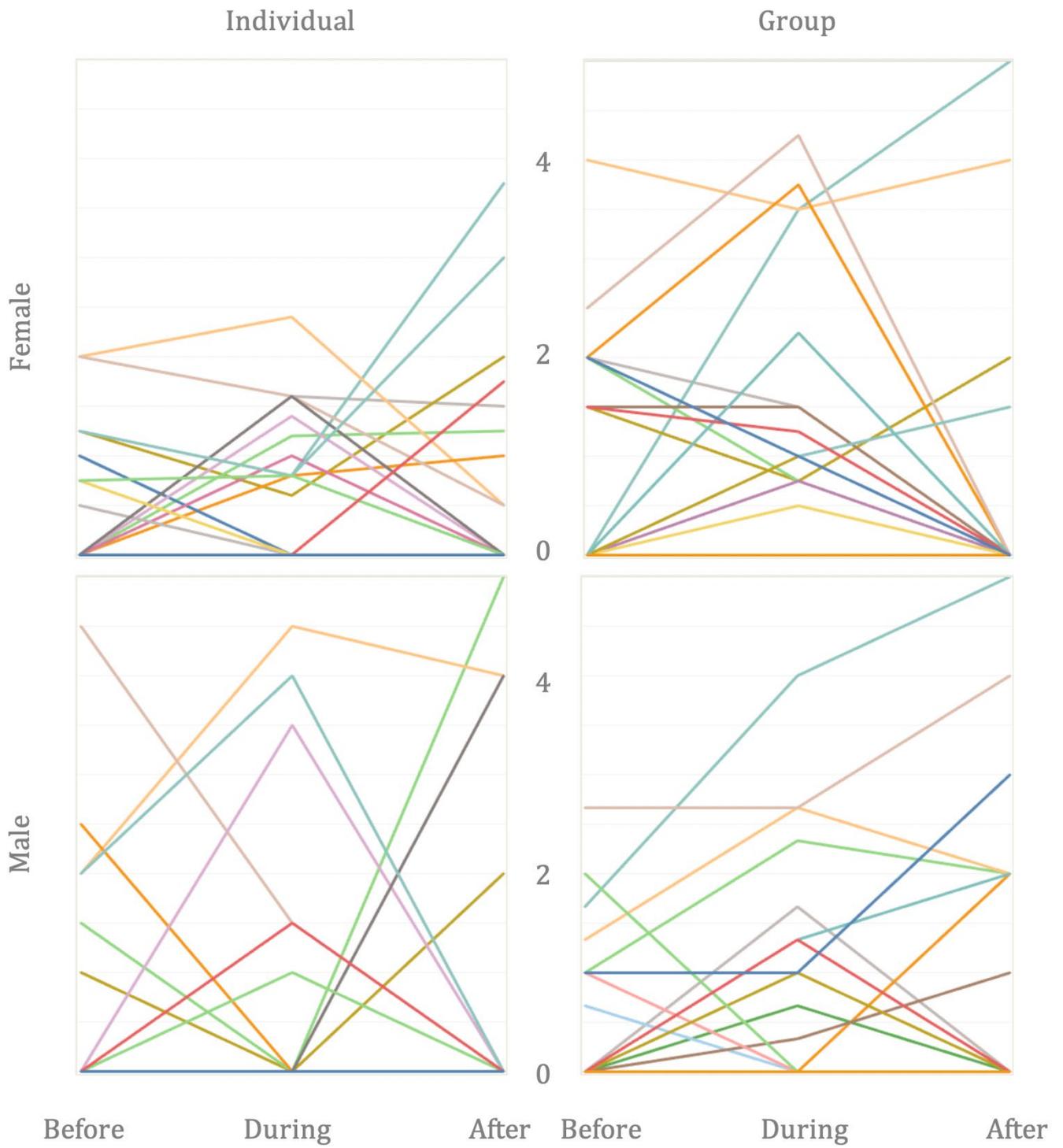


Figure 6: Map 2 : Physical Activity of Running at Competitive Level : Emotions v Scenario (Before/During/After) : Individual v Group : Male v Female
 Number Scale = Intensity of Emotion

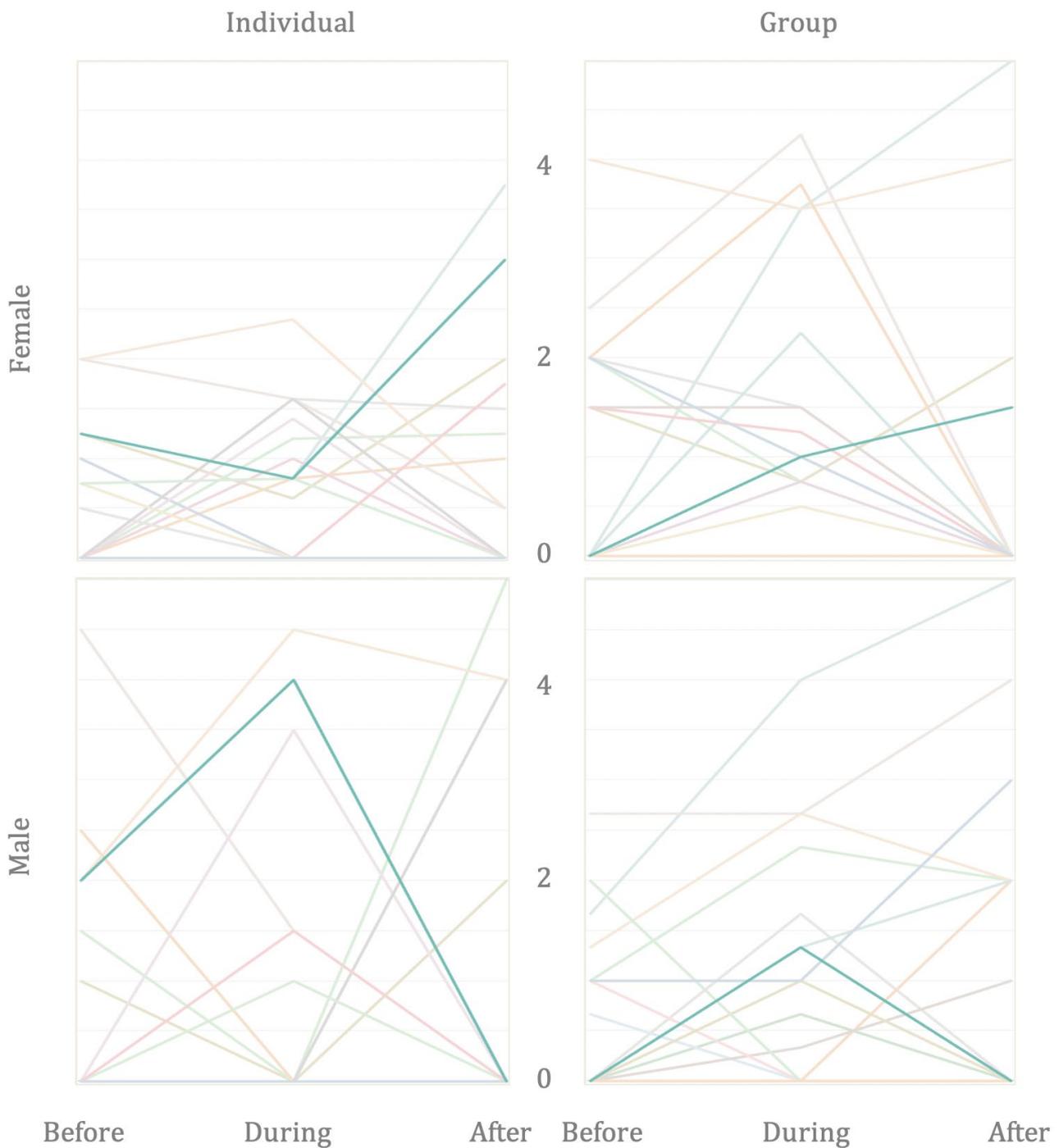


Figure 7: Highlight of Calmness on Map 2 (Physical Activity of Running at Competitive Level : Emotions v Scenario (Before/ During/After) : Individual v Group : Male v Female)
 Number Scale = Intensity of Emotion

Discussion

In his book *Emotional Design (Why we love or hate everyday things)*, Norman (2004) writes,

‘that people can be passionate about their belongings, the services they use, and their experiences in life.’

Physical activity falls into the category of experiences with interventions to aid the uptake of PA falling into the former two categories of belongings and services. However, Norman’s study did not include activities such as sport and points to the need for a deeper understanding of such activities. This paper has started to address this need with future work aiming

to expand and develop a more meaningful understanding of the relationship between emotions and PA.

This paper successfully uncovers a new set of emotions felt throughout the PA experience. By including the intensity at which each emotion is felt before, during and after PA we start to understand more deeply the emotional rollercoaster that humans experience throughout PA. Further to this, the Emotional Design inspired method of understanding visceral, behavioural and reflective levels through before, during and after is effective in further uncovering the full experience of PA through emotions and provides the base of a new design framework that will be used to design PA interventions that help people become more active and stay active.

The analysis in this paper includes a relatively small number of participants, which show potentially prominent trends including how men and women respond differently in varying PA experiences, how key emotions vary depending on type of PA and level of athlete and how emotions differ throughout the stages of a PA experience. This creates the need for a journal paper with further analysis on a greater number of participants (including beginner level athletes) which will provide more reliable data and significant analysis.

The data collected in this study and the maps created from it start to bring to light more questions surrounding PA and emotions: Are casual athletes less predictable? Does the number of people taking part in PA have a greater effect on our emotions than the type of PA that we're taking part in? By further understanding the relationship between human emotions and PA through the work completed for this paper and the future work that will unfold as a result, a new set of design tools can be created.

Future research will continue to collect more data, expanding the maps and increasing their validity within both sports psychology and emotional design. In depth fieldwork will explore further the reasons behind the emotions felt in particular scenarios by different people.

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BEYOND SCIENCE COMMUNICATION: A SERVICE DESIGN APPROACH TO BUILDING MUTUAL STAKEHOLDER UNDERSTANDING IN THE DEVELOPMENT OF NOVEL BIOTECHNOLOGIES

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Abstract

Traditionally, designers communicated from one knowledge area to another largely through graphics, using conventional linear models where information is provided in a unidirectional flow from the experts (who know) to non-experts (who don't know). This is problematic because the communication is based on experts' assumptions about the 'audience' and does not necessarily understand or address audiences' actual concerns and existing knowledge or enable audiences to interact with the knowledge. Additionally, when we consider the distinct forms of knowledge, such as scientific - explicit codified elements, and tacit - informal processes and experience based on know-how - we need to find ways to reconcile knowledge-sharing between them. To counter this top-down and passive approach to communication, designers have a role in shaping

knowledge sharing between the scientific and tacit by involving diverse stakeholders in action-orientated activities that are characterized by social interaction. Drawing on early findings and insights from design researchers working in the public engagement work package of Pharma Factory, an EU H2020 pharmaceutical biotechnology innovation project, this paper argues for a service design approach to healthcare communication, taking into account multiple stakeholder perspectives in knowledge co-creation and interpretation. The value of a more democratic, open and bidirectional approach to healthcare communication and 'public engagement' is considered, along with challenges and limitations.

Keywords: service design, co-design, biotechnology, mutual understanding, multidisciplinary



Introduction

Multidisciplinary working has, in recent years, become a desirable feature of science & technology projects funded by the European Commission's Horizon 2020 programme. In particular the inclusion of 'social sciences and humanities' has been cited as being particularly important (FET Advisory Group 2016). This has provided design researchers with the opportunity to work in H2020 projects, such as the Pharma Factory project, where previously their value would not have been considered. While the FET Advisory Group warns against paying 'lip service' to the inclusion of other disciplines, the challenge of describing the value of design research for such projects remains significant. Within biological sciences the traditional role of design might be to support science communication through graphics and exhibition design (Burns et al 2003); with a move towards increasing democratic ways of involving the public in open dialogue around technological developments (Irwin, 2006), design can interactively and collaboratively engage in co-producing knowledge for new technological futures.

Design's role as a process-orientated and facilitatory set of practices is still relatively new and unfamiliar with disciplines such as the biosciences; design, with its naturally human-centred mindset and creative practices, is still often conceived as focused on translating the complexities of codified knowledge into digestible and entertaining forms. In these situations, designers might adopt 'tricky tactics', being invited into the fold on the premise of established ideas of designs' contribution, before prompting, provoking, adapting and reframing that contribution in response to presented situations, adding value beyond what was anticipated (Fisher & Gamman 2018).

Pharma Factory focuses on four novel pharmaceutical technologies being developed using Plant Molecular Farming (PMF), a) an enzyme for treating Lysosomal

Storage Disorders (LSDs), b) an edible vaccine for farmed fish, c) a molecule for treating HIV and, d) a diagnostic kit for Sjögren's Syndrome or Rheumatoid Arthritis. Each technologies development sits within a specific work package and is located at different stages of research and development. Two strategic work packages straddle the technologies, focusing on public engagement and regulatory pathways. A team of design researchers from University of the Arts London, collaborating with social scientists from St George's University of London were tasked with the public engagement package. Applying service design principles and co-design methods the team aim to understand opportunities and challenge barriers and for public acceptance of these new pharmaceutical technologies.

Service design is established in healthcare settings in Europe (Springham & Robert 2015, Bailey et al. 2019) and in the global south (Tseklevs et al. 2019), to address public health issues, involving multiple stakeholders in co-design processes to innovate and deliver new and improved services for a range of health and social care contexts. Less common is the application of service design at the very front end of biomedical research such as the Pharma Factory project. The adaptability of co-design tools and methods makes them ideally suited to this challenge, as they seek to avoid assumptions and first understand a person's experience, then to enable that person to co-design an alternative future (Sanders & Stappers 2008).

Whereas service design is most often used to design services (with or without a product focus), this research focuses on adapting these methods to facilitate the co-creation of knowledge, enabling mutual understanding of the value of novel technologies between stakeholders and scientists. In this frame the 'service' element is a co-created shared understanding of the value of that technology at different points of the stakeholder's current and future

experience (Akoglu & Dankl 2019; Sanders & Stappers 2008).

The purpose of this research approach for Pharma Factory is twofold:

1. to understand the value of the technologies afforded by PMF to a range of stakeholders.
2. to understand the perception of genetically modified (GM) plants when used within the context of pharmaceuticals, providing potential narratives and language that could be used to challenge (assumed) barriers to acceptance.

Beyond science communication

Science communication - or 'the deficit approach' (Bubela et al. 2009) - can be understood as the unidirectional flow of information from scientific knowledge domains to lay audiences to fill apparent gaps in understanding. Often this includes assumptions about what those audiences want or need to know, and what they already know. Science communication has evolved to some extent to include 'audience research' but in doing so there is the additional risk of promising too much in order to engage and entertain those audiences (Bubela et al. 2009). Once an understanding of an audience's values or expectations of emerging biotechnologies has been achieved, there is an ethical responsibility to ensure that the communication 'frame' doesn't obscure the specificities of the science, which can damage trust. These shortfalls have been recognized within the field of biotechnology with authors calling for greater focus on 'dialogue' with lay people (Bubela et al. 2009; Burns et al 2003). While multidisciplinary is seen as essential in contemporary critiques of science communication (Fischhoff 2013), the value of design has not been considered in this context.

A service design approach using co-design tools and methods can help to address these challenges of 'science communication', as it goes beyond 'audience research' to involve the participants in validating co-created artifacts, and in subsequent design of artefacts and events informed by the resulting co-created knowledge (Chamberlain & Partridge 2017). As a methodology distinctly different from the biosciences and social sciences, design research arguably provides something fundamental that science communication has been missing. Being flexible, problem-oriented and empathic, co-design provides designers with the tools to build a bridge between the highly specific, but abstract science with its codified language, and the values of specific stakeholders or wider audiences. By revealing hidden values and providing narratives or 'frames' (Burns et al 2003) it makes the science empathic and relatable to wider audiences. Furthermore, co-design provides the means to build that knowledge through an iterative, guided process. In this way the methods and tools challenge assumptions and reveal deep-seated value systems through participatory research activities.

In Pharma Factory, the research process involves co-designing first with the scientists, then with stakeholder groups, feeding back to the scientists and then communicating with wider audiences (fig. 1). Akoglu & Dankl (2019) argue that mutual learning and understanding are a central outcome of a co-creation design research approach, building empathy amongst stakeholders. This makes co-design well-suited to the challenges of communication in healthcare where new technologies are highly specific, and their production and use impact particular groups of people with non-standard needs and values.

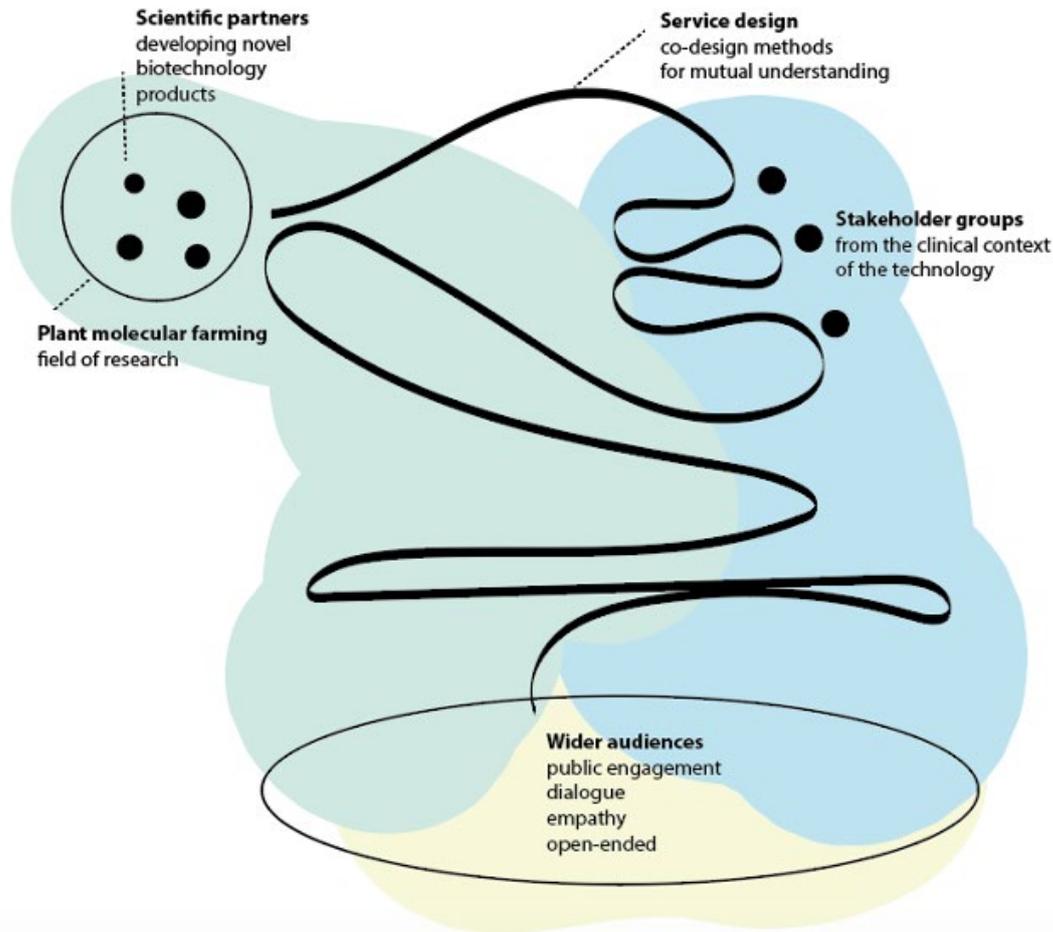


Figure 1: Service design research process pathway in Pharma Factory

Methodology

This project uses a service design approach with co-design tools and methods - some adapted from standard tools, and others contextually designed (Chamberlain & Partridge 2017). The approach of the design facilitation was in the spirit of emergent practice as described by Aguirre et al (2017) which relates to a ‘research by design’ methodology: “designers fly in complex patterns—they act as both participants and facilitators. In the latter role, they must foster participant interactions that generate emergent material. Such emergence is “brought into existence by the way a whole [event] is bound together by substance and order through relationships and connections.” (Aguirre et al 2017:199). In the current project mutual understanding can be considered the ‘emergent material’, afforded through revealing hidden values

and challenging assumptions, in turn leading to translation and bridge-building between biotechnology, stakeholders and wider audiences, as described earlier.

The design research team first designed and delivered co-design workshops with the scientific partners to identify and understand the stakeholders connected to the novel technologies and to explore scientists’ assumptions about the value of their technology to them. After analysis and sensemaking phases, the design researchers sought to engage a range of stakeholders, designing and developing workshops for each group recruited. Currently, the design researchers are recruiting, designing and conducting this ‘stakeholder engagement’ phase of the research. Early findings presented relate to the first of these stakeholder workshops conducted in February 2020. As described earlier, once

complete the findings of the engagement will be reported back to the scientific partners and the European Commission to inform their ongoing work, as well as providing valuable insights to inform public engagement activities, including interactive exhibitions and pop-up events within the timeframe of the Pharma Factory project.

As the research is ongoing and there are limitations in reporting the full findings at this stage, this paper reflects on one of the four technologies - the production of a molecule to be used in the treatment of Lysosomal Storage Disorders (LSDs) - and the discussions that took place in a workshop with 8 specialist Pharmacists. The aim here is to discuss how a service

design approach may have contributed to original insights and understanding of stakeholders' perceptions and values, and how this supports the production of mutual understanding.

A short case summary

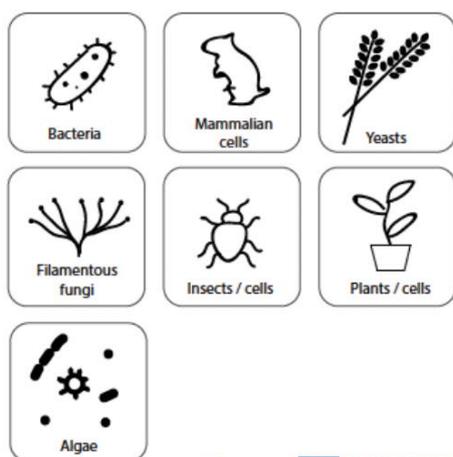
This case summary reflects briefly on the first Stakeholder Workshop conducted within the Pharma Factory project with Pharmacists as described above.

A 'Project Glossary' was co-designed, to enable the translation of some of the codified scientific language and key concepts into narrative tools, so that workshop participants could easily engage with the technology (fig. 2).

1. How are medical proteins produced?

Modern medicine increasingly involves using proteins, peptides and other small molecules to treat a variety of medical conditions.

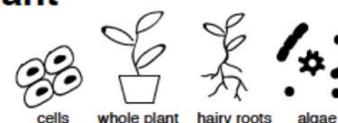
Industrial protein production typically involves engineering cells from an existing organism to produce large quantities of proteins, enzymes and peptides for medical and other biotechnology products. The following organisms, or cells derived from these, have been engineered to express proteins for pharmaceuticals:



Pharma Factory This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 774026.

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2. What is Plant Molecular Farming?



Plant Molecular Farming (PMF) is one type of recombinant protein expression system where plant cells are used to produce proteins, peptides and small molecules.

- The process involves introducing recombinant (genetically modified) DNA into a plant to 'tell' the plant to produce a protein of interest, this either temporarily or permanently alters the plant's genome.
- The production typically takes place in a 'contained' manufacturing unit, which prevents accidental release of genetically engineered organisms and also protects the product from external factors.
- Waste plant material is disposed of in an auto-clave, using heat and pressure to destroy genetic material.
- The production process is regulated in the same way as other types of pharmaceutical production under a license for Good Manufacturing Practice (GMP).

Figure 2: Biotech concepts and terms were translated into narrative workshop tools

During the first activity in the stakeholder workshop - an ecosystem map - pharmacists revealed an interesting micro-network of stakeholders involved in treatment provision for LSD patients. During the task pharmacists were encouraged to think about who they interact with during their work with these particular patients. Design facilitators were then able to prompt additional questions iteratively, building detail incrementally, supported

by worksheets for visual reference. Through this exercise the important roles of 'Prescribing Nurses', 'Specialist Nurses', 'Homecare Coordinator' and 'Dietician' were identified, which added detail to the 'hospital' as a general stakeholder. This challenges assumptions that pharmacists are the sole operators bridging between prescription (clinician) and treatment (patient) and are in fact part of a more complex network of actors (fig. 3).

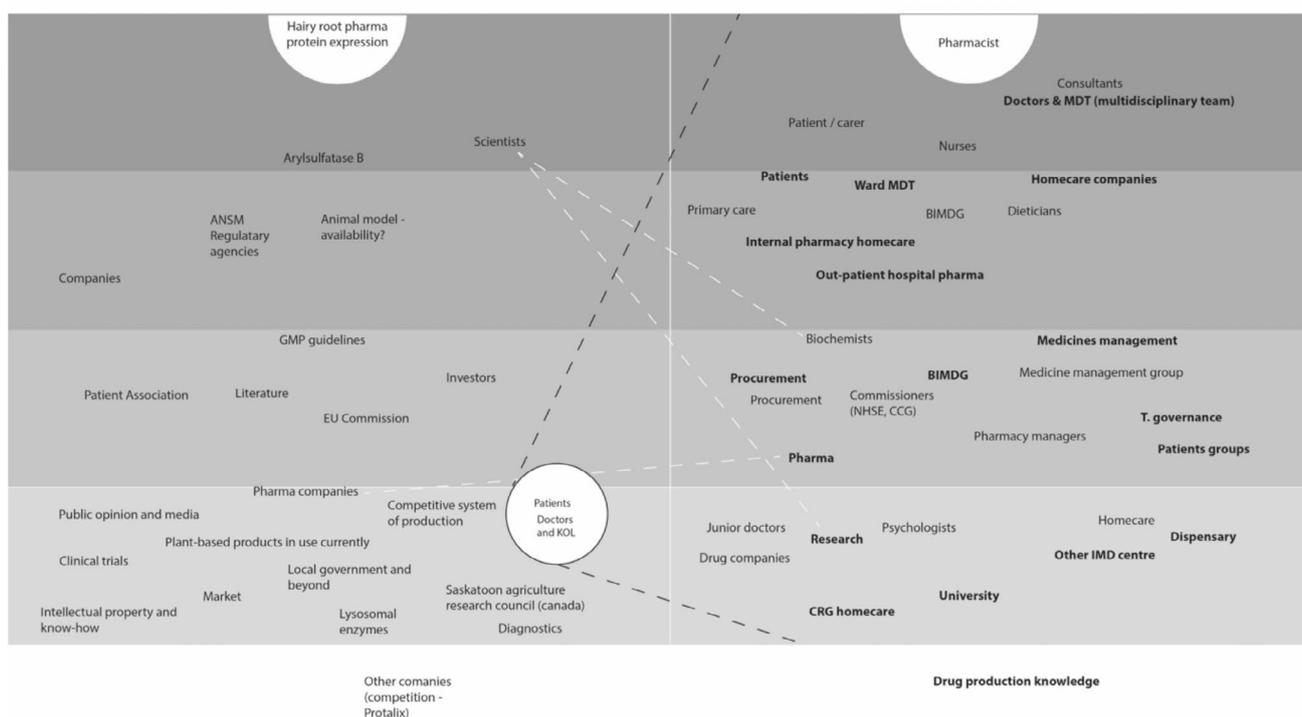


Figure 3: A visual comparison of the scientific partners' ecosystem map with the pharmacists' map, showing the expansion of 'hospital' into a more detailed network of actors.

In a subsequent activity the scientists were fairly accurate in their assessment of the value of their technology to patients and clinicians. They identified 'safety' and 'efficacy' as key values and this was echoed by pharmacists. However, the definition of 'efficacy' was seen as incredibly important to the pharmacists and how this translated into clinical impact. There were additional values that the scientists had overlooked such as 'ease of use' when administering the drug, and 'the novelty value' as patients seek to try new treatments to improve their condition.

The workshop also provided insights around terminology when engaging general audiences. For example, the term 'recombinant' was familiar to the participants and normalized in relation to pharmaceutical production, whereas 'GM' appeared to be rarely used or associated with pharmaceuticals. When participants were given information about PMF and the term 'GM' was introduced for the first time, they immediately switched to a more populist view of the implications, seeing that 'the media' could have both a positive and a negative role in how people perceive the new technology (fig 4). Interestingly,

when focusing on the actual medication, whether it was produced by one method or another (for example, recombinant plant or mammalian cell, or chemical) was not a concern to the pharmacists, but as soon as they were encouraged to zoom out and think from the general perspective, they began to think about how the use of GM plants could cause concern to 'the public'. This raises the question of whether those who are not directly benefiting from the

products would be more likely be concerned by the use of GM.

Speculative prototyping provided participants with the tools to address this challenge: what would they do to allay peoples' fears of the technology? Using their own experiences, they shared how they would reassure patients about the robustness of treatments, largely through established government-owned information platforms, regulation and standards (fig. 4).



Figure 4: Speculative prototyping: participants explored possible public perceptions of PMF (PNs on left) and discussed how they might allay peoples' fears (PN on right)

How co-design affords mutual understanding

As discussed previously, service design takes a different approach to the central challenge of PMF - indeed any novel biotechnology - in enabling lay-understanding and acceptance, than conventional methods used by the sciences and social sciences. Central to this approach are co-design tools and methods which can reveal hidden values and enable dialogue between diverse stakeholders.

Although analysis and theory building is ongoing, the case summary provides preliminary evidence for how the approach has already laid foundations of building mutual understanding, by:

- challenging or adding detail to the assumptions of the technology developers, for example in expanding upon the stakeholder ecosystem of 'the hospital' and revealing important additional care and coordination roles in pharmaceutical provision;
- revealing the values of the technology to stakeholders which were hidden from the scientific partners prior to the workshop, for example the importance of 'ease of use' to the specialist nurses in particular and the 'novelty' of trying a new product for patients;
- translating and facilitating, in the workshop preparation - for example, translating the codified technology into understandable narratives around pharmaceutical production, and during the workshop - and by facilitating mindset shifts from the micro frame of the clinical context to the macro context of the populous view.

This paper aimed to demonstrate how design researchers can resist the conventional roles for design in service of 'science communication', by facilitating emergent solutions, not simply providing them (Fisher & Gamman 2018:215; Aguirre et al 2017) and creating open-ended co-

designed interpretations of stakeholder experiences and values (Mattelmaaki, Brandt & Vaajakallio 2011) in relation to novel biotechnologies.

The early results show that stakeholder engagement in healthcare is often challenging, opportunistic and therefore imperfect. However, service designers perhaps more than other fields of research, employ exploratory, sensemaking, co-design methods which can be adapted to the changing situation as it evolves and as the research scenario unfolds.

The value of our approach for the project is not only that we can communicate these insights back to the scientific partners, but also that it provides us with possible mechanisms or narratives for challenging peoples' fears of the technology.

A shortcoming perhaps of this type of multi-disciplinary project is that there are limitations on design's role and the subsequent research design. Invited into the fold, we - the design researchers - are not leading the show, we are guests and must tread carefully along the path of expected design roles. This poses challenges for the service design approach, particularly in a project that is organised on a science and technology innovation premise, defined by scientific conventions. However, we can be the 'tricksters' (Fisher & Gamman 2019) working with the co-design tools and methods at our disposal to reveal hidden value and meaning both of the technologies and of design's role.

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EXPLORING THE INTEGRATION OF SOUND-BASED DESIGN INTERVENTIONS IN DEMENTIA CARE

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Abstract

For people with dementia, listening to everyday sounds can elicit recollections of positive valued life events or personal associations with loved ones. These responses to sound provide opportunities for individualized activities and social interactions between residents and their caretakers in dementia care homes. Therefore, designers are exploring how these beneficial effects of sound can be incorporated in everyday dementia care through the in-context deployment of sound-based design interventions. Yet, these interventions are often not compatible with existing care structures and tend to fail in being successfully integrated within everyday care practice. We present the results from a series of workshops where professional caretakers explored the integration of everyday sounds in long-term dementia care. The caretakers did not serve as spokespersons for the residents, but as stakeholders with their own view and opinion on providing everyday care for people in later stages of dementia. The caretakers first provided insight into a typical day in the care home by mapping

existing care activities or routines on a timeline. Next, the caretakers linked claims taken from previous research on the effects of sound in dementia to their personal experiences in the care home. Lastly, the caretakers were introduced to Vita: an interactive sound pillow, and asked to design specific scenarios for using the device within everyday care. The outcomes of the workshops reveal opportunities for integrating sound-based design interventions in existing care practice by: 1) providing rest during moments of unrest; 2) supporting playfulness and stimulation during 'in-between moments' of boredom in the care space; 3) easing moments of care for both the caregivers and residents; and 4) supporting social contact and relations. These outcomes motivate and inform future research on the in-context evaluation of sound-based design interventions in real-life care environments.

Keywords: care practice, dementia, participatory design, professional caretakers, sound-based design interventions



