Design 4 Health

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Proceedings of the 6th International Conference on Design4Health
Amsterdam 2020

Editors: Kirsty Christer, Claire Craig & Paul Chamberlain

Volume 3

Lab 4 Living

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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)
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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.

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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CONSTRUCTING A FRAMEWORK TO DESIGN WITH AND FOR EXCLUDED FACTORS IN MENTAL DISORDERS: A PROPOSAL FOR EATING DISORDERS ATTUNEMENT TO RECOVERY AND THE OTHER SELF

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Abstract

This paper is an extract from my Ph.D. candidacy proposal, which aims to develop a framework to explore and design for the multidimensionality of the experiences of people who struggle with mental disorders in their context, including their relational and material everyday life surroundings.

Considering that the aim of design research is 'to provide alternatives to deeply ingrained habits of thinking' (Koskinen et al. 2011, 47), this framework should aim at providing insights in the disorder's experience as it unfolds in context, inspiring the generation of newly distributed and material systems of care that seek to shift our perception of everyday lives practices which would shed new light on how mental disorders emerge. The research focuses on the field of Eating Disorders (EDs).

The paper starts with a review of the mental disorders discourse and EDs research. It describes the model used to analyse mental disorders and identifies the factors have been excluded from such analysis, which may prevent new understanding of disorders. Moreover, it provides a brief overview of design research, its affordances and the state of the arts on the topic of mental disorders, pointing out that a cohesive and critical standpoint of design in mental health is missing. The paper ends by describing the framework and how it applies in the context of EDs: by including factors excluded by the biomedical model and proposing new ways of looking at EDs, a networked and participatory systems of care for recovery attunement from EDs can be proposed.

Keywords: design in mental disorders, eating disorders, excluded factors, biopsychosocial model, actor-network theory, framework, recovery attunement, participatory approach

Mental Disorders and Eating Disorders: a brief review on models and exclusions

WHO defines mental disorders as a broad range of problems comprehending different symptoms which can be generalized in abnormal thoughts, emotions, behaviours or relationship with others (Saxena et al. 2014). Although the causes of mental disorders are still unknown (Graham 2013), they lie between a combination of individual, socio-cultural, environmental, and economic factors (Saxena et al. 2014). The main disciplines who historically took care of mental disorders are medicine, psychiatry, and psychology, which identify the mental disorder inside the individual or address it through therapeutic practices applied to the individual experiencing the disorders, and when possible, to close relationships.

The model used to conceptualize mental disorders is the biomedical one. The rationale behind that choice is that psychiatry still questions whether it is possible to apply the same model for the medicine of the tissue to the mind (Bracken et. al. 2012). Specifically, the biomedical model affords researchers in the field of mental disorders to operate by reducing factors to observe and by excluding all the factors that resist measurements (Garrett 1997) and that do not allow for high comparability amongst different experiences of mental disorders (Valentine et al. 2017). This reductionist approach provides incremental and detailed information on the efficacy of treatments but leaves behind a richer understanding of the multidimensionality of the patient's experience of the disorder, which fails to provide new points of views on the understanding of mental disorders. The biomedical model has been subsequently amended into the Biopsychosocial Model (BPSM) in order to include the social sphere of individuals and to allow a holistic understanding of mental disorders (George and Engel 1980).

However, how are the factors outside the individuals addressed in practice? By providing a brief review of EDs research advancements, the aim is to highlight that the understanding of mental disorders and the relative care approach depends on the epistemologies used to look at the disorders, which provide frameworks for including or excluding certain factors from the analysis.

EDs are considered coping or existential problems displaced in a complicated relationship with food (Bruch 1974). Such disorders are multifactorial: heterogeneous factors merge uniquely in different individuals so that it is impractical to generalize to others (Polivy and Herman 2002). However, general standardized treatments exist for EDs: some of these treatments exclude factors, some exclude bodies and experiences, and others exclude context. EDs treatments have a relative efficacy (Federici and Kaplan 2008) and for these reasons, Fassino and Abate-Daga (2013) describe them as disorders that signal a crisis in the reductive approach of the biomedical model in understanding mental disorders. What can we learn and, consequently, do about EDs if we embrace the various dimensionality and complexity of such disorders as it unfolds in context, by allowing design research to be part of the discourse, in ways of looking at the disorder and by proposing new ways of caring for the disorder?

Design research in the context of mental disorders: affordances, state of the art and gaps

Design research affords idiosyncratic interpretations, values subjectivity, and includes participation and context in the process of designing (Groeneveld et al. 2018). It embraces and makes sense of complexities and ambiguities, flirts with uncertainties, and aims to provoke change. Design research develops propositional theories (Zimmerman et al. 2010) and

describes alternatives to how reality is by challenging habits of thinking (Koskinen et al. 2011). Design intrinsic, imaginative skills can provoke superficial change or challenge the underlying assumptions of the issues tackled while making reality more malleable (Dunne and Raby 2013).

Although design research approaches are opposite to health research ones, design interventions embrace a wide range of health-related topics, such as improving the experiences of everyday life by product design or tackling experience, emotions, and mood (Hassenzhal et al. 2013; Desmet and Pohlmeyer 2015). Design focuses to purposefully steer behaviours by means of design function in topics related to wellbeing, e.g., improving eating habits (Niedderer et al. 2017). Design improves health care experience, too (Tsekleves and Cooper 2013).

In order to individuate the role that design takes in the context of mental disorders, it is useful to distinguish between design interventions for 'cognitively impairing' and 'functionally challenging' issues (Shepley and Pasha 2017). Dementia is an example of the former category. In that case, design interventions take the form of products that enhance personhood, developed by using codesign processes (Niedderer et al. 2020). My research, however, refers to the latter category, to which EDs belong. In this category, design interventions focus on improving the experience of therapy for people affected by psychosis (Nakarada-Kordich et al. 2017), bipolar disorder (Matthews et al. 2015), recovery from addictions (Champ 2018), and burnout (Visch et al. 2011).

This review shows the existence of scattered design frameworks that tackle singular mental disorders; however, a wholesome and cohesive design framework and standpoint for mental disorders are missing. The use of participatory design approach is one commonality among the design interventions mentioned above. The use of this approach shows an orientation towards the inclusion of patients' voices in the design of their healthcare experiences. Considering design research affordances, the current design interventions for mental disorders limit themselves in provoking change by materially translating current paradigms of mental health. Such interventions miss the chance to learn more about the conditions that produced the disorder and its experience and miss the opportunity to provide alternatives to ways of caring, preventing us to learn more about the way we conduct our everyday life.

One design intervention, mentioned in the field of Design for Behaviour Change (Niedderer et al. 2017), seeks to remind people in workplaces to take breaks in order to avoid burnouts. This intervention, however, does not allow us to know more about the phenomenon of burnout nor critically consider the context that produced the burnout or how people work. As Nöel (2017) states, there is a lack of understanding of what design can do for healthcare: design interventions for health should focus on rethinking how healthcare is implemented rather than aiming at superficial solutions.

A proposition: describing an unwieldy framework to design for EDs

The heterogeneous factors that play a role in the insurgence of EDs and their recovery are complex, networked, and embedded in everyday life. Polivy and Herman (2002) mention that a model that holds together such factors can become unwieldy, but Fassino and Abate-Daga (2013) invite complex models to look through this disorder. The critical psychologist Dreier (2008) claims that therapy gives clients agency to change and that happens in their everyday life settings rather than in 'a privileged nowhere of mental change' (Dreier 2008, 5). Dreier, thus, emphasizes the importance of contextualizing therapy. 'Extra-therapeutic factors' are a combination of individual, relational and

situational factors that contribute to a therapy's 40% success rate (Dreier 2008).

A 'sociological imagination' (as the capacity to see how social forces interact with individuals) (Mills 1959) is needed in mental health discourse, together with medical humanities, in order to provide new conceptual and systematic understandings of the disorder experience and its meaning (Kleinman 1988). In the same way, the design's imaginative skills might afford us to include the subjects' voices and their presence in the design process of a possible distributed and material system of care. The imaginative skills include elements as they assume importance through people's narration of their experiences while embracing their complexity and heterogeneity. Additionally, these imaginative skills afford us to look at the disorder as it unfolds in its context and, thereby, design for that social fabric, to make idiosyncratic and unexpected interpretations, and to tweak materiality in order to propose new practices of care. Finally, they afford us to show reality under a new light and to propose different ways of living, communicating, encountering and being together. By redistributing the responsibility and care of mental disorders in the design of our everyday lives, we might find out about ways to 'design away' (Tonkinwise 2013) the conditions by which the mental disorders appeared in the first place.

Actor-Network Theory (ANT) (Latour 2008) is a theoretical framework that can hold together such complexity and heterogeneity. ANT allows us to see the social fabric as a heterogeneous assemblage of actants, made of humans and non-humans (e.g., artefacts). Such networks have agencies. We can create new assemblages and their agencies by adding or removing elements in the networks.

ANT allows to describe ED as an assemblage with a disordered agency: it is a network of elements (individual, relational,

social, and contextual elements) in tension, which allows the ED's agency to emerge as a coping mechanism to mediate the everyday life. The ED, therefore, is not enclosed in a subject, since the subject is already a network of heterogeneous elements. By mapping how the agency is distributed (Storni 2015), we might dissolve the condition by which the ED is needed (the ED network): by designing new artefacts with a specific program of action and adding them to the network, we might be able to modulate the behaviour of the assemblage.

Tweaking the Eating Disorder network by design: a participatory, networked, contextual approach

A framework to design with and for people who experience EDs is missing. Design interventions that address eating habits are relatively relevant in this case since the disordered eating in EDs is the symptom of an existential, relational, and networked issue. Mental disorders are a response to an unsustainable system (Watzlawick et al. 1971). The ED assemblage is co-created: the heterogeneous factors, which constitute the assemblage, are in tension and have a different starting point from where they emerge, which is usually in a disordered eating actor. To allow other modalities of being to emerge (e.g., from disordered eating selves to recovered selves), we can rearticulate the agency of ED assemblages.

The design framework to look at and design for and with EDs new agency should incorporate the physical context in which the disorder unfolds (e.g., the home). With this framework, we can develop a system of care that acts on the outside of the individual too, as a temporary material aid that suggests new everyday life practices toward healing, including the relationships, the communication and the beliefs system that take place in the context observed, in the network analysis, and design interventions.

The design framework should furthermore include recovery as a process (Lester 2019). Qualitative studies show the necessity of tackling the underlying issues of an ED in the process of treatments rather than focusing only on symptoms reduction (Bardone-Cone et al. 2018). The authors describe how the interviewees cannot imagine themselves as recovered. It is of extreme importance to infuse a strong attitude to change and to inspire to develop an identity- the other self - outside EDs (Lester 2019). Furthermore, incorporating patients' needs and recovery stories from former patients in the framework can improve the understanding of the disorder. (Garrett 1997)

Cedar Grove, a Centre specialized on treatments of EDs (Lester 2019), has implemented best practices in which every action is 'imbued with therapeutic potential' (Lester 2019, 139). Those practices suggest various non-linear approaches: developing new forms of eating control, which would outgrow the disordered control, and shows its fallacies to the patients; developing a holding environment (Winnicott 2009) and techniques to hold and process emotions; addressing boundaries and communication.

Scattered frameworks of various design disciplines target issues such as managing control, enhancing moods, regulating emotions, and supporting therapeutic communication. Such approaches can construct the framework to design for EDs.

In my prospective research design, I plan to adopt a participatory design approach, guided autoethnography, and probes. This methodology will respect the sensitivity of working with patients who currently experience and have experienced EDs while mapping how the EDs network articulates in context. Additionally, I will organize workshops with former EDs patients in which we will co-design tools that enable new practices aiming at eliminating the required conditions of EDs.

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DESIGNING A CULTURALLY APPROPRIATE KANGAROO CARE BABY CARRIER, 'SANGAM' USING HUMAN-CENTERED DESIGN AND BEHAVIOURAL SCIENCE

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Abstract

15-20% of all births worldwide (>20 million births/year) are low birth weight (<2500g), with a great majority of them reported in lower-middle income countries. Every year, the State of Uttar Pradesh (UP India loses ~254466 newborns due to preventable causes. However, Kangaroo Mother Care (KMC) defined as early, continuous, and prolonged skin-to-skin contact between the mother and baby (≥20 hours/day) and exclusive breastfeeding, has the potential to save a quarter of deaths, both globally and in UP.

Despite its advantages, the global uptake of KMC is only 1%. Several studies have shown the improvement in adherence to KMC led by a baby carrier. However, lack of deep understanding of the mother's needs, challenges, social norms, etc. may be a few reasons for its low uptake in UP

Therefore, the objective of this study was to develop a socio-culturally appropriate KMC baby carrier that promotes continuous KMC (≥20 hours/day) for caregivers in UP.

The study adopted the Human-Centered Design methodology (Understand, Define, Iterate, Prototype, and Test) to co-design with mothers and health providers in Lucknow and Raebareli districts of UP.

Guided by four key principles (safety, mobility, comfort and convenience) and several iterations, 'Sangam, the Kangaroo Care Blouse' was born and pilot tested with n=8 mothers, who found Sangam to be socio-culturally appropriate (easily worn with the traditional garment), intuitive, user-friendly, safe for their newborns and comfortable for both of them. It facilitated breastfeeding and ambulatory KMC (mean duration = 13 hours) while performing routine activities in hospital and domestic duties both inside and outside their home.

Hence, this socio-culturally appropriate KMC baby carrier, Sangam, can help increase the adherence to continuous KMC and be a potent tool in newborn survival in UP and similar States of India.

Keywords: kangaroo mother care, newborn care, human-centered design, baby carrier, behaviour science

Introduction

Low birth weight (LBW), defined as weight at birth of less than 2500 g, irrespective of gestational age, has an adverse effect on child survival and development, and a potential risk factor for adult disease (Barker 1995). Overall, it is estimated that 15-20% of all births worldwide representing more than 20 million births a year, involve LBW, the majority of them reported in lower-middle income countries (LMICs) (WHO 2014). An estimated 4 million infants die globally during their first 4 weeks of life (neonatal period) (Lancet 2005). The largest State of India, Uttar Pradesh (UP), loses ~254466 newborns every year due to preventable causes (Census 2011). As the global epicenter of newborn and maternal deaths, this state has extremely compromised human development indicators.

Health technologies such as incubators can help improve outcomes in high-risk infants; however, such equipment is not widely available in LMICs, where 99% of all neonatal deaths occur. Hence, effective and low-cost alternative methods of neonatal care are much needed in such low resource settings (Nyqvist 2010).

An easy and convenient method of providing neonatal care has been previously devised and termed as Kangaroo Mother Care (KMC). KMC is defined as early, continuous, and prolonged skin-to-skin contact between the mother and baby (≥20 hours/day) until the latter's weight reaches >2500g or more, and exclusive breastfeeding. The KMC manoeuver involves placing the infant upright between the mother's breasts, chest to chest (Kangaroo Position), similar to how a Kangaroo places its young one in its body pouch (WHO 2003). This technique has the potential to save ~450,000 of 1 million preterm babies who die each year globally and ~50,000 newborns in UP alone. Also, based on a meta-analysis of 21 randomized controlled trials, KMC was found to be significantly better than incubator care for affected infants. The KMC infants had 40% higher survival, 40% lower risk of severe illness, 72% lower risk of hypothermia (extreme low body temperature), 40% lower repeat hospitalization and 20% higher rate of exclusive breastfeeding (Conde 2016). Other benefits of KMC include improved neonatal outcomes, improved physiological and neurological development, promotion of milk let-down and thus good nourishment, promotion of mental and emotional development, fostering attachment between the mother/KMC provider and the infant, and so on (Nyqvist 2010).

Despite its advantages, the global uptake of KMC is only 1%. Several systematic reviews have explored the enablers and barriers of KMC, with some of the reported barriers being low motivation among mothers, lack of information about KMC and its benefits, shortage of time due to domestic duties, pain/fatigue due to prolonged duration of KMC, to name a few (Chan et al. 2016, Smith et al.2017, Seidman et al. 2015).

Several studies have shown that a baby carrier or binder can lead to improvement in adherence to continuous KMC (Jain & Sarkar, 2000; Amaliya et al. 2017; Thapa et al. 2018; Mazumder et al. 2018; Chavula et al. 2020). However, lack of deep understanding of the mother's needs and challenges, and social norms, may be a few reasons for its low uptake in UP

This study, therefore, focuses on the development of a socio-culturally appropriate KMC baby carrier facilitating adequate, continuous KMC (≥20 hours/day) by caregivers in UP by adhering to the social norms.

Methodology

Participants

a) Sensing Phase (Understand and Reframe): N=29 mothers of LBW infants admitted in the KMC Lounges of n=5 public health facilities (n=2 district hospitals - DH and n=3 community health centers - CHC) were included in this phase. From these facilities, nurses of KMC Lounge and Sick Newborn Care Unit (SNCU), doctors, Agrimaa (respectful care champions), bua (support staff involved in birth-related activities) and Accredited Social Health Activists (ASHAs, community level health workers, for home visits and referral for reproductive and child health services) were also selected. In addition, mothers and family members of n=2 households of Raebareli district, UP were included in this phase.

b) Design and Testing Phase (Iterate, Prototype and Test): N=15 mothers of LBW infants admitted in the KMC Lounge of a public health facility of Lucknow and 6 mothers from Raebareli district, UP were selected for this phase.

Study Design
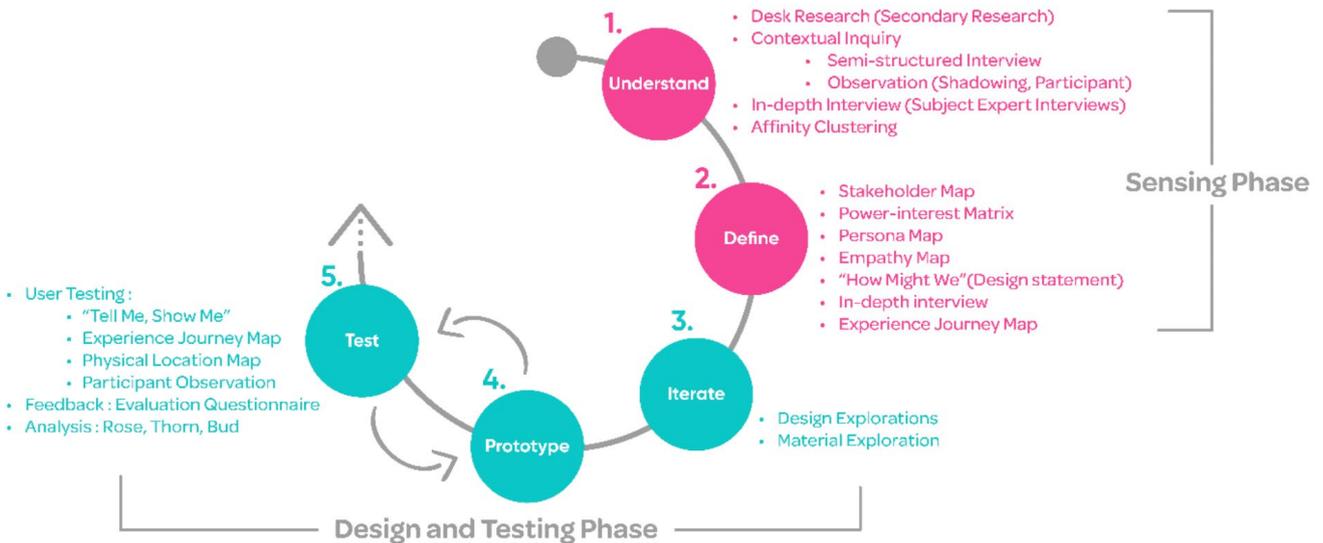
Figure 1: Design Process

The study adopted a Human-Centered Design (HCD) methodology involving an iterative process to develop a socio-culturally appropriate solution for increasing adherence to KMC in hospital and home. The components of the HCD model devised were Understand, Define, Iterate, Prototype and Test.

The study was divided into two main phases:

a) **Sensing Phase (Understand and Define)**: Findings from the Formative Research conducted by Community Empowerment were used in this phase for Contextual inquiry (semi-structure interview guide) and Observation (participant and shadowing) with different stakeholders. Data was categorized using Affinity Clustering tool that led to key insights, which were synthesized using Empathy Map and Stakeholder Map. This led to the following problem statement:

How might we make KMC a part of a mother's daily routine?

In-depth interviews (semi-structured) with different stakeholders and Experience

Journey map (n=1 mother for six hours) were conducted to build a deeper understanding of their needs, challenges, and existing behavioral and cognitive biases. Additionally, mapping of existing baby carriers for newborns and KMC baby carriers, along with their features was done.

b) **Design and Testing Phase (Iterate, Prototype and Test):** The above insights helped develop iterations that were transformed into mock-ups and further refined into working prototypes.
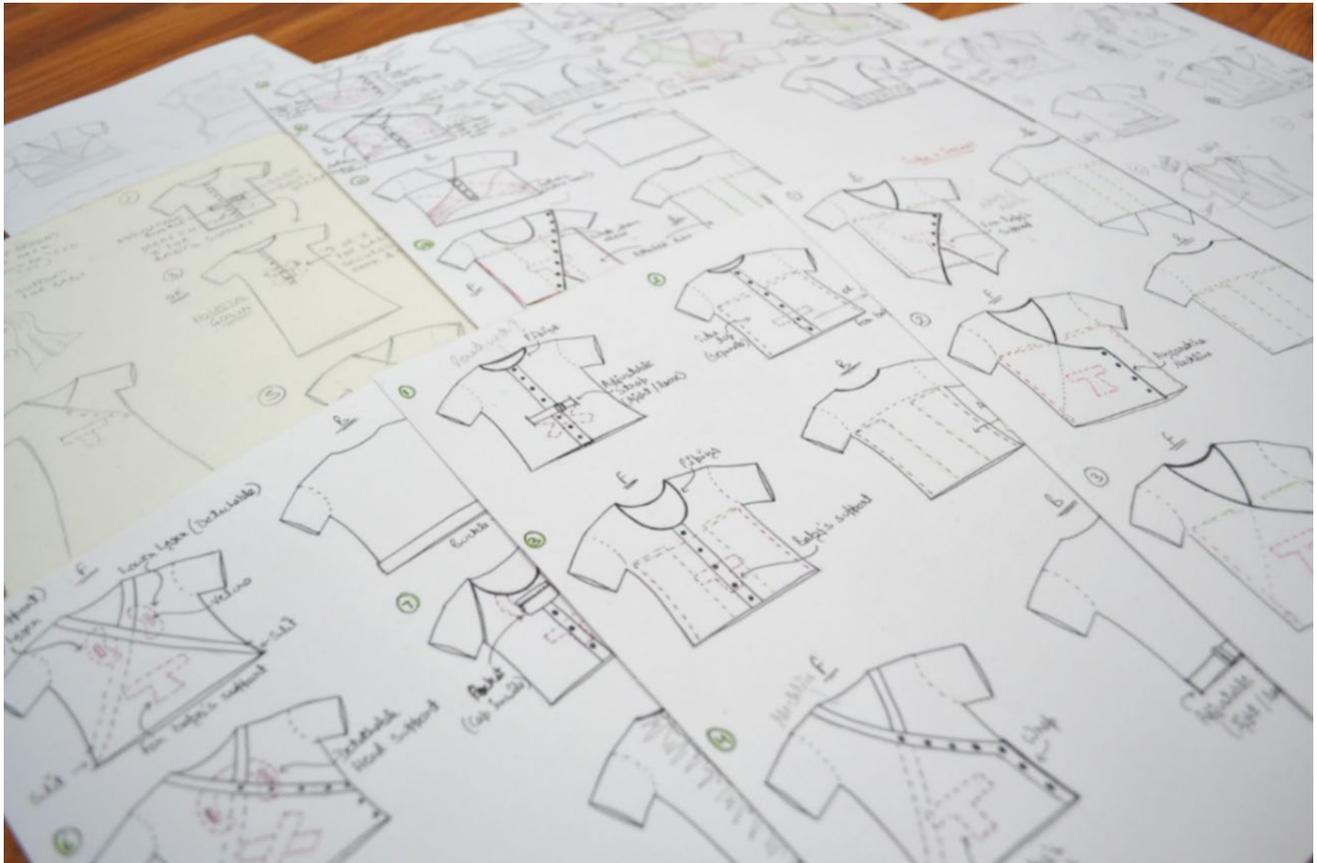
Figure 2: Iterations (Flat sketches)

All the iterations were guided by the following 4 key principles, in addition to its socio-cultural appropriateness:

- Safety: Is it safe for the newborn?

- Mobility: Is the KMC Provider 'hands-free'? What activities are they able to do wearing the product?

- Comfort: How comfortable is it for the mother and infant?

- Convenience: Is it user-friendly, intuitive (easy to use - understand and use design immediately), and autonomous (especially when putting the infant in and out)?

A total of n=11 prototypes (including mock-ups and revised prototypes) were developed and tested with n=7 mothers at a public health facility in Lucknow and n=6 mothers at their home across villages in Raebareli district, UP Preliminary observations from *'Tell me, show me'* session were documented for each prototype after which the mothers they were given to the mothers for 24 hours each. Feedback was obtained using an Evaluation Questionnaire guided by the four key principles (safety, mobility, comfort and convenience), whose data was analyzed using the *Rose, Thorn, Bud* method.

The final product, named *'Sangam'* was piloted with n=8 mothers admitted in the KMC Lounge of a Public health facility in Lucknow, where the mothers were encouraged to use the product during their hospital stay. Data was collected over 3 days, using an *Experience Journey Map and Physical Location Map* (adapted from LUMA Institute's Experience Diagramming), and photos/videos. Feedback was collected everyday by the researcher using an Evaluation Questionnaire. Participant observation by giving KMC to an infant in Sangam was also conducted by the researcher, which enabled the researcher to gain a deeper understanding of a mother's experience, challenges in Sangam, etc.

Findings

There are various designs of KMC baby carriers available within India as per the cultural appropriateness in respective regions. Since *saree (a long piece of fabric draped around the body, which is worn along with a blouse)* is the most widely worn Indian traditional garment by the women in rural UP and none of the other existing KMC baby carrier designs available in India seemed to suit their needs, inspiration was drawn from a t-shirt/shirt to substitute the saree blouse to make the product more socio-culturally appropriate for these mothers, and reduce the likelihood of any social hesitation (preservation of women's modesty) which they may experience otherwise.

Figure 3: Evolution of designs from mock-ups to working prototypes for final selection

After several iterations with four designs (Figure 3), *Design #01* was selected by the mothers based on the mothers' preferences as per indicators within the four principles of safety, mobility, comfort and convenience. This product was **named Sangam, the Kangaroo Care Blouse** (*'Sangam'* means 'a sacred union' in Hindi).

Figure 4: Final design selected by mothers and named *'Sangam'*

1. Design Features

- Its blouse-like design makes it very intuitive. When covered by the *pallu (long hanging end of the saree)*, it virtually eliminates social hesitation which is crucial for adoption by users.

- It has a pouch attached on the inside for the infant to sit safely, with adjustable belt ties which accommodate infants of all sizes.

- The pouch has a detachable and reusable diaper insert for families unable to afford market diapers. It's made out of a highly absorbent local fabric called 'suti gamcha' (100% cotton) and terrycloth towel.

- The broad waist band made of woven cotton and thick foam padding allows equal weight distribution and prevents backache. Its adjustable belt tie provides additional support for the infant and flexibility of fit for the mother.

- The front panel allows ease in putting on the infant and also breastfeeding in Sangam itself.

- Simple fastenings that the rural community of U.P is familiar with have been used, such as zippers, buttons and belt ties. These fastenings have been carefully placed to avoid harming the infant in any way.

2. Fabric

Blended cotton Jersey knitted fabric, woven cotton fabric and blended cotton mesh have been strategically used across the product:

- Jersey knitted fabric for areas where elasticity and snug fit is needed.

- Woven cotton fabric where for some stiffness and support is needed (e.g. front panel for baby's back support).

- Blended cotton mesh used around the V-neckline to provide adequate head support and nose airway for the infant.

3. Colors and Patterns

The colors for Sangam were selected by mothers based on what complemented with their sarees. Additional suggestions on prints/patterns were also made - Motifs of objects used to ward away bad omen (cactus, fire, knife, etc) or prints depicting their aspirations for their infant.

4. Size

In addition, in order to better adapt the KMC carrier to the various body types of rural women in UP, a customized Size Chart was developed which led to 6 garment sizes in which Sangam was stitched for the pilot test.

Table 1: Customized Size Chart for rural population (women) of UP

Size	Measurement	Level of Flexibility
Extra Small (XS)	30.5"	29" to 31"
Small (S)	32.5"	31" to 33"
Medium (M)	34.5"	33" to 35"
Large (L)	36.5"	35" to 47"
Extra Large (XL)	38.5"	37" to 39"
Extra Extra Large (XXL)	40.5"	39" to 41"

5. Customization

Sangam also has a scope of customization in other regions of India where saree is not the traditional garment (for eg. convert it into a *kameez/kurta i.e. a long tunic worn over a salwar i.e. traditional loose pants,* by increasing its length) or can be further refined for male caregivers.

Sangam was pilot tested with n=8 mother who found its design to be intuitive, user-friendly, safe for their newborns and comfortable for them as well as the newborn. It facilitated breastfeeding and ambulatory KMC (mean duration = 13 hours) while performing routine activities in the hospital such as personal care, spending time and having meals with family, playing board games, strolling outside the KMC Lounge, etc. At home, they were able to perform most of their domestic duties both outside and inside the house (such as mopping/sweeping, washing utensils, feeding cattle, etc.) while giving KMC to their newborns in Sangam.

Figure 5: Mothers practicing ambulatory KMC while performing routine activities at hospital and home

Sangam was also introduced in the implementation study, Kangaroo Care Project, conducted by Community Empowerment Lab across Lucknow and Raebareli district of UP. As part of the study, Sangam was also used by the caregivers, whose results on adherence for continuous KMC are awaited.

Limitations of Sangam include its production and cost. However, these can be overcome by involving SHGs (Self-help group) for manufacturing and using locally available alternative raw materials. Mass production of Sangam would reduce its cost to as low as ~400-500 INR (~5.23-6.53 USD) or less. This cost can be incurred by the government by selling it at subsidized rates or renting it out to mothers through ASHA workers. Additionally, donations, sale and/or advocacy by multinational companies (as part of Corporate Social Responsibility activities), development agencies and medical companies working on newborn health, and private hospitals/practitioners may be done.

Conclusion

Sangam's socio-cultural appropriate design guided by the four key principles of safety, mobility, comfort and convenience, has enabled mothers in rural UP to wear it as part of their routine traditional garment (*saree*), and provide continuous KMC to their LBW newborns at the hospital and home alike. Hence, this KMC baby carrier, *Sangam*, can help increase the adherence to continuous KMC and in turn be a potent tool for newborn survival, not only in UP but across India.

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OPEN-ENDED DATA PROBING TO INFORM THE FUTURE OF HOME HEALTH CARE

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Abstract

Chronic heart failure (CHF) is a complex disease with a high mortality rate, affecting millions of patients worldwide (Savarese and Lund, 2017). In many countries, healthcare systems are already under stress and with the ageing population the number of CHF patients is expected to increase even further. Remote patient monitoring has already been shown to decrease length and frequency of hospitalization in patients with heart failure, as well as mortality (Hindricks et al. 2014). Thus far, the monitored data has been primarily clinical, while heart failure patients also struggle with personal and emotional challenges and with changing relevant aspects of their lifestyle. As each CHF patient copes in their own way and context, effective data collection requires high degrees of personalisation and versatility.
In this research, we focus on collecting and curating non-clinical data that qualitatively describe patient lifestyle changes and psychological condition. We investigate forms of complementary use with clinical data sets and outline the benefits of personalised care through remote monitoring techniques in the home environment. To gain a nuanced understanding of how individuals track personal health data in an everyday context, we are developing a methodology for open-ended data tracking.

Through iteratively designing probes, we are creating a system that will allow patients to assign which data they want to monitor and share with their health care professionals, based on best practices in data tracking. Results of our preliminary field deployment show that the data collection activities provoke the reflection of participants and further encourage them to envision the better cases, as they were more aware of their needs. The positive findings warrant our next phases of expedition with more participants.

Keywords: human centred design, participatory research, design approaches, rehabilitation

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IMPLEMENTATION AND INVOLVEMENT OF A DYNAMIC INSTRUMENT AS A PRACTICE SUPPORT IN REHABILITATION PROCESSES OF CHRONIC DISEASES

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Abstract

In the rehabilitation of chronic and severe illnesses, it is common to use paper-based questionnaires to capture experiences of symptoms associated with illness or treatment. Managing such instruments consumes time, and offers care professionals a narrow space of possible actions toward the patients. The purpose of this paper was to report the initial concerns we encountered in the early phases involving a dynamic instrument in nursing practice. This project is based on the Self Management Assessment Scale (SMASc) with the purpose to provide digital support that enables personalized work methods with the patient. With SMASc, patients answer questions on a mobile phone, tablet or computer. The compiled result is provided instantly before the patient-nurse consultation. SMASc is here understood as an interactive artefact with dynamic affordances. A dynamic instrument manifests a theoretical foundation aligning to the use situation, is programmable and digitally distributed, and offers individually compiled datafied views that connect the person's situation and the theoretical apparatus - in this case, a person's need for self-management support. The data this report builds on was produced during two project meetings and throughout the design and development of the instrument prototype. Data analysis approach applied was an analysis focusing on emerging concerns surfacing from discussions that followed the introduction of the prototype. We found that the nurses cared for the development of their practice and strived to advance and steer it in a more nursing-oriented direction. They did not fully comply with the instrument's item formulations and how these should or could be used. Further work has to be done to involve more stakeholders in the future work so that everyone feels engaged and can put their views on the design of the instrument, and on the implementation work itself.

Keywords: caring, co-design, dynamic instruments, implementation, nursing, ownership, rehabilitation, trust.

Introduction

This paper focus on the initial concerns encountered during the early phases of the design and implementation of a dynamic instrument. In the rehabilitation of severe and chronic illnesses - such as diabetes, heart failure and cancer - it is common to ask patients about their symptoms associated with the illness or treatment via paper-based questionnaires. However, managing such instruments is known to be time consuming, and offers care professionals a narrow space of possible actions toward the patients.

Rozendo et al. (2017) define nursing as a transformative practice; nurses care for other people's situation and intervene in the world caring for people's needs with an aim to improve their health. Nurses manage and cultivate transformation in their workaday, thus dealing with patients whose health situation demands reflexive stance and approach. Nursing is also subject to transformation and change. Healthcare practice is already technologically intensive from decades of computerization (Aanestad et al. 2017). Digitalization transforms healthcare practice and adds dimensions of complexity that challenge the organization and the workaday (Greenhalgh et al. 2017; Fitzpatrick and Ellingsen 2013). No technology is however introduced in a vacuum. Within the current ongoing wave of digitalisation in healthcare, nurses are given new opportunities following the introduction of new digital platforms following a person-centered logic (Grisot et al. 2020). These platforms offer new ways in which healthcare professionals and patients can interact digitally and physically. During the Covid-19 pandemic, digitally mediated interactions have offered safer options for interaction. Besides being a resource during extreme times, digiphysical practices also have a potential to pave paths towards person-centered care practices (Ekman 2018).

This project is based on the Self Management Assessment Scale (SMASc) (Öberg et al. 2019) with the purpose to provide digital support that enables the development of personalized work methods. It takes a person-centered perspective (Håkansson Eklund et al. 2019) and puts the patient's self-care ability in focus. The instrument captures five knowledge dimensions combining domains from self-management; the person's knowledge of the illness, perceived social support, everyday routines, future plans and well-being. With SMASc, patients answer questions on a mobile phone, tablet or computer and the compiled result is provided instantly before the patient-nurse consultation.

Figure 1. Digital prototype 1.0, Self-Management Assessment Scale (SMASc).

SMASc is here understood as an interactive artefact (cf. Janlert and Stolterman, 2017) that have dynamic affordances. A dynamic instrument manifests a theoretical foundation aligning to the situation. It is programmable and digitally distributed, and offers individually compiled datafied views that connect the person's situation and the theoretical apparatus, which in this case is a person's need for self-management support. These affordances together provide means for both the nurse and the patient to facilitate interaction in both physical and digital contexts. We aim to explore the design and implementation of this instrument through the research question: How to involve and implement the affordances of digital instruments as a part of the rehabilitation process of chronic diseases? The purpose of this paper is to report initial concerns we encountered in early phases involving a dynamic instrument in nursing practice that will guide the coming design of the new work routine.

Method

The point of departure of this study was an invitation to present a digital prototype of the SMASc instrument. The instrument served as a probe (Sanders & Stappers 2014) intending to facilitate a discussion about the current state affairs at the health care clinic, and from the nurses' first encounter with the digital instrument understand what they see as matters of concern (Latour 2004) to guide the design process forward.
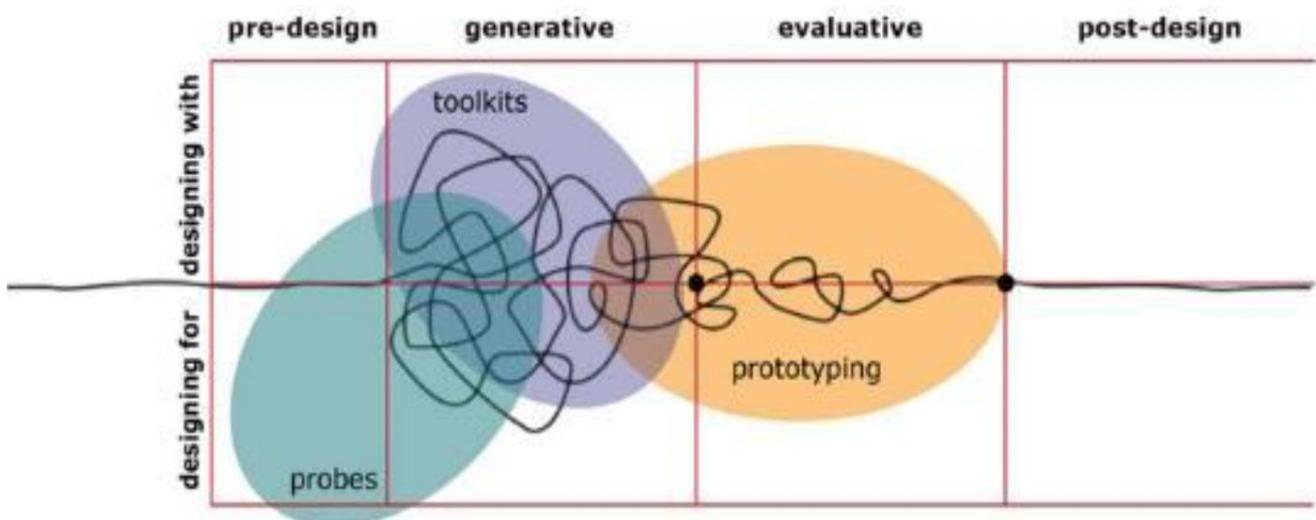
Figure 2. Sanders and Stappers (2014) revised CO-design framework

The introduction of the prototype initiated a co-design process (Sanders & Stappers 2014), which is expressed through the structure found in the Quality Implementation Framework (QIF) (Meyers et al. 2012). We use this process model to support and guide the implementation process, but also to provide a bridge between the disciplinary fields combined in the study translating research into practice (Nilsen 2015). The QIF provides practical guidance in both planning and execution of implementation and provides strategies to facilitate the implementation with a structure to address barriers and enablers for translating research-based interventions into clinical practice. QIF consists of four phases and fourteen critical steps. In this paper, the focus is primarily on phases 1 and 2. For an overview, see Figure 3.
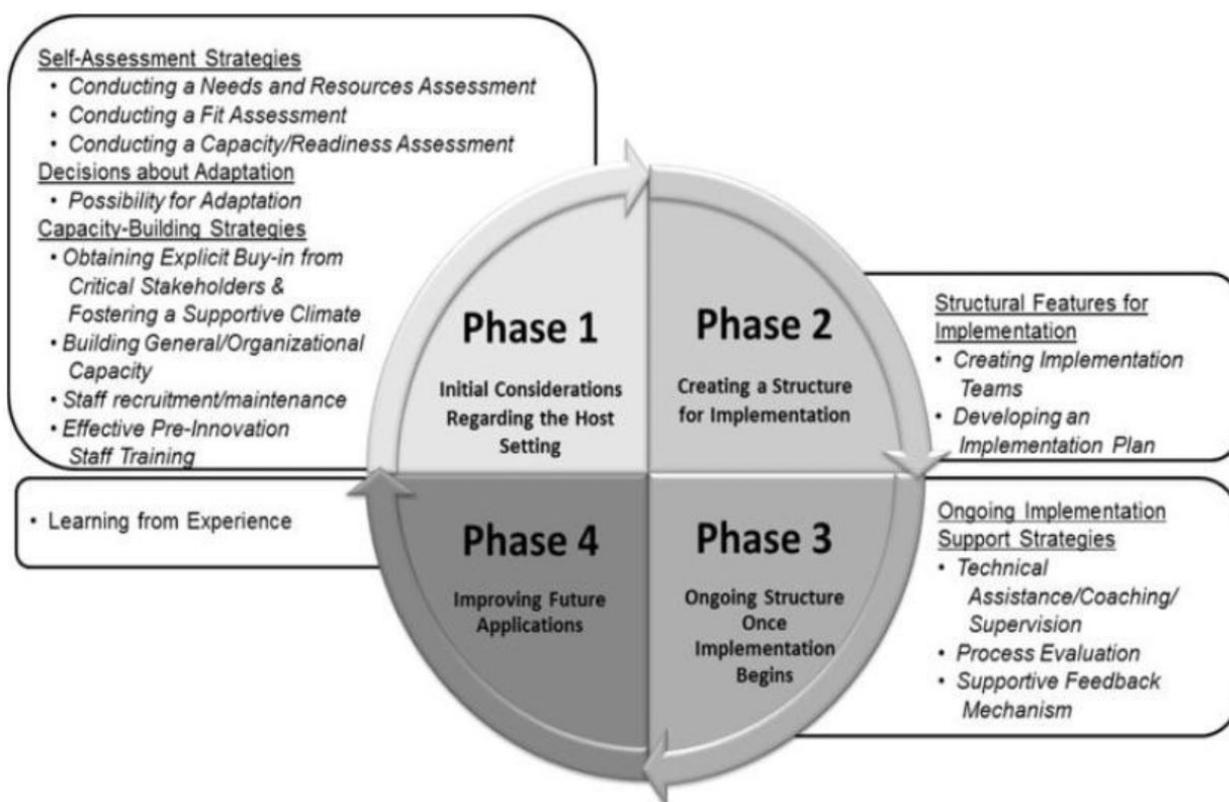
Figure 3. Overview of the application of QIF (Meyers et al. 2012).

The data this report builds on was produced during two project meetings and throughout the design and development of the instrument prototype. Persons participating in these meetings were the head manager and three nurses. The nurses worked at three different wards (diabetes, cardiovascular disease and rheumatology) within the same health care clinic. The first author was on site for both meetings. In the second meeting, the second author participated via a Kubi Robot setup. The data analysis approach applied was an analysis focusing on emerging concerns surfacing from the discussion that followed the introduction of the prototype. Design choices taken until this point were decided by the researchers. The participating nurses gave informed consent regarding audio-recording the meetings and using the material in this paper.

Involving dynamic instruments in nursing practice

Phase 1: initial considerations regarding the host setting

During the first phase, the setting was considered regarding assessment, possibilities for adaptation and capacity building strategies (cf. Meyers et al. 2012). The initial meeting between the collaborating partners resulted in identifying and considering concerns (Latour 2004; Andersen et al. 2014) that need attention in the implementation of SMASc.

The first meeting
The first meeting was initiated by the head manager at the health care clinic against the background that the nurses at the health care clinic had been using other questionnaires in their work that they were not totally satisfied with. Additionally, the questionnaires was experienced having a medical focus instead of nursing focus, experienced as hindering their intention to work with a nursing perspective.
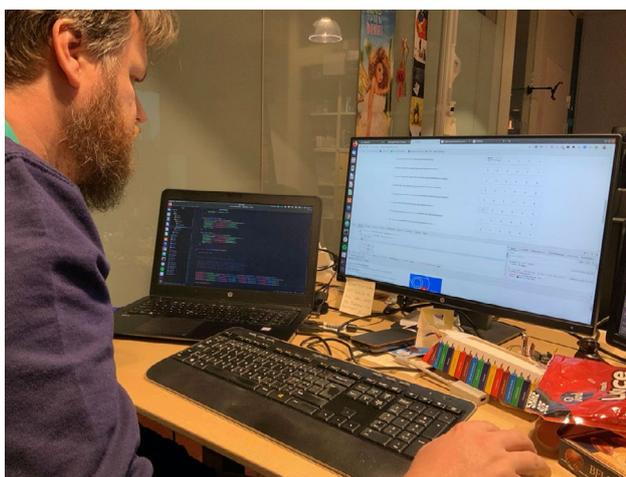
Figure 4. Design and coding of prototype

A prototype was developed before the first meeting based on ten questions in SMASc (Öberg et al. 2019). During this first meeting, the first author, the head manager and three nurses at the health care clinic participated. The instrument was introduced, which initiated discussions and reflections about how the dynamic instrument could support the change activity the nurses at the health care clinic had already initiated. When studying the items, one nurse expressed:

> 'If we were to use this instrument in our work with our patients, it would mean a paradigm shift for us…'.

The presentation of the prototype opened up a discussion regarding the nurses' way of working and the possibilities of changing this towards a more person-centred work. In addition, the nurses also raised curious and critical reflections on the design of the instrument and how it could be introduced in the workday with patients. One concern that surfaced came out of their experience with other instruments the nurses used or had used before. They could see that the rationale of the SMASc differed since it provided them with other possibilities to act and use in the meeting with the patient. It was clear that the instrument could complement those instruments already used, but with a possibility to advance their work practice. Another concern was directed towards how to deal with the

results that the SMASc provided. The spectrum of the knowledge domains making up the instrument raised concerns regarding which profession would be most suitable to care for the patient depending on the results of the instrument.

> '…If the answer is red all over- what does that really mean? Is it me the patient supposed to meet, it might be better if the patient is taken care of by either the doctor or someone more fit to meet the needs of the patient…'

It became visible that the nurses aimed to bridge an existing gap in their practice. The nurses expressed that in everyday work their role primarily focused on the medical concerns of their patients' needs, forcing them to downplay their nursing role to provide self-management support and health promotion for their patients.

The second meeting

Before the second meeting, the activity got project approval by the management. The prototype was redesigned; ten questions were added. Five of these were added to enhance validity, and the other five questions were aimed to give the patient a possibility to emphasise a certain domain of importance. The second meeting focused primarily on the instruments design, content, and appropriateness of the included questions.

Figure 5. Meeting going through the questions asked in the instrument

This meeting took the character of fit assessment, where questions like to what extent the dynamic instrument is to consider the feasibility and accord with needs, values and priorities in the health care clinic. In this step, it was clear that cultural beliefs and preferences played a central role. This can be viewed as both possible facilitating as well as a possible constraining factor for implementing the instrument. When discussing the instrument, some questions were raised about the design and content of the questions, as well as suggestions for further additions to the questionnaire.

> '...is this question, one I would understand myself? Are there any possibilities that I can add questions on my own?'

Concerns surfaced that the instrument needed to be contextualised as they wanted to have examples or personalise the items. There was an evident concern in making these questions their own. More importantly, the nurses' concern was: will the patients understand these items? We are currently working on this in two directions, partly by planning for further discussions about the content of the instrument and the meaning of the questions together with developers of the instrument, and by looking at possibilities for adaptation and revision of the instrument based on nurses' perceptions. One more practical note is that the distribution of the instrument to the patient is a bit problematic in terms of making it easy for the patients to access and answer the instrument. At the meeting, a possible solution raised was to give the patient the possibility to answer the instrument when in the waiting room on an iPad. In the light of the current pandemic, the routine for distributing the SMASc to patients is an option in need of development and re-evaluation.

Phase 2: creating a structure for implementation

In phase two, the structure is planned, which includes the outline of the implementation team and developing an implementation plan (cf. Meyers et al. 2012). One concern focused on the possible cultural differences between professions (i.e. nurses and physicians) in the workplace. The nurses expressed a fear that the physicians might not have the same positive attitude to involve SMASc in the interaction with the patients, which could influence the implementation in a negative direction.
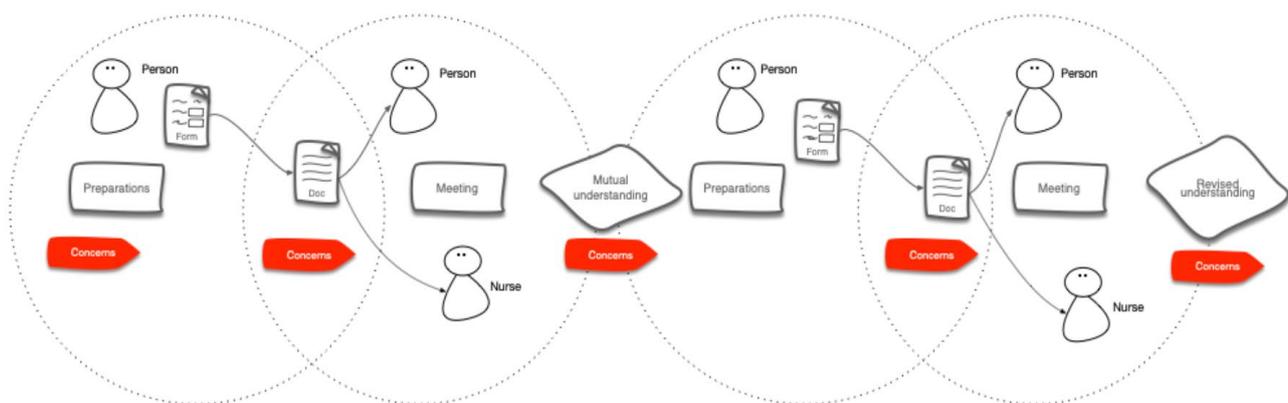
Figure 6. The discussed process model illustrated.

It here becomes apparent that a facilitating concern for the implementation lies in the fact that the nurses initiated the activity of using SMASc as a tool to redirect their practice. These two concerns, and the dynamics involved, will require a certain amount of sensitivity from all parties involved in the following steps in the development of the activity (see figure 6).

Concluding remarks

In this study, we identified concerns raised by the nurses in the early phases when implementing and involving a dynamic instrument as a practices support for nursing practice. Some concerns were raised by the nurses throughout the discussion over the digital prototype, concerns belonging to the nurses' knowledge and experience of caring, trust and ownership.

On the note on caring - in the nurses' care for the development of their practice and strive to advance and steer it in a more nursing-oriented direction, the use of SMASc could harmonise towards that goal.

On the note on trust - the nurses did not fully comply with the instrument's item formulations and how these should or could be used. Thus, we aim to create activities and opportunities to support the nurses' confidence and trust in the instrument, both regarding the instrument itself (i.e. structure and items) as well as in the use of the instrument with their patients.

On the note on ownership- it was clear that the nurses were actively working to maintain their ownership of the change activity. Onwards, more stakeholders need to be involved, i.e. patients, other professions and leaders. It is important that the nurses are given support to maintain their ownership; at the same time as, other stakeholders feel shared ownership. Their engagement and their views on the design of the instrument, and on the implementation process itself will be crucial.

The coming steps of this work will continue to explore the design and role of the dynamic instrument in the rehabilitation processes as a support for care professionals and their work giving patients person-centred care. Furthermore, it is of importance to investigate, not only the instrument's effect on self-management but also the outcome of the implementation process.

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DESIGNING VIRTUAL REALITY EXPERIENCE TO ENHANCE EMPATHIC CONNECTIONS BETWEEN PHYSICIANS AND PEOPLE LIVING WITH DEMENTIA AND THEIR AT HOME CAREGIVERS

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Abstract

Despite the evidence that expressions of empathy by healthcare practitioners appear to have a positive impact on patient pain, anxiety, satisfaction, and healthcare outcomes, significant variability of the expression of empathy among healthcare practitioners is prevalent. People living with dementia present multiple challenges for physicians due to complex medical, behavioural and psychological care needs. Designing innovative interventions to support the development of clinical empathy among healthcare practitioners has the potential to increase quality of care and positive health outcomes for both people living with dementia and their (at home) caregivers. Virtual Reality (VR) provides a unique medium for designing scenarios that enable a participant to step into the perspective of another. Perspective taking in VR has been shown to reduce negative stereotyping and increase empathy.

The project (VR Experience of Dementia) and design methodologies presented here are the foundation of an ongoing two-year study between collaborative practitioners in Design, Theatre, Social Work and Medicine. Using arts-based enactment methods within VR, physicians are immersed in the role of the person with dementia enabling them to experience 'a year in the life' of that person and their caregiver. The immersive scenario highlights the effects of short-term memory loss, as well as time and place disorientation. A discussion group activity, designed as a social support system for enhancing the understanding and development of empathic connections concludes the experience.

The presentation describes the process of designing and developing a scenario and bringing it to life in a VR environment, including designing for the unique affordances of VR. The development of the social work led discussion is described. Initial analysis of data, quantitatively analysed from pre/post surveys and thematically analysed through discussion transcripts, is discussed.

Keywords: dementia, virtual reality, perspective taking, empathy, immersion, enactment

EXPLORING THE SERVICE SYSTEM PERSPECTIVE ON DESIGNING INTELLIGENT HEALTH ECOSYSTEMS: THE CO-RESPONSIBILITY STUDY

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Abstract

Data-enabled design is an approach used when designing for intelligent ecosystems. It makes use of open-ended design probes situated in participants' everyday life. These probes are employed both to gain contextual, behavioural and experiential insights and to remotely conceptualize and deploy new design interventions. While the user-experience oriented perspective and the experimental, prototype-centric perspective on designing for intelligent ecosystems through a data-enabled design approach have been extensively described in previous literature, an examination of a service-system perspective is missing to date. In the present contribution, the latter perspective is explored through the lenses of a first-of-a-kind case study. The study was directed towards the development of an intelligent ecosystem for post-operative bariatric care, fuelled by clinical, behavioural, experiential and contextual data, able to provide tailored and personalized care and connecting patients, partners, and health professionals. Practical challenges and opportunities related to the adoption of a service-system perspective within the study were identified and connected to a reflection on the role of service design in contemporary eHealth innovation.

Keywords: service design, data-enabled design, intelligent health ecosystem

Introduction

Data-enabled design (DED) is an explorative and situated design approach in which both objective and subjective data, remotely collected from the users' everyday context, is used to design for intelligent ecosystems of products, services and people. Previous case studies showcase applications of this design approach in the health domain (van Kollenburg et al., 2018; Bogers et al., 2018).

DED is an inherently multidisciplinary design approach, in which the main relevant competences (design research, data design, software development, data science, domain experience) are represented by team members from different backgrounds. In previous literature (van Kollenburg and Bogers, 2019), two specific design roles have been presented as essential to the DED approach;

- The role of the design researcher, adopting a user-experience oriented perspective rooted in qualitative and ethnographic research techniques;

- The role of the data designer, adopting an experimental, prototype-centric perspective rooted in digital prototyping, software development, data analytics, and visualisation techniques.

In this contribution, we introduce service design capabilities as a third design skillset that can be relevant to a DED process. First, we provide brief theoretical considerations on these capabilities. Following, we present the results of the introduction of a service system perspective in DED through the Co-responsibility case study, review the encountered challenges, and propose relevant opportunities for further research. By doing so, we intend to enrich the DED approach with a novel and relevant perspective, and to stimulate a more general reflection on the role of service design in novel paradigms of value creation in digital health.

Service design for intelligent ecosystems

Service design is a branch of design knowledge and practice which is "concerned with systematically applying design methods and principles to the design of services" (Holmlid and Evenson, 2008). Secomandi and Snelders (2011) indicate service design to be concerned both with the service interface and with the service infrastructure, identified, respectively, as the sociotechnical resources involved on the 'front-end' and 'back-end' of the exchange relations between service providers and clients. They place emphasis on the service interface as the locus in which service-related exchange relations are materialized, to the point of suggesting that the design of the service interface constitutes the design of the service itself.

Such considerations can support us in identifying a role for service design capabilities within a DED process. In fact, DED processes aim at developing propositions that reach users through specific kinds of service interfaces: those of an intelligent ecosystem.

Van Kollenburg and Bogers (2019, p. XIII) characterize the intelligent ecosystem as:

> 'a collection of products and services, that can together gain a detailed and nuanced understanding of the user and context. This understanding allows the intelligent ecosystem to adapt, to deliver experiences at the moment and place where they matter most.'

If we adopt Gadrey's (2000) definition of a service as the provision of a 'temporary right to use' a technical system, we see that, within intelligent ecosystems, service interfaces themselves need to be adaptive in order to ensure the timeliness of the service provision. Focusing on designing services that explicitly embed such timeliness and personalization at the level of the interface is deemed to constitute a relevant concern within DED, and one that

we recognize to pertain to the disciplinary domain of service design. Because this aspect of service provision is intimately linked to the functioning of the intelligent ecosystem, we will refer to this as the service-system perspective.

Like the other roles within DED, the service designer cannot work in isolation. To design services that possess the aforementioned qualities, the service designer needs to obtain an understanding of the flow of information and knowledge through the ecosystem, and of its use in different touchpoints (in a certain context, at a certain moment). This understanding connects to both experiential and technical aspects of the ecosystem. In this sense, the role of the service designer in a DED process could be preliminarily identified as that of an integrator of:

- Experience-related insights, provided by the design researcher from a user-experience oriented perspective; and

- Infrastructure-related insights, provided by the data designer from an experimental, prototype-centric perspective at the level of the service interface.

Furthermore, the characteristics of services in intelligent ecosystems can be connected to a perspective that is specifically explored in traditional service design literature; the one of the facilitator of co-production. A central tenet of service design lies in fact in the difference between products and services, identified in the need for services to rely on a certain degree of participation from their users to become visible and tangible. Edvardsson and Olsson (1996) link service design to the responsibility of facilitating the engagement of customers in co-producing the outcome.

In intelligent ecosystems, the element of co-production is materialized not only in the user interacting with the services as intended, but also in the passive and active production of the contextual data fuelling the ecosystem. From a service system perspective, the user of the intelligent ecosystem is a continuous 'co-producer', whose actions and interactions, materialized in the form of data, sustain the ecosystem intelligence. An additional potential role for service design in a DED process is therefore recognized in the capacity to safeguard, prioritize and facilitate digitally mediated co-production in the intelligent ecosystem.

Case study

The Co-responsibility study

The 'Co-responsibility' study was a clinical trial following an explorative data-enabled approach. The study focused on the time following a bariatric or weight-loss surgery, in which keeping up with suggested lifestyle changes (e.g. regarding nutrition and physical activity) can prove challenging for patients.

Long-term success in maintaining optimal lifestyle appears to be significantly affected by the support provided by the healthcare professionals and the social circle surrounding the patient. Therefore, it was decided to investigate the potential value of an intelligent ecosystem designed for co-responsibility between patients, partners, and healthcare professionals. In line with Neutelings et al. (2017), we defined co-responsibility as the "responsibilities of people being intertwined, not in the sense that people share the same responsibilities, but in the sense that peoples' responsibilities are interdependent".

 An intelligent ecosystem consisting of a communication platform (chatbot and mobile application), a Fitbit activity tracker, open-ended data trackers (flic button, rotary buttons) and event trackers (smart power sockets, motion sensors) was designed and deployed at the homes of six participating families. Using this system, we were able to explore the context and to develop and test design interventions involving the patient, partner and a team of healthcare

professionals. Each family was recruited via the Obesitas Clinic of the Catharina hospital residing in the Eindhoven region of the Netherlands. The study was classified as a clinical trial and its setup was approved by the Philips internal ethical committee (ICBE), the medial ethical review board of Santeon Hospital group (MEC-U), and the local feasibility committee of Catharina Hospital.

The project was initiated by a team of design researchers and a data designer. By decision of the team, a service designer adopting a service-system perspective was then involved to support the project. This introduction surfaced both practical challenges and opportunities, which will be described in the next section.

Challenges and opportunities

Service designer as the integrator of the other data-enabled design perspectives

By the time the service designer had joined the team, extensive data-enabled explorations had already been performed. This had resulted in the accumulation of rich insights both into experiential factors related to the post-surgical context, and into the technicalities related to the explorative ecosystem built for the study. Several ideas and intuitions related to possible (smart) functionalities and features of services in a future ecosystem had emerged.

Among these, we can mention;

- Ideas on how to provide the intelligent ecosystem with adaptive capacities (e.g. based on a user profile including medical history, baseline questionnaires, etc.);

- Ideas on how to surface and foster co-responsibility within the intelligent ecosystem;

- Ideas on how to provide health information previously delivered through non-digital media;

- Ideas on how to use specific probing devices (e.g. Fitbits, smart sockets, open data trackers) within the intelligent ecosystem.

From a service system perspective, each of these sets of ideas could provide valuable insights into desirable characteristics of service interfaces, and as such could be used as service design input.

Yet, early efforts to sketch the map of an integrated digital infrastructure that would permit the development of these ideas within an ecosystemic framework proved challenging. This is because each of the indicated interface-level features required the conceptualization of an automatized sub-process at the level of the infrastructure. For instance, the interface-level feature of 'adaptivity of service based on user profile' required, at the level of the service infrastructure, the conceptualization of a sub-system that would automatically manage options for personalization in a structured way, and would influence ecosystem interactions accordingly.

To this end, it is important to note that the conceptual complexity of the infrastructure behind an intelligent ecosystem tends to increase exponentially, rather than incrementally, with the addition of each element of 'smartness' perceivable at the level of the interface. This is because each newly added subsystem needs to interrelate to all other subsystems in a planned and rigorous way to ensure system coherency. Consequently, even simplified conceptual maps of an intelligent ecosystems' underlying infrastructure appeared overcomplicated and lacked capacity to show all of the relevant logical interdependencies (see Figure 1.) From a service-system perspective, this challenge surfaced opportunities for future efforts to improve the integration of rich experiential and technical data-enabled insights through:

- A strict prioritization of the features considered for service design, at least in early conceptualizations of the ecosystem;

- A strong alignment between the service designer and the data designer in order to manage technical trade-offs;

- A clear value proposition to guide interdisciplinary design choices.

Service designer as the facilitator of data-enabled co-production

Some of the most interesting service feature ideas emerging from the study relied on active user participation. For instance, the idea of embedding a way to track 'co-responsibility' trends between a patient and partner relied on both participants periodical filling of a fixed questionnaire, thus on their disciplined co-production of ecosystem-relevant data. From a service system perspective, this raised questions on the possibility and opportunity to impart designerly control over the behaviour of the users in the ecosystem setting. In these terms, a challenge was identified in reaching an appropriate balance between the designerly control necessary to guarantee the intended functioning of the ecosystem, and the flexibility necessary to embrace and accommodate users' possible non-compliance or deviation from expected behaviour.
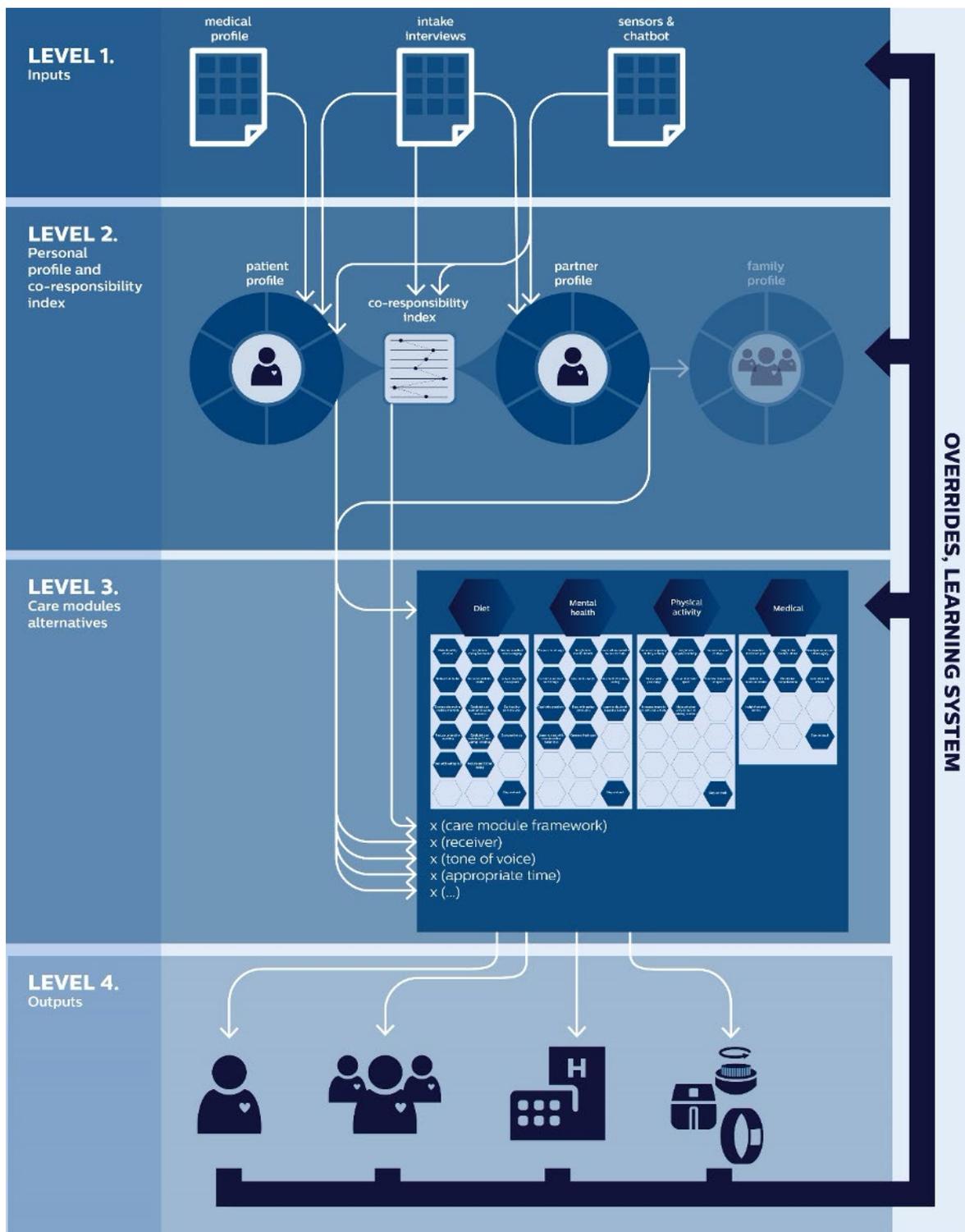
Figure 1. Early system map

An opportunity to overcome this challenge could be found in Snelders at al. (2014), who can be credited with the notion of an appropriate balance of designerly control in service design, and who posit that 'the degree of control that designers possess should be contingent on the degree in which people in a service setting can accept the intervention of external parties to improve their social well-being'.

Their contribution suggests a connection between the levels of user tolerance for designerly control and the perceived utility of the service for the 'greater good' of improving social wellbeing. Similarly, in the Co-responsibility case, we can imagine that

acceptance for designerly control would be conditional to the perceived utility of the service in supporting users' successful post-operative recovery. Future research could investigate the accuracy of this expectation, and further inform service design best practices when balancing between control and flexibility in digital health.

Discussion

Relationships between service designer and data designer

As previously specified, service designer capabilities can only be integrated within in a DED project through close collaboration with the other capabilities involved in the project, mainly design research and data design. However, we would like to reserve special attention to the relation between service designer and data designer. In fact, we experienced the establishment of mutual understanding between these two roles to be possibly hard, but indispensable for successful collaboration. This is because the sketching of even just early service ideas within an intelligent ecosystem does require an iterative back-and-forth between a service-system and an experimental, prototype-centric perspective. During our project, we sometimes struggled to reconcile the two perspectives due to important differences in approach, knowledge, experience, and even vocabulary. However, we have found such struggles to be not only fruitful for the project, but also, ultimately, mutually enriching.

Implications for service design in eHealth

The considerations contained in this contribution can lead us to a more general reflection on the role of service design within the contemporary discourse in eHealth innovation. eHealth is in fact a domain in which both the integration of different disciplinary perspectives and the facilitation of digitally mediated service co-production appear to be recognized as largely unanswered needs.

Regarding the former aspect, Pagliari (2007) offers a compelling overview of the need for improved interdisciplinary integration in eHealth design and evaluation, while Romm and Vink (2019) reflect on the capacities of service designers in healthcare to act as 'catalysts' of the multiple relevant points of view.

Regarding the latter, Tummer et al. (2016) points out the opportunity to improve care co-production through enhanced use of Information and Communication Technologies (ICTs), and Boye (2012) provides an early theoretical framework for digitally mediated health co-production. In this sense, we believe our contribution's relevance to extend beyond the borders of DED, and to connect to the broader discourse at the intersection of service design and digital health.

Limitations

An important limitation of our work consists the uniqueness of the presented case study, a first-of-a-kind project under several points of view. Furthermore, we acknowledge that the dynamics we observed in the project might have very well been drastically influenced by independent circumstances, such as the team members' backgrounds, skills, and personalities. Accordingly, we see our preliminary considerations on the service-system perspective in DED to be project- and team-dependent. Finally, we believe our conclusions should not be interpreted in a way that constrains design professionals into too rigid roles and definitions. To this note, we point out that tasks that could be considered to be afferent to service design have been successfully executed in previous DED projects without the involvement of a formally trained service designer.

Conclusions

In this contribution we introduced the role of the service designer within the data-enabled design process. After touching on some theoretical considerations, we reviewed the challenges and opportunities related to such role as observed in a single case study. Finally, we briefly reflected on the relationship between the role of the service and the data designer and situated our contribution within the larger context of digital health innovation.

Acknowledgements

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BEYOND SPECULATION: USING IMPERFECT EXPERTS FOR DESIGNING THE COLLECTIVE FUTURES OF HEALTHCARE FOR SPACE

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Abstract

From healthcare products and services to hospital environments, designers have been involved in shaping tangible transformations and improvements for the future of health(care). Lesser developed are design practices for shaping care models, strategies, sustainability, policies and other less tangible and longer-term health(care) futures. Critical speculative design, scenario planning and road-mapping have been practiced by designers to address such futures. However, there are problems with using these methods to envision new futures in action: critical speculative design has poor feedback loops and dissemination issues, confining it to special interests, and scenario planning has the top-down issues of 'impartial' observation, making it unsuited to wicked problems.

The further we look into the horizon the more unknown-unknowns we encounter, the harder it is to rely on existing knowledge, trends and extrapolation for envisioning new health(care) futures. Inspired by these issues, we explored a new method to generate alternative futures - encouraging wider participation and in the context of complex technology-driven healthcare for space. Through abductive thinking and participant observation, a new concept of the 'imperfect experts' was developed to address the issues of design futures, scenario planning and participation in complex futures.

Keywords: imperfect experts, collective imagination, healthcare futures, healthcare design

Introduction

Design is embedded in healthcare systems to support the delivery of tangible transformations through solving well-scoped problems - typically as product, service or innovation design in medical devices or in a hospital management. As the world's population increases, urbanises and ages, the demand for sophisticated and complex healthcare intensifies. Meanwhile, connectedness and mobility add further complexity and reduced predictability. Beyond reduced predictability, known-unknown healthcare issues such as rare diseases and antimicrobial resistance persisted in the background. On top of that, flash surges of unknown-unknowns for healthcare induced by black swan events are not that rare: Ebola, Zika, Covid-19 outbreaks, violent political protests in Hong Kong, Chile, Iran, and Brazil and extreme weather events are in recent memories. Finally, new brittleness and capabilities are added by digital technologies, which take effort and time to be proven and integrated, then, disproven or reintegrated with updates. The problem space in healthcare is increasingly wicked as a result. The increasing wickedness calls for new approaches for designers to contribute to future healthcare issues.

How might we design future resilience for healthcare products, services, systems and policies, given the wicked and chaotic nature of the problems?

Healthcare Futures

There are many methods available to designers to tackle future issues e.g. anticipatory design science (Fuller 1992), prospective design (Galdon and Hall 2019), speculative and critical design (Dunne 1999), scenario planning (Kahn and Wiener 1967) and design roadmapping (Simonse 2018). We have identified specific examples of speculative and critical design (SCD), scenario planning and design roadmapping in healthcare settings to illustrate the disciplinary diversity of and the common limitations when addressing unknown-unknowns in futures design methods.

SCD emerged from industrial design and was largely established by Anthony Dunne and Fiona Raby at the Royal College of Art in the 1990s. The idea is to shift from designing manufacturable technology products to designing speculative objects that provoke critiques on the social implications of technologies in the future (Dunne 1999). For example, Chamberlain and Craig (2017) created speculative objects by merging furniture with medical objects, e.g. infusion lamps, to critique the invasion of healthcare into domestic home spaces. Whilst the objective of speculative design is 'not to be didactic' (Dunne 1999, 13-14), such speculative design requires the viewer to be imaginative, reflective and be able to enlarge the conversation into wider cultural, social and political concerns. Design fictions, a recent evolution on SCD, appears to address this issue by providing a hypothetical context for the speculative objects.

> 'A design fiction is (1) something that creates a story world, (2) has something being prototyped within that story world, (3) does so in order to create a discursive space.' (Lindley and Coulton 2015)

For example, Uninvited Guests (Jain et al. 2015) is a short film that explores the implication of speculative smart objects for healthcare. In which, the organised disharmony created by the technological objects was illustrated in a spelt-out context - at the home of an elderly man whose children cannot be present to care for him. In the United Micro Kingdoms (Dunne and Raby 2013) , Dunne and Raby have further structured the alternative future contexts. Instead of one context, four alternative contexts are created: Digitarians, Bioliberals, Anarcho-evolutionists and Communo-nuclearist. Within each context, a corresponding speculative object (transportation) is situated.
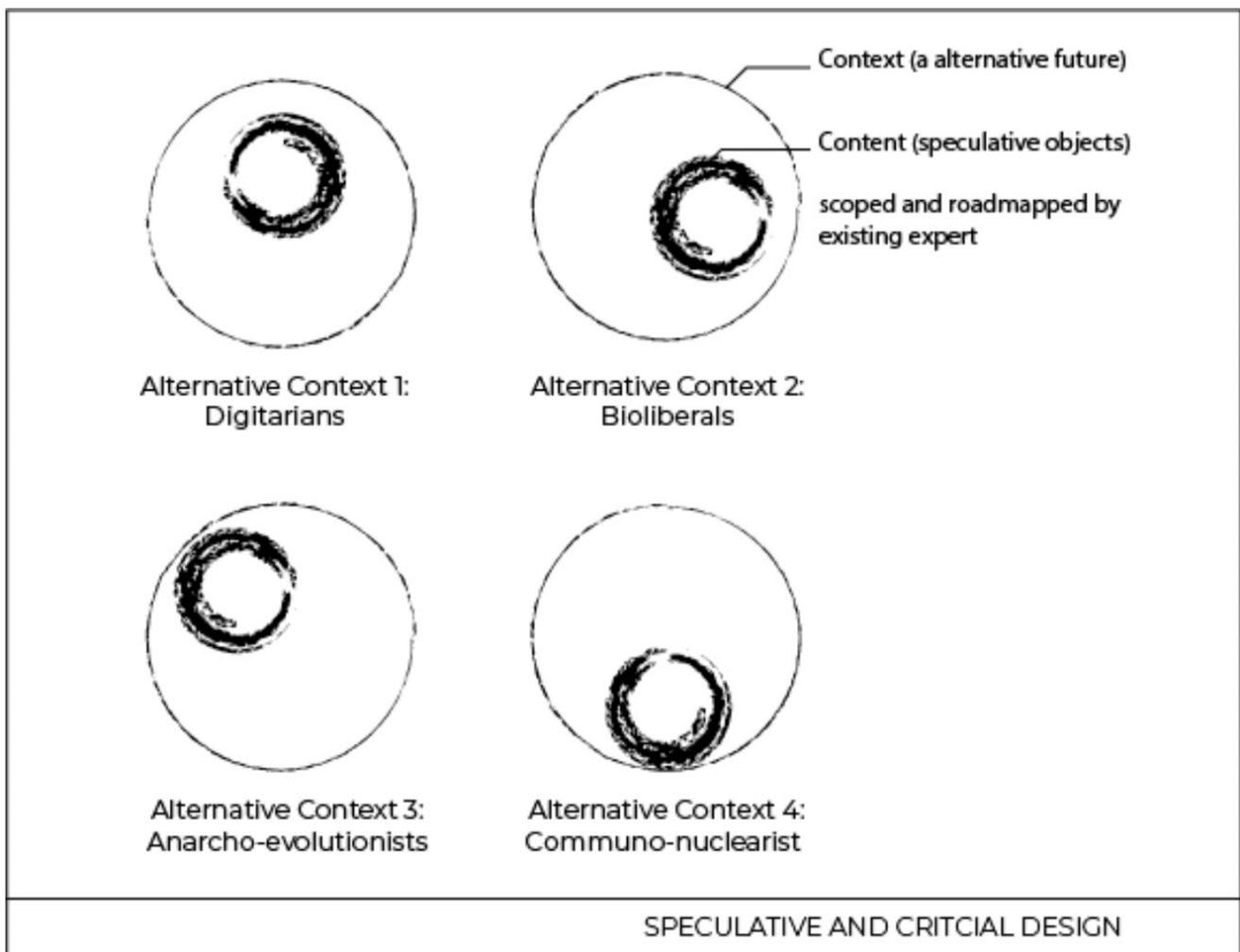
Figure 1: Structure of design fiction (SCD)

By placing the alternative futures into the same temporal world, interactions between alternative futures are afforded in thought-experiments. The limitations are that thought experiments are, however, not automatically a discursive space and certainly not part of a systematic feedback loop to design a resilient healthcare system and policies.

Scenario planning stems from military-political practices in the 1950s, the formalisation of the field is attributed to Herman Kahn. A scenario is defined as 'a set of hypothetical events set in the future constructed to clarify a possible chain of causal events as well as their decision points' (Kahn and Wiener 1967, 6). It is only one aspect in 'a framework for speculation', situated within a systematic context. The context is known as an alternative future

- a 'canonical variation' from the 'standard world'. The standard world is constructed based on extrapolation on trends and the canonical variations are based on the main expectations of the policymakers and other cases of interests. Kahn and Wiener (1967) defined three alternative futures: a 'more integrated world', a 'more inward-looking world' and 'a greater disarray world'. This structure of using four contexts has been adopted by many other scenario planners (Amer et al. 2013).
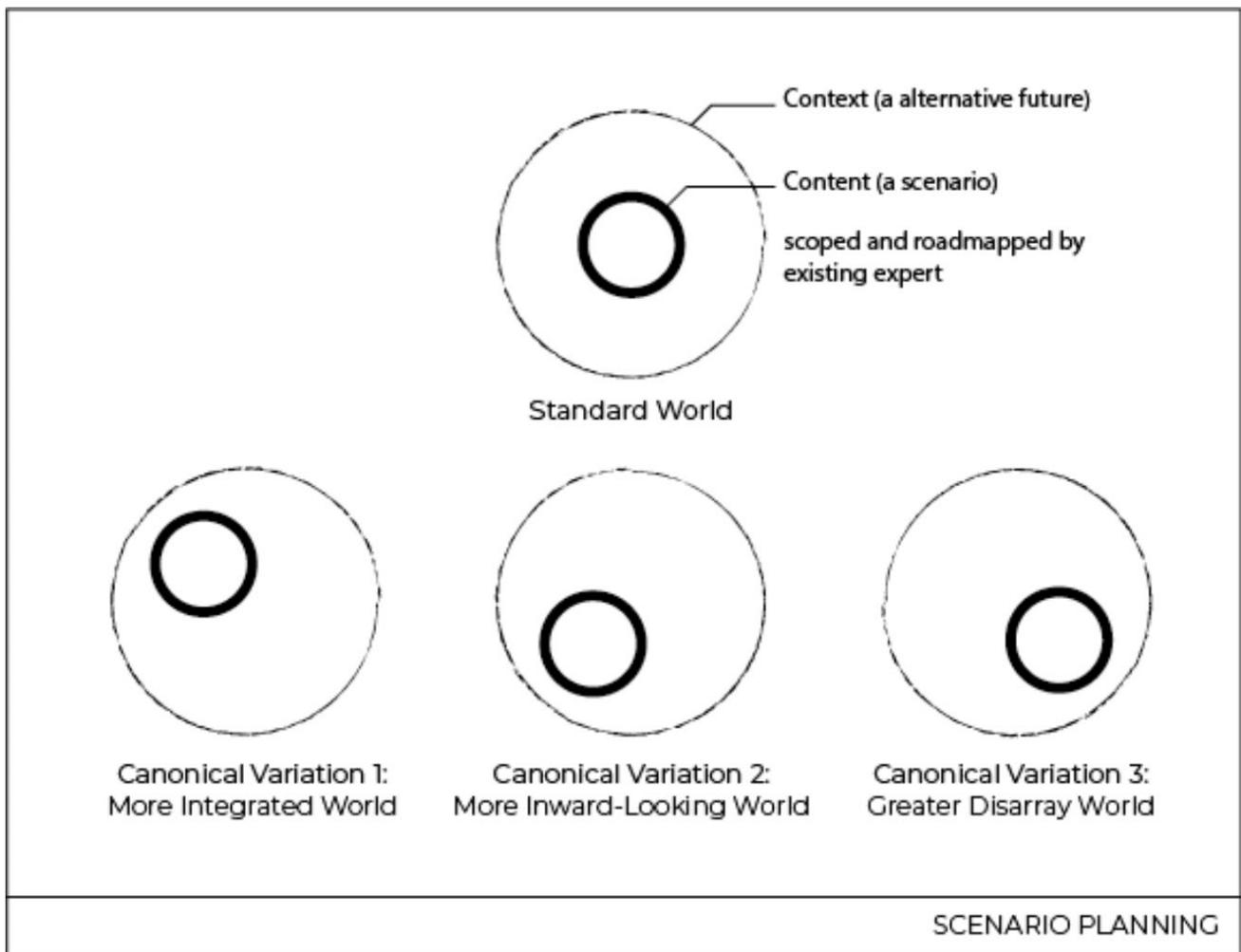
Figure 2: Structure of scenario planning

In a way, the structure of scenario planning and design fiction is not dissimilar: an alternative future (context) and one or more tangible content (scenarios or speculative objects) within it. Where a 'design-for', expert-led approach is taken to construct the contexts and contents. The speculative designer or an invited group of experts in scenario planning design for the public.

Finally, the alternative futures do not exist independently from the present. Design roadmapping is a visualisation tool, used by designers, to map out products and services, forming tangible links between the present and future.

The issue, in all three methods, remains that the further we look into the horizon, the more unknown-unknowns we encounter and the harder it is to rely on existing knowledge, trends and expertise.

The ability to design for unknown-unknowns is a critical weakness in all of these methods - in that they are invariably limited by current expertise that is largely based on the historical knowledge of what is known. A number of key questions emerge: Who can we design with for healthcare futures characterised by unknown-unknowns? What is the designer's role? How can we link future experts with current experts?

Imperfect Experts

The problematic nature of wicked healthcare futures is exemplified in the extreme context of healthcare in space - the context of our 18-month research project. Firstly, experts are rare and hard to access: only 600 spacefarers have been to space to date. Secondly, known knowledge is limited: health hazards, system and knowledge are developed from and for a population of narrowly selected and highly trained spacefarers. Finally, the trends in human spaceflight are at odds with the existing healthcare knowledge and system, as commercial spaceflight will change the demographics of spacefarers. Although less visible, such wicked healthcare problems also exist in everyday healthcare problems: in designing for rare diseases or responding to black-swan events. Views on alternative futures are extremely vital to address the unknowns in these cases as the projected future (business-as-usual extrapolated) is a vision of false-safety. The concept of 'imperfect experts' emerged from exploratory research to design for such context.

Methods and Approach

The overarching research method used was research-through-practice, driven by abductive thinking.

One imperfection probe (online), three design games (over seven workshops), one co-speculative design workshop and one design improv was created to facilitate an effective process for the collaborative design of the contexts and contents of wicked healthcare futures. Many issues are addressed beyond the issue of expertise in the project. In this paper, we are only discussing aspects of the project of significance to addressing this one issue: expert for unknowns, which can be broken down into smaller objectives: (1) who are the future-experts and (2) how to form a feedback loop with the experts. The two most relevant methods and associated tools created are described below:

The Imperfection Probe and Future-Zines

Taking inspiration from the cultural probe (Gaver et al. 1999), the imperfection probe was developed in order to probe the distance of imperfection in speculation. An implementation takes the form of an online participatory design fiction activity, technically using a tool that is widely used for online surveys. A short fiction (a job advert: New Opportunities for Adventurers to join Mars Occupational Adventure) and the ground rules for participation are embedded at the start of the 'survey'. Participants were invited to read the short fiction and perform participative storytelling using the navigation mechanisms of a survey, i.e. survey 'questions' were part of an extended storyline that guided narrative contribution. To facilitate abstract and visual thinking, a tool called future-zines is created. Future-zines are a set of front-covers of reading materials from the world of fiction. For this study, they are related to health and wellbeing on Mars, these specialised future-zines are called Marzines.

Figure 3: Marzines

Design Improv: 'Design Fiction: Mars Adventure'

The design improv takes inspiration from improvisation theatre to evolve a collective narrative, but without the focus on character work. The warm-up and planning stage is facilitated by visual thinking via Mars Landscape Cards (images of real Mars landscape with simple descriptive text), pre-created props and materials for props creation by participants. The session is three hours long, with mostly warm-up and prop creation activities, leading up to the performance of a sketch of the alternative futures (which is then iterated once more).

Both methods are designed to create a permission to voice alternative views and articulate tacit knowledge. Alternative views and tacit knowledge are ways to uncover future unknowns, to 'know' beyond the standard world and expert knowledge.

Discussion

We started with the experts before arriving at the imperfect experts. The experts, in this context, are the extreme/space medicine researchers and astronauts. These (perfect) experts provided views that are cutting edge but firmly grounded. As de Bono puts it: 'It is not possible to look at the different direction by looking harder in the same direction.'(De Bono 1974, 26) The 'perfect experts' are perfectly disadvantaged by their expertise, as it imposes a self-limit on the permission to imagine with unknown-unknowns.

Who can contribute context and content of the alternative futures? We propose that they are the imperfect experts. But who are the imperfect experts?

In June 2018, a workshop was conducted with a community of practice to co-speculate the future of healthcare in space. A community of practice is a group of the public with a shared concern - the participants to co-speculation as proposed by Julia Lohmann (Lohmann 2017, p.90). Such a group naturally diversifies the point of views when envisioning the potential and possible futures (Lohmann 2017, p.74). The twelve participants are invited by a living lab (Living off the Earth II). Divided into two groups, the community of practice created two design fiction (included speculative objects): (1) space nomads that can manipulate and collide stars for entertainment to relieve wellbeing issues and (2) the design of a 'hoppercraft' and other facilities for mountain rescue in terraformed Mars. Whilst the co-speculative process was very much enjoyed by the participants, it was not immediately clear how this set of results would work as a feedback to the experts. The contexts appeared to be not expansive enough, such that the content reached dead-ends: with the space nomads, dead-end of not being able to further imagine was encountered at one point; with the terraformed Martians, dead-end takes the form of all problems solved.

In parallel, the imperfection probe was being designed. The imperfection probe was sent to people who work and/or study in design, space, healthcare or related industry. The self-limitation observed from the perfect experts was also observed to a lesser extent from terrestrial healthcare professionals who participated in the imperfection probe. People who worked in terrestrial healthcare or related industries have consistently juxtaposed a present-day medical issue with a well-known space environment effect in a rather objective way; in one case, a participant remarked that 'it's too hard for someone who doesn't know much about space'. Whereas the designers and some outliers have taken their content further and alluded to contexts of alternative futures in their narratives. The outliers are attendees to a technology-culture festival in the UK and are additional participants to the original list. In the technology-culture festival, a three-hour workshop entitled 'Design Fiction: Mars Adventure' was attended by eleven participants. The two groups of participants were facilitated to create props and perform an improvisation act of three to five minutes each. Team Deuterium Scouts performed a design fiction in the early days of terraforming Mars, where humans are enveloped in life-supporting technologies; complicated, action-fuelled, power dynamics unfolded between the medical professionals and the explorers within the team - all for the sake of the new energy source. Team Plant Fodder performed a design fiction where humans come into contact with unknown lifeforms on Mars; a series of everyday issues were raised and a drama of profiteering by pharmaceutical organisations has twisted and turned towards a comical end of total galactic infection.

Figure 4: [top] Participants posing after the improv with props constructed by themselves (except helmet) [bottom] Props generated in the workshop

This group of culture-sensitive-technologists created deep contents (props as speculative objects/diegetic prototypes) and rich contexts about alternative futures of healthcare in space. Without turning into the extremes of utopia or dystopia, hopes and fears, facets of wicked problems of the futures are explored. The expression is succinct and articulated. Overall, the output can easily be imagined as feedback for perfect experts. This, as it emerged, are the views created by the imperfect experts.

During this process, a new requirement emerged. Given the qualities of the alternative futures created by native imperfect experts is identified and our role is to facilitate: Can we facilitate people into acquired imperfect experts who would produce results of the defined quality? Can we scale up the approach?

Such is the question XHealth Lab is trying to answer. XHealth Lab is founded on the tools and techniques that have succeeded in facilitating imperfect experts to imagine alternative futures. The objective is to shift from the construction of the context of the alternative futures from a design-for to a design-with approach, addressing the 'impartial' construction of the structure in which experts speculate. In this way, perfect and imperfect experts collaborate in a way that combines their strengths and alternative future perspectives.

Conclusions

Imperfect experts are defined as people whose expertise is not an obvious match with the problem and futures that are being researched and might not even share the concern of the topic. The imperfect experts (1) do not have to have a recognised profession, their expertise can be in their tacit knowledge, for example, for being a cyborg and (2) do have the permissions to imagine. The outputs from the imperfect experts are the deep contents (props as speculative objects/diegetic prototypes) and, more importantly, rich contexts about alternative futures.

Participatory speculation with imperfect experts leads to results that are the inverse of speculative design. It does not explore the unknown implication of the latest technology but explores the well-known hopes and fears for the futures from the imperfect experts. The gap of unknown knowledge is addressed by answering a different question: what is desirable, as opposed to what is preferable given the state of technology or forecasts. Unlike utopia or dystopia, hopes and fears are not dead ends and can be expanded and explored. It is by setting the context of alternative futures using different hopes and fears that we would be able to account for and deeply engage in wider stakeholder perspectives. Ultimately this has allowed us to reposition the issue of expertise of the future.
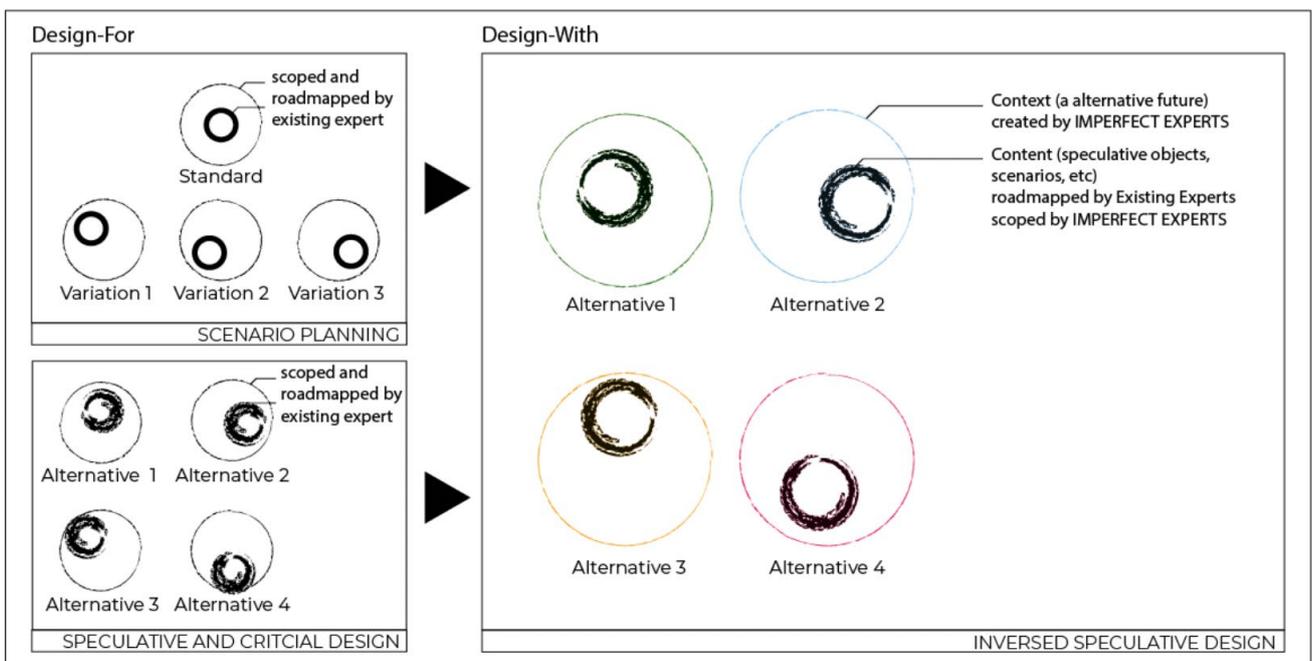
Figure 5: Structure of inverse speculative design with imperfect experts and experts

By bringing together the experts and imperfect experts we have a new opportunity to avoid further polarisation or disconnection in the design of resilient future healthcare products, services, systems and policies.

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CO-DESIGNING AGED CARE CONVERSATIONS: STUDENTS ENGAGE WITH OLDER ADULTS THROUGH TOOLS EXPLORING GOALS AND INTERESTS

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Abstract

While interest in co-design is growing, young designers have little experience in co-designing with older adults to understand their needs. This paper presents a study where 16 Master of Design students visited aged care residents running iterative co-design workshops, over two months. The students designed toolkits to facilitate conversations with older adults, aiming to improve their quality of life and better tailor services provided by the aged care sector. The aged care provider had no existing tools to assist open and caring conversations between staff and residents. We found the older adults were delighted to have conversations with open-minded, energetic, multicultural students invested in finding out about their goals and interests.

Most of the students had never visited an aged care home, hence the co-design activities served two purposes. Firstly they supported conversations between the students and the older adults despite mutual language barriers. Some students were not fluent in English, while some older adults were hard of hearing or unable to talk. Secondly they became early versions of the final toolkits whose creation we consider a highly relevant skill for future designers. Learning co-design skills built the students' confidence as communication designers to make language choices and create materials to facilitate difficult conversations around emotions, shifting conversations from a drab future and possible declining health to positive terminology. E.g. it was better to talk about current goals as some older adults felt they 'don't have a future'. Co-design activities allowed them more control and on what information was given when picking images from a variety of cards without the pressure to verbalise choices. Students provided the aged care provider with creative toolkits that deviated substantially from existing assessment forms that usually guide structured conversations in the aged care sector, prompting a power shift in aged care conversations towards person-centredness.

Keywords: Codesign, communication toolkits, aged-care, education
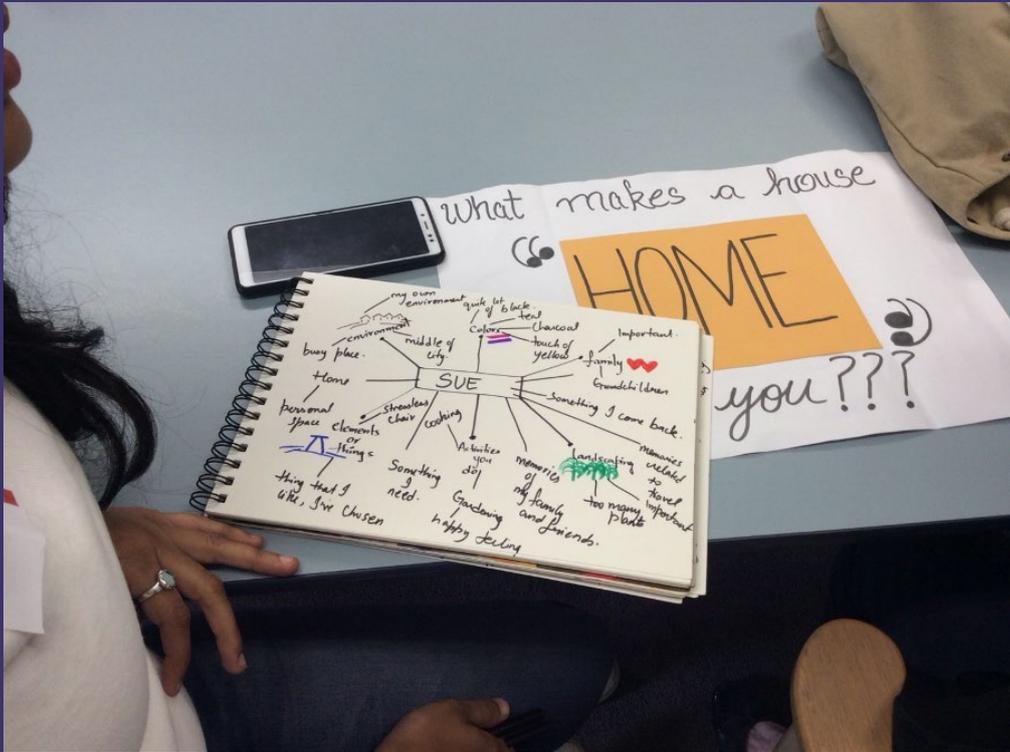
Figure 1. Early co-design activity to understand what constitutes "home" for residents

Figure 2: Final Do/be/feel Toolkit for person-centred staff – resident conversations

HEALTHY AND HAPPY AGEING IN RURAL AREAS: THE CONTRIBUTION OF ARCHITECTURAL INTERVENTIONS

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Abstract

In Belgium, the share of persons aged 60 years and older is projected to reach 32.4% by 2050. Moreover, the older population itself is ageing, and is continuously becoming more diverse. At the same time, it is clear that people entering old age have different housing experiences, expectations and needs. As home and the home environment gain importance when growing older, it should be considered as a significant type of place providing the link between one's dwelling and one's wellbeing and identity.

In Belgium, the housing landscape is scattered over urban and more remote, rural areas. Although most people are aware of the paradoxes that rural living brings along (e.g., tranquillity of living vs. lack of services and poor infrastructure), an over-representation of Belgian older people live in non-urban areas.

In a Masters class, we explored how older people living in a particular selection of two small-scale villages in rural areas, try to perform 'healthy and happy ageing' in place today. Via the application of an intergenerational approach, Masters students in Interior Architecture performed research with the help of local inhabitants. They first documented how people living in these villages, organize their daily life and living practices. Various research methods were applied: students performed interviews, used walking as a research method as well as observations throughout the villages. Evidently, also sketching was applied. As a next step, students developed spatial scenarios of inspiring (living) practices for the villages involved in the project, all enabling healthy and happy ageing. The designerly 'solutions' to stimulate healthy and happy ageing in place demonstrate students' efforts to design and reassure sustainable rural community living, contributing to people's subjective well-being.

Keywords: design for wellbeing, ageing in place, spatial scenarios, lifelong living, interior architecture

Introduction

Living in general, and living for older people in particular, faces many challenges today and tomorrow: there is the double wave of the greying of older people, the changing zeitgeist and a shift in mentality regarding ways in which older people want to be able to live when getting older. In addition, there are changing family structures. Also, like many other population groups, older people are very heterogeneous and diverse, and ideally this diversity should be reflected in the residential landscape (Petermans et al., 2019). To date, however, this is not self-evident; this is also the case in the region of Flanders, the Dutch-speaking northern part of Belgium.

Many Flemish municipalities pursue a policy of lifelong living, and are increasingly trying to take account of the influence of the ageing of the population which also affects the so-called 'Leader' area (see Figure 1), which concerns a region in the South of Limburg (one of the Flemish provinces).

Figure 1. Leader area in the province of Limburg, Flanders, Belgium

Source: Provincie Limburg, 2020

We know from research that the countryside in particular colours 'grey' if one looks at the composition of the population

(De Decker et al., 2018). In 2020, at least 25% of the inhabitants of every Leader municipality will be 60 years of age or older; in 2030 this percentage will already increase to +/- 33% (Steunpunt Sociale Planning, 2013). Many older people will be in need of care. But does the Flemish countryside lend itself to this? In what follows, we concisely summarize noteworthy findings regarding housing in the Flemish countryside:

(i) Flanders is characterized by a spread of housing, whereby houses often are concentrated along main roads that form a kind of line or 'ribbon' of development.

(ii) On the countryside, the presence of services is an issue. There are many small villages, many of which lack facilities (e.g., a bakery, a small-size supermarket). Due to this, people become more dependent on surrounding cities. This has an impact on many aspects, for instance mobility.

(iii) There is a high percentage of house ownership in Belgium, thus also on the Flemish countryside, certainly among older people. The fact that many people in Belgium are owner of the house where they live, is inextricably linked to the desire/necessity/feeling to adapt (or not) something in one's house. Moreover, we know that today, a relatively large proportion of older people in Belgium live in relatively old houses, which are generally not (well) adapted to ageing and possible difficulties that older people might experience in this phase of life (Petermans et al., 2019).

(iv) Although we know that the housing situation of older people in Flanders is far from good (i.e., 40% of older people live in dwellings that are highly inadequate for old age) and moreover, it appears that 37% of Flemish houses have insufficient housing quality (measured by objectifiable parameters), Flemish people appear to be very attached to their own house.

Over the past few years, research projects have been launched in which consideration has been given to housing modifications and/or innovations in housing for older people, but this usually involves a great deal of attention to objectifiable parameters and ways in which these can help improve or stimulate the quality of living and, ultimately, people's well-being. Internationally, however, attention to people's well-being and happiness has also been growing in recent years, calling for more attention to be paid to subjective aspects (Desmet & Pohlmeyer, 2013) and the importance of 'activity' in these (Lyubomirsky, 2007).

This paper elaborates about the set-up and results of a Masters class, focusing on healthy and happy ageing in rural areas via an exploration of the contribution of architectural interventions.

Master Class

Set-up

In a Masters class that was set-up as a two-week full-time workshop, students were offered a mix of theory and practice. In this intense class of 2 weeks, all Masters students of the Interior Architecture training program were involved and in different teams, focused on two small villages: Montenaken and Binderveld. This Masters class was part of a Leader project on 'lifelong living' in which the aim is to learn from people how they already try to 'live lifelong' in a number of small villages in Haspengouw. We have consciously chosen to do this research in dialogue with residents: older people, but also the young generation, i.e. the children who live in the selected villages and / or go to school there. In this way we hope to indirectly strengthen the social dialogue in the village.

Successful ageing has to do with activities, and with the ability to be or become older in an active way. This depends partly on older persons themselves, of course, but is also related to a present local offer (regarding various aspects) & the 'desire' of older people to participate in these offerings. For instance, are there (enough) local opportunities and possibilities for older residents to meet others, to do things they like (physically, cognitively, emotionally, ...)? In the Masters class, such considerations were taken into account.

Locations

In the Masters class, we focused on 2 municipalities in South Limburg: Gingelom and Nieuwerkerken. In Gingelom, students focused in particular on the village of Montenaken. In Nieuwerkerken, the students focused on the village of Binderveld.

Montenaken is a village in Gingelom that has 1442 inhabitants. Today, Montenaken already has more than 30% of inhabitants who are 60 years of age or older. Montenaken is well equipped in terms of facilities: there is a residential care centre, a primary school, and there are several basic facilities: bakery, butcher, etc. There is also a sports hall and a culture house. The board of the residential care centre that is present in Montenaken is currently considering expanding and creating a larger department for people with dementia. In addition, consideration is also being given to the start of a 'village house' in Montenaken, as this could be a real meeting place for the inhabitants. In this Masters class, both avenues (i.e., an extension for the residential care centre and new village house) were presented as inspiration for the students: can a kind of hybrid concept be developed around this that facilitates lifelong living and healthy and happy ageing in place in Montenaken?

Binderveld is a village in Nieuwerkerken that has 663 inhabitants, where the number of people over 60 currently fluctuates around 25%. The village is 'cut off' from neighbouring villages or municipalities. In Binderveld there is a kindergarten;

above the spaces that accommodate the kindergarten, there is a meeting place present. No other facilities are present. In the class, we want to find out how this village currently works, and how the residents organise their daily lives. How do they work? How do they shop? How do they live? In other words, how do they organize themselves in terms of many facilities, care, mobility, … So the key question in the Masters class for the teams focusing on this village, is what the future prospects are for this village, and for the houses in this village. Is it possible to live here 'lifelong'? This is already happening today (see the number of older people currently living in the village), but can this also be realised in the future? Is that possible; is that desirable?

Methodological approach

The group of students as a whole was split into 5 teams who focused on Binderveld and 5 teams who focused on Montenaken. Every team consisted of 4 students.

After being offered an introduction and a variety of inspiring lectures, the students were triggered to 'break out' of the faculty building and go explore the small villages concerned. Here, they documented their experiences and observations via a diversity of research methods, ranging from (i) walking through the villages in order to get to know and grasp the context (ii) making photographs of various kinds of inspiring things, aspects and people they discovered (iii) studying maps of the village (iv) doing interviews with inhabitants of various ages (v) performing observations in the village to learn 'how things are being done'. This diversity of methods was employed in an effort to learn how the concerned villages 'work', how people organise their daily lives, and what kind of movement patterns they develop in order to structure their lives. The students also collected stories and experiences of residents regarding 'lifelong living' by exploring how inhabitants of these small villages 'live' in their houses, gardens and neighbourhood. Starting from these

accumulating insights, the student teams pitched their design concepts at the end of the first week of the Masters class. In the second week, they further developed their ideas in detail. At the end of the second week of the class, their final results were shared in a jury, consisting of design studio teachers, involved researchers and a policy maker of the involved municipalities.

In what follows, we describe one project per village, that was very positively welcomed by the final jury.

Results

Montenaken project: "Buurtkast"

After their exploration of the small village, this team soon decided that inhabitants could easily have contact with each other, but they also noted a feeling of solitude; people do talk to each other, but often these talks are not very profound. They also look forward to getting to know new people. Inspired by this finding, the team proposed to work on an intervention in public space where people could share something, or where they also could leave a note about who they are and what they're good at. In that way, people could 'offer' something that could be of use or meaning to somebody else. This resulted in the 'Buurtkast' (see Figure 2).

Figure 2. Concept sketch of the 'Buurtkast'

The 'buurtkast' concerns an old cupboard that one of the inhabitants of Montenaken donates to the neighbourhood. A small group of volunteers transforms the cupboard into a mobile cupboard that is easy to use and transport. The cupboard is an important gathering point for cards that in first instance are spread all over the village via a postal mailing. Evidently, inhabitants also will be enabled to print the cards at home, or they can find them in the facilities that are present in the village. On the cards, they can mention who they are, where they can be contacted, what they like or want to share, or with what kinds of activities they would like to help or assist others. For instance, a person who is living alone, loves to bake cakes, and is looking for people to want to share a piece of cake with her. Or a girl for instance likes pets but doesn't have one of her own, but would love to help others in taking care of a pet. Such messages can be shared on cards they bring to the 'buurtkast' to share their qualities or capabilities with others and broaden their networks.

Figure 3. Spread over cupboards over Montenaken

In the design, this student team foresaw various cupboards to be spread over Montenaken (see Figure 3). As these cupboards can be considered as 'strange objects' in the environment, which 'travel' over the village, they have the ability to quickly become a kind of 'landmark' that triggers curiosity from various inhabitants. By coming up with this intervention, this team contributed to community building and a feeling of connectedness among the inhabitants of this village, instigating their subjective wellbeing.

Binderveld project: "Opening (up) the landscape – a park in Binderveld"

Overall, this team of students noticed that people enjoy living in this peaceful, quiet village and would prefer, if possible, to be able to live here for life. The interviewed people discussed how they mostly have a good contact with direct neighbours, but contacts of less quality with new neighbours or people living a bit further away from their house. They are aware their house probably would need some kinds of adaptation in order to perform 'lifelong living', but they demonstrated a willingness to do so if that would make 'lifelong living' possible. In their view however, taking initiatives or setting up architectural interventions that could help boost social contact among inhabitants is more important than providing co-housing or kangaroo houses, for instance.

This team took up this challenge, and decided to open up the landscape in Binderveld to create a place where people from various generations, from in- and outside the village, could meet up. By walking around in the village in the first week of the Masters class, they discovered a park-like environment that is currently informally closed-off from the village (see Figure 4).

Figure 4. Location of park-like environment in relation to the village of Binderveld

By proposing to 'clean up' this environment and designing installations that would be created with natural materials, they re-designed the space and came up with a beautiful park environment where people could meet up. The different symbols, present in Figure 5, demonstrate how this team foresaw places for being physically active, exploring nature, having a coffee, playing or just relax and enjoy nature. These different interventions appeal to a diversity of people of different generations and allow them to take part in activities that contribute to their subjective wellbeing and health.

Figure 5. Concept overview of activities in Binderveld park

Discussion of results

Overall, the design results mainly came down to a focus on space for meeting other people, as well as the importance of the social fabric of the village as a healthy space that is safe, accessible and attractive. Students' concepts that were presented in this paper can be synthesized as (temporary) interventions in the public space (street or inner area), or as a 'hub' where people could meet up. Within the framework of life-long living, students thus looked at how a space could be arranged carefully, functionally, experiential and meaningful, contributing to the subjective wellbeing of the people living in the concerned small villages.

Conclusion

This paper discussed the results of a Masters class studying how older people living in two small-scale rural villages in Belgium, try to perform 'healthy and happy ageing' in place today. We hope that the set-up and results of this pedagogical project inspire, certainly because the selection of results illustrates the importance that inhabitants attach to social contact and being enabled to meeting others. As the project was limited to a specific rural area of Belgium, future research might open up this particular focus to other areas so as to broaden perspectives.

The results show that designing in collaboration with local stakeholders has a lot of potential. Formulating answers to this project's focus didn't have to do solely with performing studies 'about' older people, but about discussing 'with' older people, as well as with other citizens of various generations so as to explore 'their' lifelong living practices to date. In future research, the intergenerational approach that was applied will be more actively explored. In addition, various avenues for sharing the accumulated knowledge on healthy and happy ageing in rural areas with a wide audience, among which evidently the inhabitants of the concerned villages as well as local and regional policy makers, will also be explored in more detail.

Acknowledgements

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HAND REHABILITATION FOR CHILDREN WITH CEREBRAL PALSY: FROM CLINICAL SETTINGS TO HOME ENVIRONMENT

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Abstract

For children with unilateral spasticity, therapy plays a crucial role in the improvement of their motor skills. Of particular interest are Constraint-Induced Movement Therapy and Bimanual Training (BiT) for children between 4 and 18 years old. These therapies are intense programmes that focus on training unimanual and bimanual skills. Moreover, these skills help children perform everyday activities that promote their sense of independence, such as preparing food or dressing themselves. However, after these short training sessions are finished, the lack of adherence to follow up programmes at home increases the risk of losing the gained skills. Technology supported home-based therapies offer opportunities to provide personalized training that will maintain and improve the developed fine motor skills. A question is how to design these home-based therapies in a way that they are complementary to regular therapy and extend their benefits. In this study, we observed two successful and commonly used interventions for the treatment of children with Cerebral Palsy in The Netherlands: The Pirate and the Handig2Handig groups. We analysed current literature of these programmes and observed assessment and therapy sessions, which provided further information about the process, the structure and the tools used. Then, we identified which elements that characterize these therapies could also be used at home, and what are the challenges for their implementation. Finally, this study resulted in a list of elements that can be implemented in the development of future home-therapies; the identified elements are: BiT, goal setting, feedback, opportunity of repetition, the role of the caregiver and the role of play. We discuss these findings while considering the opportunities that smart personalized technologies in the home environment bring to a future vision of technology supported at home-therapy for this group.

Keywords: hand therapy, home-therapy, children, cerebral palsy, motor skills

Introduction

Cerebral Palsy (CP) is a disorder caused by damage in the brain with consequences for movement and posture impairments. According to CP Nederlands, the Dutch organization of people with CP, cerebral palsy is the most common cause of impairment in children and spasticity is its most common form. This creates obstacles in development, confidence and overall quality of life. Physical and occupational hand therapies intend to help children increase manual performance to overcome these obstacles. Constraint-Induced Movement Therapy (and its modified version) (CIMT) and Bimanual Training (BiT) are such therapies. They are commonly used to treat hand spasticity and have shown to be successful (Chamudot et al. 2018). Specialized rehabilitation centres are able to successfully provide these therapies; however, specialists recommend additional daily home-therapy to maintain the skills learned. In the case of children, there is a lack of continuity of progress in the home environment. Some of the reasons mentioned for this are low motivation in children to perform repetitive activities, tiredness after school activities and the disruption of the family routine. Then the question arises: what are the elements of the therapies at rehabilitation centres that could be taken into the home environment to motivate children to exercise? Therefore, we studied two groups based on CIMT and BiT that are widely used in The Netherlands (Pirate group and Handig2Handig group). A better understanding of these programmes can lead to design tools for home-therapies to improve the wellbeing of children with CP and their families.

Hand Therapy

Hand therapy for children with CP aims to increase the range of motion, coordination and strength of the affected upper extremity and thus gain autonomy. A lack of treatment can lead to fixed contractures of the muscles and joints, which in turn contributes to physical and emotional pain.

Constraint-Induced Movement Therapy (CIMT)

In CIMT the unaffected (non-spastic) hand is restrained with a sling or similar device that limits the movement of the arm. The core elements are repetitive practice and shaping used through activities selected to elicit movements in the joints with most deficit and with potential for improvement, and considering age and preferences of the children (Gordon, Charles, and Wolf 2005). In the modified version for children (mCIMT) the therapy is done during 3 to 6 hours per day instead of 24 hours as in the original version for adults. Daily play activities are broken into repetitive tasks with increasing complexity. Feedback is given to explain the appropriate movement and to give encouragement. Two example activities are puzzles to elicit precision grasp, release accuracy and in-hand manipulation and board games to elicit supination, wrist extension and precision grasp. According to Novak et al. (2013) CIMT is effective in providing improvement of motor activities (speed and dexterity) while being aligned to the families' goals.

Bimanual Training (BiT)

BiT focuses on the use of both hands to provide functional independence during daily activities. According to Charles and Gordon (2006) bimanual interventions are needed to increase the coordination of both hands, something that children with CP struggle with. The objective of BiT is to learn to use the affected hand as an assisting hand in predefined goals (e.g.: dressing, eating, cutting with scissors). Children learn movements via bimanual activities in a child friendly setting. The activities involve repetitions of the movements that have deficit. This is accompanied by strategies to increase the difficulty of the task to match the increasing ability of the child and the desired goals.

Activities include card games, video games and arts and crafts. Furthermore, BiT also has a family centred approach. Studies (Novak et al. 2013) have shown BiT to be effective in improving motor activities .

Pirate group and the Handig2Handig groups

The Pirate group is an intervention protocol designed for children with CP aged 3 – 8 (Aarts et al. 2012). It is based on four components: (1) combination of mCIMT with BiT, (2) motor learning theory and strategies, (3) play in a group therapy context and (4) involvement of parents in a homework programme. The Pirate group is an 8 weeks programme where children attend the rehabilitation centre 3 times a week, 3 hours a day. During the first 6 weeks the focus is on mCIMT activities followed by 2 weeks of BiT aimed at extending play and self-care activities. The intervention has a 'pirate' theme as a way to motivate the children to use only the affected hand.

Handig2Handig is an intervention based on the Pirate group but aimed at older children, 8-18 years old (van der Burg, Aarts, and Steenbergen 2013). It is an intense one-week programme where mCIMT and BiT activities are practiced working towards predetermined goals. In Handig2Handig the exercises are also done via playful activities with opportunity of repetition. During the programme children work on mCIMT and on BiT activities in an equal amount of time. In the last two days of the intervention, extra attention is given to the initially set goals.

Method

Observations of the Pirate and Handig2Handig groups were conducted at Roessingh Rehabilitation Centre in Enschede, The Netherland. Due to the availability of the therapy programmes the observations were divided into two stages. In the first stage, two assessment sessions of participants of the Pirate group and one assessment session of a future participant of the Handig2Handig group were observed in June 2019. There were 3 female participants in this session (aged 4-17). The second stage was an observation of the Handig2Handig rehabilitation group in August 2019, with 6 participants (3 female, aged 9-17). Qualitative data was gathered via field notes where the following themes were recorded: setting, exercises, material used, role of the therapists and behaviour of the children. Interviews with the therapists were done to understand better the process, the limitations and the possible role of new technologies in the therapies. With the compiled information we made a list of possible elements that characterize the therapies, this was later verified with the existing literature and finally an expert reviewed the items and provided feedback. Photos of the materials (toys, drawings and equipment) were taken with the authorization from the organizers of the sessions.

Results

Pirate Group and Handig2Handig assessment session

The assessment sessions for both groups have similar structure and they mainly differ by the use of age-appropriate toys.

Setting: Table 1 shows the description of the setting.

Table 1 Setting of the assessment sessions

Objective	To establish comparable metrics at the beginning and at the end of the programme to determine improvement.
Participants	Child Occupational therapist Physiotherapist Parent (to accompany)
Structure	1 hour of bimanual exercises directed by an occupational therapist and 30 minutes of Unilateral exercises directed by a physiotherapist.
Protocols used	Assisting Hand Assessment (AHA) Melbourne Assessment Video Observation Aarts Aarts (VOAA)
Observed hand movements	Pinch, hold and release, grasp, reaching with elbow extension, supination and dorsiflexion.
Physical space	Room with a table, one chair for the child and one chair for the therapist. The parent is present in a place close to the child to give reassurance but at a distance to not interfere. The session is video recorded. All the tools used are at a close proximity from the therapist.

Exercises and materials: The session consist of a series of exercises (Table 2) that allow the therapists to observe the child's quality of hand movements. The exercises are playfully done in repetitions in an allocated amount of time. A variety of materials are used to maintain the motivation and as a reward (the child can later eat the cake and chocolate).

Table 2 Exercises and materials of the assessment session

Bimanual exercises: These activities help identify how the children do movements with both hands, and if/when there were compensatory movements.	
A chocolate in a cake	Take a cake from an oven, make a whole in the cake and place a chocolate in it
Store the cookies	Pass a rope through a wooden ring and store them in a container
AHA	Handle different toys: music box, crown, marbles in a bottle, etc.
Cubes storing	Move cubes, from one side of a box to the other, first with the non-affected hand then with the affected hand
Unimanual exercises: Following the Melbourne Assessment, the child is asked to only use the "pirate" (affected) hand.	
Activity	Observed movement
Button	Reach forward
Crayons	Grasp and release
Chocolates	Pincer grasp and release
Block	Manipulation
Image	Pointing
Caress the head and neck and reach out and touch shoulder	Supination, pronation and reach

Role of therapists: The therapists provide instructions of the actions to be performed. Because the exercises are a sequence of steps, sometimes the children need reminders of the following step. Encouraging feedback was often heard like "Goed zo!" [Well done!].

Behaviour of the children: Most participants were willing to take part in the activities. However, frustration and embarrassment were observed in challenging activities, while defiance was noted in easy exercises.

Handig2Handig rehabilitation sessions

After an initial assessment, the children together with their parents define their goals (Figure 1), which are displayed in the common room as a reminder.

Setting: Table 3 shows the description of the setting.

Table 3 Setting of the rehabilitation sessions

Objective	Reach predefined motor goals by improving the fine motor skills of children.
Participants	6 Children 6 Therapists
Structure	Group activity: a shared moment between all the children and therapists, parents are also present. 4 hours of mCIMT 4 hours of BiT
Observed hand movements	Pinch, hold and release, grasp, reaching with elbow extension, supination and dorsiflexion.
Physical space	Several rooms in the children's rehabilitation department, including the swimming pool, carpentry workshop and music classroom.

Exercises and materials: Exercises (Table 4) were done with the aid of toys (Figure 2) to promote hand movement related to the goals. For example, to learn to zip a jacket, a pincer grasp is exercised by moving the pegs of the smart pegboard (Figure 2). These activities are designed and proposed by the therapists, but the children can also choose.

Table 4 Exercises and materials of the rehabilitation session

Unimanual exercises: Wearing a sling to practice mCIMT activities	
Therapy putty	To exercise grasp and release
Wooden tic tac toe, clothespins and Smart pegboard NEOFECT	To exercise pincer grasp and rotation
Cosmo Training	To exercise upper limbs extension and to run
Bimanual exercises: Children do more practical daily activities without the sling.	
Lunch	Half of the children and therapists are in charge of preparing lunch
Carpentry workshop	The other half work on a wooden box, they exercise by assembling, nailing and painting the box
Music class	With a percussion class different rhythms and combinations are practiced
Swimming pool	Different team games like tossing the ball and racing
Goal training	Allocated time to specifically practice the selected goals

Role of therapists: During this process the therapists play close attention to the improvement of the children, provide feedback and adjust the complexity of the exercises accordingly.

Behaviour of the participants: All the participants were enthusiastic to participate, showing improvements and camaraderie through the activities. Furthermore, the trust in the therapist was noticeable.
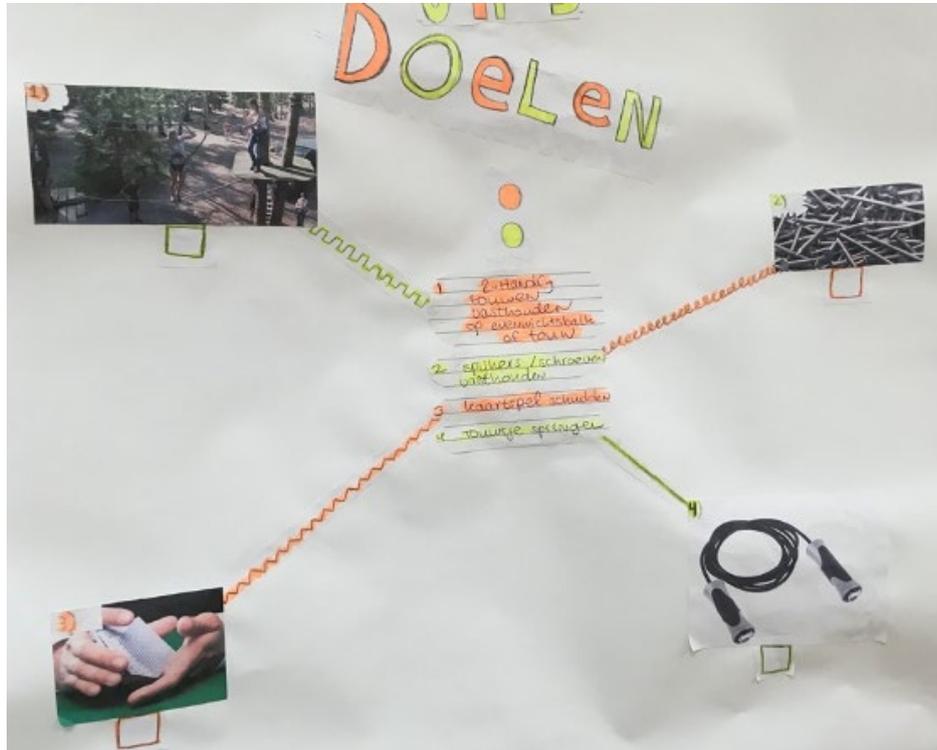
Figure 1 Goals of one of the participants [climbing, tightening screws, shuffling cards, jumping rope,]
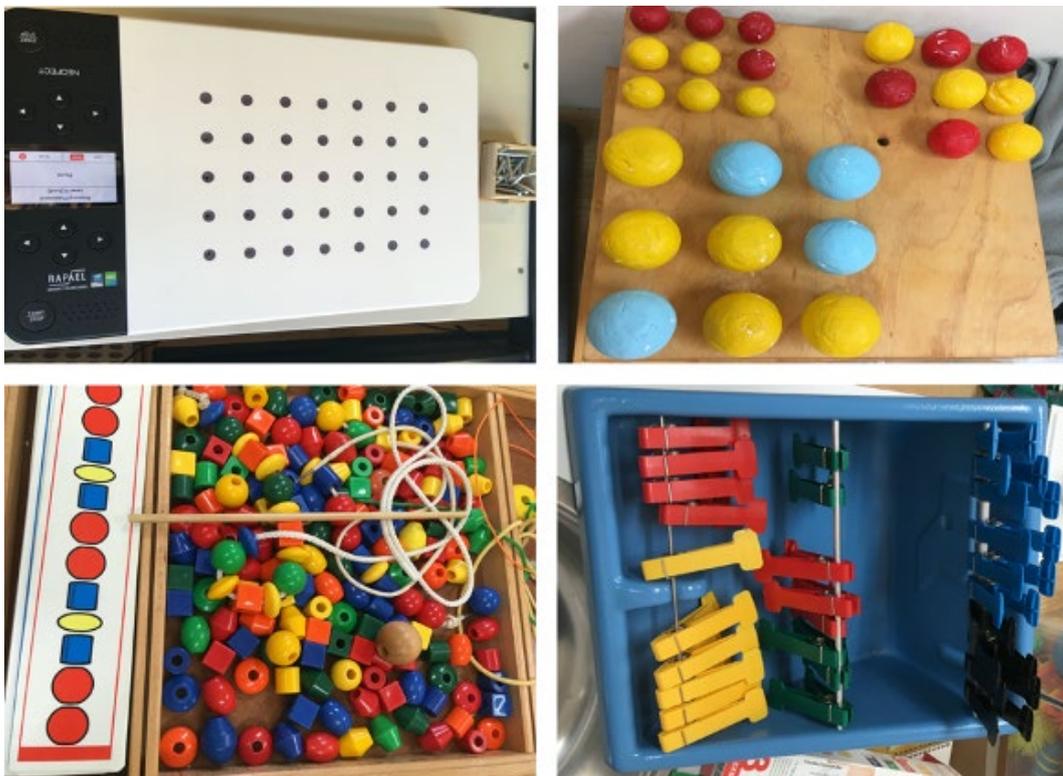
Figure 2 Example of toys used: Smart pegboard NEOFECT, beads and string, balls, clothespins.

Interviews: At the end of both sessions we asked the therapists a series of questions to clarify what was observed, the protocols used, the overall structure of the sessions and what they consider the motivating factors to participate: shown improvement, playfulness, fun, nice games, little presents like stickers, verbal encouragement and commitment of the family. As well as the demotivating factors: exercises too difficult, lack of variation in activities, tiredness and pressure on parents. We also interviewed Dr. Pauline Aarts, creator of the studied programmes, we discussed the programmes, the role of new technologies in home-therapies and reviewed the list of characteristic elements which is outlined in Table 5.

Table 5 Characteristic elements of the therapies that can be used in home-therapy

BiT	The importance of using both hands in activities at home gives confidence and independence. Although mCIMT is highly effective in hand therapy, it is preferred to do it only at the rehabilitation centres where there is a constant attention of the therapists and falls or accidents can be prevented
Play	Children find playing an appealing activity and they are naturally drawn to engage in them, keeping them motivated
Role of the parents or caregivers	Similar to what the therapists do at the rehabilitation centre, parents could have a role of providing feedback, proposing variety of exercises and adjusting the complexity
Goal setting	Aligned with the practices of BiT and mCIMT, the setting of goals gives direction towards a certain achievement which will increase motivation
Implicit and explicit feedback	Provide instructions of the relevant tasks, how to perform it, number of repetitions, outcome and performance.
Opportunity of repetition	Motor learning strategy that allow children to achieve relatively permanent changes in motor skills.

Discussion

This study set out with the aim of identifying the elements of successful hand therapies that could be applied in home-therapy. These findings may be somewhat limited by the number of sessions observed and the sole perspective of the therapists interviewed. Further research should be undertaken to investigate the perspective of the children and their parents and to obtain a deeper understanding of the home situation. Nonetheless, this first list of elements highlights opportunities in home-therapy that can be supported by new technologies. For example, smart personalized technologies provide customization of exercises to match the movement disorder of the child and the established goals. They monitor the actions performed and their quality. they detect and adapts to fit improvements in hand motion and they promote playfulness and feedback to maintain motivation. During the observations a high interest from the children to use the 'smart' tools (Cosmo, Neofect, etc.) was noted, which is understandable as computer games and new technologies are popular among children. And because they can give the opportunity to repeat often in a motivating way, other researchers are starting to use them. For example, at Saint Maartenskliniek (in Nijmegen, The Netherlands) there are already initiatives to use VR and Leap Motion. Next steps are to further analyse existing home programmes and compare them with our list of elements, expand the scope of this research and involve more participants, because in times of social isolation (due to Covid-19 at the time of writing), the urgency of successful home-therapies is emphasized when access to rehabilitation centres is limited.

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SOCIAL WELLBEING IN SERVICE DESIGN: HOW DOES CO-CREATION CONTRIBUTE TO THE SOCIAL WELLBEING BETWEEN PATIENTS AND PHYSIOTHERAPISTS IN ORDER TO FACILITATE RECOVERY PATHWAYS?

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Abstract

Rehabilitation services are changing towards a Person-Centred Care approach in which physical, psychological and social wellbeing are involved in the relationship between patients and physiotherapists. However, current research has predominantly focused on the provision of solutions for physical wellbeing. Research question: How does Co-creation contribute to the social wellbeing between patients and physiotherapists in order to facilitate recovery pathways? By using a service design methodology and co-creation approach, this research investigated the relationships between patients and physiotherapists with a focus on social wellbeing. Data was collected through developing a co-creative interview toolkit that combined semi-structured interviews and co-creative design tools. The relationship was investigated from a total of eight co-creative interviews: four patients with rehabilitation experience lasting more than a year and four physiotherapists. The researchers compared and synthesized the two perspectives.

Results: Concerning the relationship between physiotherapist and patient, we revealed four critical factors evidenced with the insight tree:
(1) Lack of communication between patient and physiotherapist when sharing information about the recovery process, (2) Building respect and honesty/meaningful relationship over time, (3) Sharing emotional wellbeing, (4) Setting and reaching goals, were the commonly shared categories in both groups of participants. The four factors allowed the researchers to design the recovery pathway. This was designed to guide the implementation of a new rehabilitation process, in which social wellbeing practices are integrated in new touchpoints interactions among the two actors.

Keywords: service design, healthcare system, design thinking, co-creation, social wellbeing, second line of care, physiotherapist

Introduction

The role of the patient in the healthcare system is changing. Increasingly the patient is seen as an active actor in the centre of the care network that takes part in shared decision-making (Ekman et al., 2011). Decisions that impact and concern a patients' quality of life, on which it is of vital importance to take into account the patient's personal views: his own health and wellbeing in the areas of physical, psychological and social functioning (Polonsky, 2000).

This research paper focuses on the social wellbeing dimension, defined as the individual's perceptions, influenced and supported by other social relationships. It showcases the relevance of Service Design and co-creation as a methodology to improve healthcare services by focusing on the patient experience and by including users as a resource and part of the design process. The objective of this research is to unravel the social wellbeing in the relationships between recovery patients and physiotherapists. Service design and design thinking tools can generate insights to develop future services that improve the social wellbeing between them. We aim to contribute to a better understanding of the social interaction and the emotional connection between patients and physiotherapists that might over time prove to be a success factor for overcoming diseases.

Theoretical Framing

Service Design and Co-Creation in Healthcare

Service design is considered as the activity of design thinking, planning and implementing change in order to improve a service's quality (Josefsson et al., 2017). Design thinking is a systematic innovation process that prioritizes deep empathy for end-users' desires, needs and challenges to understand a problem and develop more comprehensive and effective solutions (Roberts et al., 2016) while introducing co-creative tools to facilitate analysis. By including interdisciplinary knowledge, service design could add value to the healthcare system, by recognizing stakeholders' needs, desires, different perspectives and voices from the various actors, while testing ideas and solutions to address real problems.

Social Wellbeing in the Second Line of Care

Healthcare has been defined as a complex service system that interacts with other service systems to co-create value (Spohrer et al., 2008). In the context of such a complex system where different stakeholders are interacting, this research is focused on the 'second line of care'. Caregivers, family, community, nutritionists, psychologists, physiotherapists, dieticians and social assistants are involved in the patient ecosystem and are influencing and extending the meaning of wellbeing. Overall, the healthcare system provides solutions strategically oriented around physical wellbeing, mostly considering physical condition and symptoms. Based on the definition of Quality of Life (Polonsky, 2000), we can extend the overview of the patient's perception introducing social wellbeing, where an individual's perception and support from others are considered.

Recovery process and Care Pathway Design

In this context, service design must work on the social perspective and social environment of the patient, developing a person-centred care pathway that provides a better understanding of the social and psychological problems that people with specific diseases may confront. Healthcare systems are changing towards a Person-Centred Care approach in order to explore new pathways and develop solutions for the actors in the complex healthcare network

(Geerse et al., 2019). The analysis of interactions between different stakeholders is the key to discover new opportunities (Seys et al., 2017).

Research question

Current research is showing a lack of depth in the study of the 'second line of care', as it is showing interest and the provision of solutions just for physical wellbeing in the 'first line of care'. By using a service design methodology and a co-creation approach, this research investigates the relationships between patients and physiotherapists by focusing on social wellbeing, guided by the research question: How does Co-creation contribute to the social wellbeing between patients and physiotherapists in order to facilitate recovery pathways?

Starting from the impact of the rehabilitation recovery process, to better understand that the emotional connection between patients and physiotherapists might over time prove to be a success factor for overcoming recovery processes.

Method

Study Design

Qualitative methods are considered appropriate to gain an in-depth understanding of the phenomenon of interest (Corbin et al., 2008) since they have the advantage of producing a wealth of detailed data on a small number of individuals (Patton, 1990), along with the capacity to analyse complex systems as healthcare services. This study employs qualitative research based on service design. For this research, we developed a social experience toolkit by a blending and co-production of methods including the TU Delft set of design thinking tools that can be used to analyse social dimensions by exploring emotions, feelings, relationships, interactions, and latent connections (Desmet, 2019). With the social experience toolkit, designers can explore the strength

and weaknesses of services through the patient's healthcare experience.

Observation

An observation template was designed in order to collect specific information about 'the who, where, when and what' factors, always focusing on the interactions between patients and physiotherapists inside the Basalt centre. The observations allowed the researchers to map the recovery process from an external point of view and structure the boundaries of the context where the participants were interacting with each other.

Sampling

This research was developed in collaboration with Basalt (Netherlands), a rehabilitation centre with a large network of professionals specialized in chronic diseases. To increase the validity of the research the topic was investigated from a total of eight co-creative interviews in which different participants were involved: four patients recovering from different situations with their rehabilitation experience lasting more than a year and four physiotherapists.

PARTICIPANTS	GENDER	AGE	NATIONALITY	YEARS OF DISEASE / EXPERIENCE
PATIENTS				
Patient 1	Male	25	Dutch	2
Patient 2	Female	38	Dutch	23
Patient 3	Female	35	Dutch	6
Patient 4	Male	65	Dutch	2
PHYSIOTHERAPISTS				
Physiotherapist 1	Female	29	Dutch	8
Physiotherapist 2	Male	44	Dutch	21
Physiotherapist 3	Male	39	Dutch	15
Physiotherapist 4	Female	35	Dutch	12

Figure 1. Sampling table
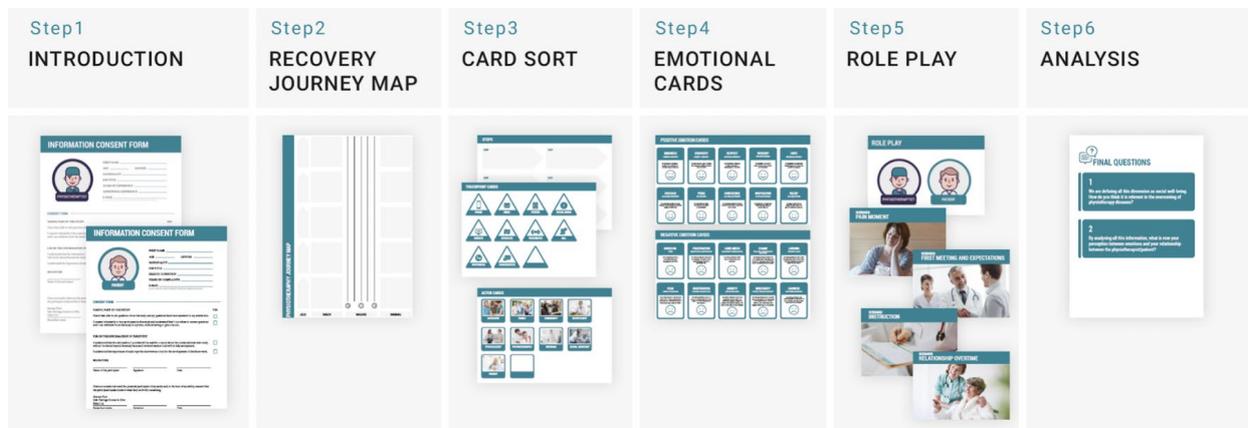
Figure 2. Co-creative interviews: social experience toolkit

Co-Creative Interview

Based on the research question, the interview guide was structured to explore the same topic with different participants in order to provide comparable data following six main steps while still maintaining the freedom to investigate specific directions (Patton, 2002). By matching co-design tools and a semi-structured interview, it became possible to define a research tool, such as the 'co-creative interview', that allows researchers to understand the emotional and psychological dimension of the participants and translate the insights perceived in visual mapping outcomes, contributing to the improvement of the level of reliability of the research. The structure of the session was divided into four sub-topics, in which the use of follow-ups/probes was implemented in addition to the design thinking tools developed by the research team. By developing an interactive and dynamic discussion, the researchers explored in detail the social and emotional participants' situation with the following tools (Figure 2). Secondly, a specific guide for each category of participants, patients and physiotherapists was defined to provide relevant answers and references for each sub-topic. All the methods were designed to explore the topic with the participants and to co-create an overview of opportunities that the researchers can define to develop new services (Scan QRCode).

Ethics

This research is performed according to the guidelines provided by TU Delft (HREC) Human Research Ethics Committees based on the Helsinki Declaration and Nuremberg principles (Human Research Ethics TU Delft, 2018-2024).

Data Analysis

The data analysis followed an inductive approach where triangulation is used to increase the level of validity. First, the field observations inside the clinic were analysed to identify the connections between the actors. Secondly, the design of the tools allowed the researchers to analyse the social wellbeing issues and topics. By clustering insights from the one-to-one co-design session, a visual map was developed to clearly represent the latent expectations that influenced the social wellbeing experience in the physiotherapist-patient relationship. Insights for each step and tool were identified to facilitate the comparison between the participants' experience and to analyse differences and similarities. The induction process of making categories and building the insight tree outcomes allowed the researchers to design a new recovery pathway, where social wellbeing enhances the interaction between patients and physiotherapists.

Results

Experienced Recovery Journey: social interaction issues

The first result (see figure 5) is the co-designed journey map of the current recovery process from the perspective of the physiotherapist and the perspective of the patient. By co-designing both journeys it became possible to generate a two-sided journey map to identify the social interaction issues by comparing the different perceptions (physiotherapist vs. patient) in relation to the main steps, emotions, actors, touchpoints, positive and negative factors involved. The findings show that in the current situation, both physiotherapist and patient have positive and negative feelings during the recovery journey. There is a clear fluctuation in the emotions expressed by the patients. Physiotherapists' perceptions are less affected by the personal interaction and the touchpoints involved.
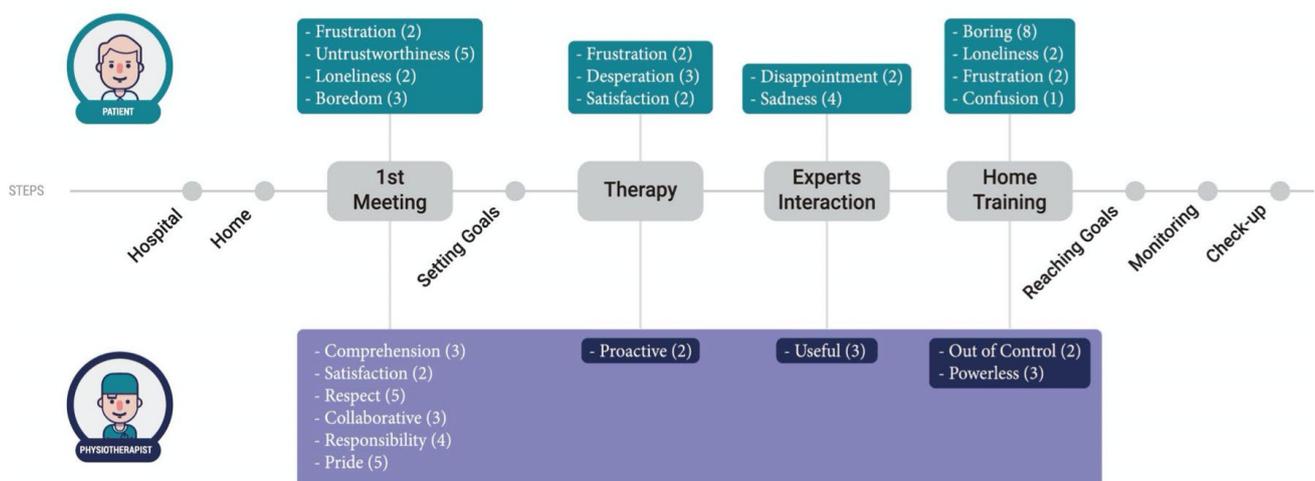
Figure 3. Social interaction between Patient and Physiotherapist Journey Map

For the main steps of the recovery journey patterns of differences and similarities were identified. Comparing the journeys, pain points from both the perspectives identified issues for new opportunities of service design.

The data analysis results identified four relevant issues during the recovery journey: (1) there is an evident lack of communication between the patient and the physiotherapist when sharing information about the recovery process; (2) building trust over time is a difficult task because of individual interests and unexpected changes; (3) the sense of belonging from the patient's perspective is influenced by different touchpoints and actors; and (4) the establishment of the recovery goals should be clear for patient and physiotherapist, and take into consideration the different actors involved. All these insights illustrated in the map, were used to design the new recovery pathway.

PATIENT	THEME	PHYSIOTHERAPIST
(8) Lacking of feedback by doing exercise at home		
(5) Receiving explanation, not just instruction		Providing a balance between exercise at home and inside the clinic (2)
(3) Interesting about the process	LACK OF COMMUNICATION HONEST, SUPPORT AND CLEARNESS (35)	Offering poster, video, website, hand draw (2)
(2) Being honest and direct during the process		Searching for connection by defining the process together (4)
(2) No connection between the exercise in clinic & home		Lacking of tools to provide right information out of the clinic (4)
(3) At home I don't have enough information to do exercise by myself		
		Understanding the past rehabilitation experience (2)
(3) Interacting with different experts provide confusion		Changing the behavior of the patient (5)
(3) Receiving respect and honesty from physiotherapists	BUILDING MEANINGFUL RELATIONSHIPS, RESPECT, TRUST AND HONEST OVER TIME (53)	Checking the progress regularly (8)
(3) Avoiding physiotherapist changing		Helping patient in the transaction between different physiotherapists (4)
(4) Integrating personal life during the regular process		Don't give promises that are not solvable (1)
(10) Building a meaningful relationship with the physiotherapist		Being honest and direct during the process (4)
		Avoiding fixing habits and long-term relationships by working over time with the same patient (6)
(11) Coping emotion along the recovery		Family and friends need to be involved in the process (10)
(5) Sharing experience with patients group session		Engaging the context around the patient (2)
(2) Receiving energy from other actors	SENSE OF BELONGING (59)	Considering community in the process (7)
(6) Avoiding feeling loneliness by sharing feelings		Giving positive sensations and good references (3)
(7) Having fun with the physiotherapist		Looking for the positive feeling during the pain moment of the process (6)
(1) Short-term goals to perceive daily improvement		
(2) Independence by doing exercise alone		Long-term goals be honest and direct during the long recovery process (6)
(8) Being aware about real problems and next processes	SETTING AND REACHING GOALS (38)	Understanding patients' desires (5)
(2) Receiving positive feedback from the goals achieved		Sharing knowledge between different physiotherapists (3)
(1) Passion about the recovery		Difficult home exercise check (2)
(5) Some patients with cognitive problems cannot understand the real dimension of long term goals		Sharing goals involving community and family (4)

Figure 4. Insights tree

Care Pathway Design

Figure 5 presents the design of the new Care Pathway for patients and physiotherapists involved in a recovery process / service. In the new service situation, the hospital, families, and friends (actors from the second line of care) have a crucial role in supporting patients. Besides that, before starting the recovery process in the rehabilitation centre, the communication between doctors, physiotherapists and other experts should be done in order to understand the previous diagnosis and particular boundaries (data reporting).

When setting goals, families are also important actors that support decisions and give relevant feedback. The community ensures that patients are sharing experiences and feelings.

Communication with other experts (including the changing between physiotherapists) during the process also ensures that professionals and decisions are the most suitable to patients' situations.

Furthermore, to ensure that the patient is sufficiently supported at home by the experts, digital communication platforms are designed to keep patients and physiotherapists up to date.

When finishing the process, I i's crucial for patients to keep in touch with physiotherapists by using social media and digital platforms. The new Care Pathway ensures that the social wellbeing of the patient is in the centre of every decision and step.
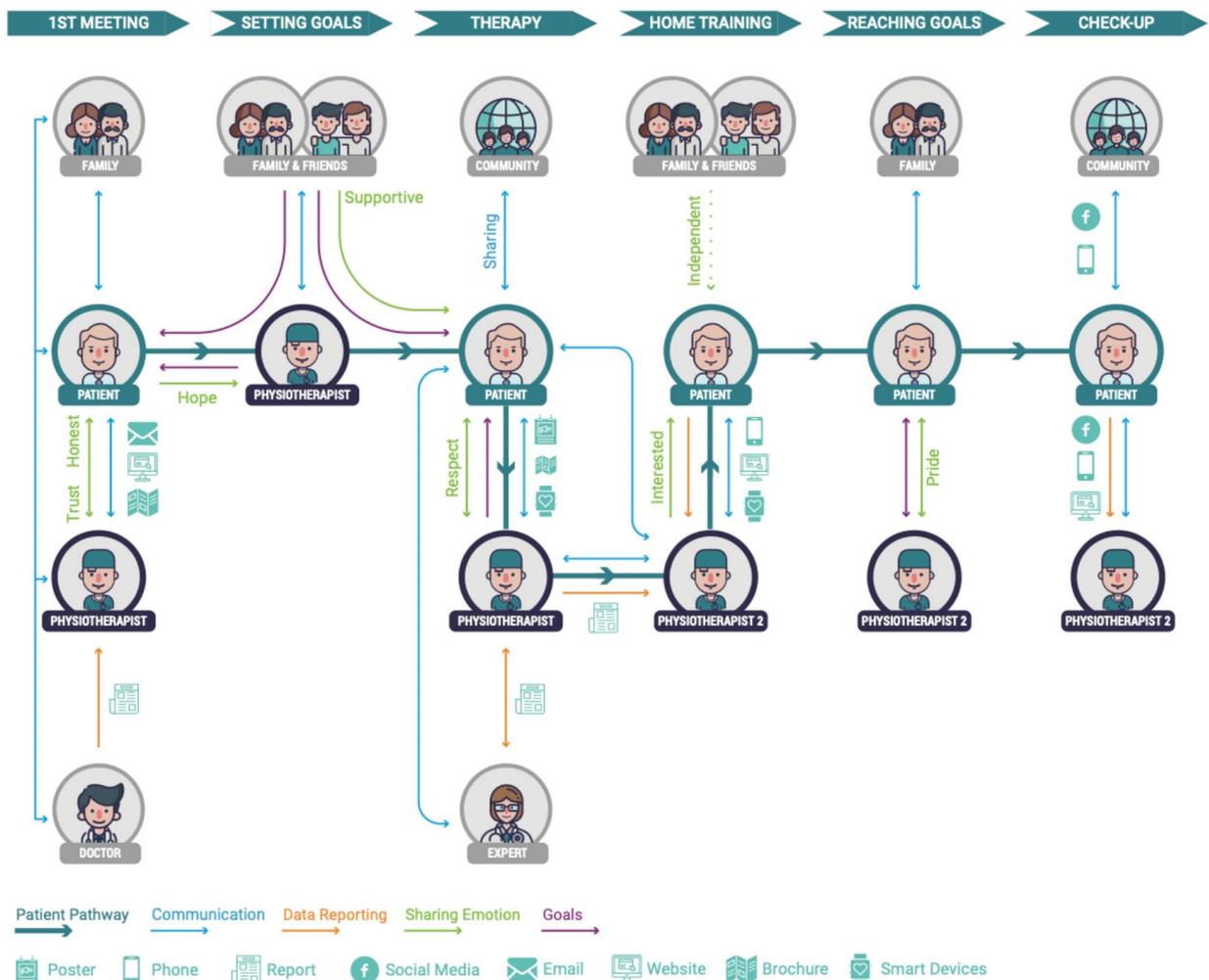
Figure 5. New care pathway design for the recovery service

Discussion

Principal Results

With this co-design study, it became possible to analyse and design the social experience and link the active roles of the patient and the physiotherapist on the different factors of the social wellbeing and ensuring the inclusion of the social dimension in the recovery process. By adopting co-creative methods, the patient recovery pathway unveiled two different aspects: (1) the emotional involvement and (2) the interactions between the actors. The research showed that in the current situation, the role of the physiotherapist in the rehabilitation process is crucial in the overcoming of diseases when the patient is fully involved in the relationship. The new care pathway design suggests improvements on the recovery journeys, in which new touchpoints are introduced and involvement of the various actors is considered. The data analysis allowed to compare the social feelings of the two groups of participants and define opportunities for re-design and implementation. Furthermore, the social experience toolkit allowed to co-create the pathway by crossing the information from both perspectives. First, building trust over time determines the starting point of the relationship in which the physiotherapist expresses his empathy in his effort to link patients' past experiences to the new recovery process. Second, the engagement of the 'second line of care' that should be practically integrated into the new recovery journey, considers the significant role of family, friends and community as external factors affecting the patients' progress and emotional stability. Third, the participants showed a lack of daily communication between them. The new care pathway implements the role of the physiotherapist outside of the physical meeting, considering as crucial the autonomous activity to be performed by the patient at home. Fourth, patients and physiotherapists are sharing experiences and activities and they must also share goals and expectations to ensure short and long term progress. The new pathway design incorporates a new procedure that defines specific steps taking into consideration the social wellbeing dimension during the recovery process; this may ensure empathy creation and development of a better experience for all the actors involved. The new touchpoints can help to solve the lack of communication and build trust.

Limitations and Future Research

Several limitations relate to the chosen method of qualitative research. For the purpose of creating in-depth understanding the study is based on one case setting. To verify the consistency across other centres and countries, more studies are required in specific diseases by adding new variables. In the area of second line care, the present research could be further extended by analysing other actors, such as family and communities, who are also involved in the recovery process.

Comparison with Prior Work

Most of the existing body of knowledge on service design in health focuses on the 'first line of care' by considering the role of doctors, nurses and pharmacists during the recovery process in which the physical wellbeing is analysed as the main consideration. Reasons to consider the relationship with a physiotherapist as a crucial factor in the overcoming of the disease have been researched in other studies (Lundvik Gyllensten Gard et al., 1999). This research adds how the social involvement of the patient meets the commitment of the physiotherapist during the recovery process.

Conclusion

This is the first study that presents a care pathway for the recovery process in which co-creation methods are used to explore the social wellbeing dimension by comparing the different perspectives of patients and physiotherapists. This study showed that service design methodologies can add value to existing qualitative research methodologies, by investigating and exploring emotions, and providing different directions for new product/ service developments. By creating the social experience toolkit, this research paper encourages future patient-centric studies to use this design toolkit for the development of new services. The care pathway displays new touchpoints to successfully implement the recovery process of the patient in the rehabilitation centre and at home.

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THE CO-DESIGN OF A PSYCHOEDUCATIONAL TOOL FOR CHILDREN AND YOUNG PEOPLE WITH ADHD

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Abstract

Attention Deficit Hyperactivity Disorder (ADHD) is a neurodevelopmental disorder characterized by inattention, hyperactivity and impulsivity. The effects of ADHD can impact on the individual, their family and community. Evidence supports a multimodal approach to ADHD management. This involves pharmacological and non-pharmacological interventions that incorporate psychoeducation specifically aimed for children and young people (CAYP). Although this approach is recommended in various clinical guidelines internationally, it is yet to be incorporated into UK ADHD clinical guidelines.

There is a paucity of psychoeducational material available for CAYP. In addition, non-pharmacological interventions for CAYP with ADHD are often not suitable or designed appropriately. Therefore, this is a promising opportunity for co-designing materials with CAYP, as co-designed interventions are reported to be more likely to be accepted by end users, resulting in better suitability, engagement and subsequent effectiveness.

This project adopted innovative methodologies to co-design a psychoeducational tool (a magazine) for primary aged CAYP with ADHD. To establish the clinical need for the tool and what it should contain we conducted focus groups, interviews and co-design workshops with specialist ADHD clinicians, parents/carers and CAYP with ADHD. Thematic analyses found the content for the magazine should include information such as what ADHD is, how it affects CAYP, how to explain ADHD to friends and family and how it affects CAYP in adulthood.

Age appropriate, short and varied tasks engaged CAYP with ADHD during the workshops. This, coupled with parent/carer and clinical involvement through the co-design process, provided a valuable insight into the requirements for a complex intervention for a complex condition, which may result in better acceptance and future impact.

Keywords: ADHD, psychoeducation, co-design, complex intervention

Introduction

ADHD is a comorbid neurodevelopmental disorder characterized by inattention, impulsivity and hyperactivity (NICE 2018) which can impact the individual, their family, their educational attainment and is associated with premature death (Harpin 2005). Children and young people (CAYP) with ADHD often experience a number of ADHD related difficulties including poor social skills, learning difficulties, disruptive behaviour, low self-esteem, unsettled relationships and lower academic attainment (Harpin 2005; Powell et al. 2018). The mean cost for the NHS, social care and education systems is around £670 million for CAYP, amounting to £5493 annually (Telford et al. 2013). This means that ADHD management creates a large economic burden on healthcare services and society.

Currently, in the UK, when a young person is diagnosed with ADHD, the parent or guardian is provided with information sources about ADHD, how it can be treated with both medication behavioural interventions such as attending an ADHD parent course (NICE 2018). CAYP are often not provided with any information for themselves and therefore rely on clinicians and parents for information about their condition. However, educating CAYP and the parent should be a first step to treatment as this can lead to more positive life choices that could help CAYP avoid falling into future crises and more expensive longer-term interventions (NHS England 2016, Ferrin and Taylor 2011).

There is some reliable and unreliable information available online, however few websites are aimed at CAYP with ADHD and are therefore unsuitable. In addition, these sources of information are often not designed in partnership with end users and or stakeholders and do not account for the variable contexts they are delivered in. Therefore, it is important for future complex interventions to be designed using methodologies (e.g. co-design) to increase the likelihood of long-term acceptance and impact (Greenhalgh et al. 2016).

Co-design involves end user(s) and stakeholders in intervention development. Co-design is defined as 'the creativity of designers and people not trained in design working together in the design development process' (Sanders and Stappers 2008, 6). Fekete and Lucero (2019) found that co-design with CAYP with ADHD was feasible if individual needs and preferences are considered, adapting the Diversity for Design Framework (Benton et al. 2014) accordingly (Figure 1).

Diversity for Design Framework for ADHD

STRUCTURED ENVIRONMENT

Understanding Culture

1. Quiet/familiar environment (A)
2. Start with visual recap, end with summary, intro to next session, energizing activity (A)
3. Weekly sessions same time/place (A)
4. Visual schedule + routine to tick off activities (A)
5. Remove any resources not required for current activity (D)
6. Start with design task fine details (A)

Tailor to individual

9. Themed to hobbies/interests (A)
10. Appropriate content for ability (E) (D)
11. Multiple modes of expression (U) (D)
12. Self–reflection to adopt a growth mindset (U)

ADDITIONAL SUPPORT

Understanding Culture

13. Team building activities (A)
14. Visual activities and design templates (E) (A)
15. Provide alternative strategies for task (U) (D)
16. Short, focused and achievable tasks (E) (D)
17. Holistic experience: Involve the whole body, activities with motion (E)
18. Rewarding:
• completing an activity
• tactile reward, not yet complete (collectable) (E)

Tailor to individual

20. Link to existing knowledge/skills (A)
21. Adult support: engagement – self esteem: encouragement (E) (D)
22. Behaviour issues: freedom to leave: feeling of missing out from rewards (E)

Figure 1: Adapted D4D Framework (Fekete and Lucero 2019).

Fekete and Lucero's study did not involve intervention development, and authors are not aware of other studies in this context. Whilst Fekete and Lucero's work was published after the co-design activities described in this paper, the latter followed many of the key principles outlined in the D4D framework. Therefore, this paper will focus on the specific tools and methods used to engage this population, and key insights generated.

Aims and questions

Prior work by the authors, including a first-of-its-kind workshop involving Lego® Serious Play (Powell, Parker, and Harpin 2017), suggested scope for an intervention targeting primary school aged CAYP with ADHD, to educate them about their ADHD in a fun, engaging age appropriate way, to help them self-manage it effectively, alongside usual care. This paper outlines two subsequent co-design workshops, conducted with CAYP with ADHD and their parents, to explore and develop this idea together, guided by the following questions:

1. What do you find difficult as a result of your ADHD?

2. In which contexts do you experience ADHD related difficulties?

3. What would you like to learn most about your ADHD?

4. What types of paper-based tasks do you like and why?

5. Which of these paper-based tasks would you like to help teach you about your ADHD?

Methods

The workshops

The workshops took place at a quiet, familiar location to participants in May 2019. The goal was to encourage creative thinking through designer-led activities.

Activity 1: An introductory task that involved CAYP colouring in a template of a superhero and annotating it with their 'super-powers', which referred to things they like about themselves that result from their ADHD e.g. lots of energy.

Activity 2: Participants watched a short (2 minute) cartoon portraying the message that everybody with ADHD is different and experiences their ADHD differently. This was followed by group discussion around ADHD related difficulties in different contexts e.g. home, school.

Activity 3: CAYP were given a packet of paper slips outlining ADHD related topics they could learn about. E.g.: 'how to manage my emotions', 'being more organized', 'what causes ADHD?', 'how to tell my friends about ADHD.' They were asked to put the slips they were not interested in; in the bin and stick the ones they did like onto a sheet of paper. They then identified topics they were most interested in learning about.

Break: Important due to limited attention spans of the population. CAYP could redeem 'golden tickets' to reward their efforts for a packet of Lego to take home.

Activity 4: The final activity looked at a number of ADHD themed activities e.g. word search, maze, true or false questionnaire and an origami fortune-teller (see Figure 2). CAYP were introduced to these tasks on a one-to-one basis. This gave them an opportunity to speak with the facilitator individually. CAYP then completed the activities, stated what they did and did not like about them and identified which tasks they would prefer to undertake in the future to learn about their ADHD.

Figure 2: Dr Wheeler introducing paper-based activities to some of the CAYP.

Results

Participants

Pseudonym/ Workshop (W)	Age (yrs1)	Gender	Diagnosis	When ADHD diagnosed	ADHD medication during workshop?	SDI4
Ryan (W1)	9	M2	ADHD	2017	Yes, Elvanse 20mg	14300
Billy (W1)	12	M	ADHD	2014	Yes, Concerta 54mg	4913
Jack (W1)	9	M	ADHD	2016	Yes, Lizdexamphetamine 40mg	32596
Laura (W1)	9	F3	ADHD, ASD	2016	Yes, Equasym 30mg	17403
Ross (W1)	7	M	ADHD	2017	No	17539
Ben (W1)	10	M	ADHD	2015	No	17290
Megan (W2)	12	F	ADHD, ASD	2013	Yes, concerta, 54mg	820
Dennis (W2)	9	M	ADHD, ASD	2017	Yes, equasym 20mg	30041

Table 1. Participant demographics
SDI4: Social Deprivation Index. 1 = indicative of most deprived area in United Kingdom. 32844 = most affluent area in UK.

The superhero warm up activity identified characteristics the CAYP liked about their ADHD:

- Lots of energy to play;
- Enjoys playing computer games;
- Having a 'super brain';
- Being 'good at maths';
- Being neat and tidy.

What do you find difficult as a result of your ADHD and which contexts do you experience ADHD related difficulties?

Group discussion identified difficulties in different contexts (Table 2).

Context	ADHD related difficulties identified
School	Difficulty concentrating during lessons Difficulty making friends Difficulty keeping old friends when moving to secondary school Hard to tell others about ADHD Daydreaming during lessons Keeping up with lesson pace Forgetting PE kits/other equipment Missing out on parties/playing games during break/lunchtimes Lots of noise/hard to concentrate
Playing with friends	Trying to save energy for tasks the following day when it is too tempting to play with friends the day before (makes him tired the following day) Hard to make new friends and keep old friends
Home	Waking up in the morning Wants to play with friends outside at unsociable hours (not allowed!) Telling the truth Managing emotions
Family	**[Participants preferred to focus on other contexts]**
Hobbies	
Other	Disliking loud environments

Table 2. ADHD difficulties in different contexts

What would you like to learn most about your ADHD?

This was addressed in activity 3 (described above). The CAYP had specific comments around the topics listed. For example, Dennis stated he wanted his friends to understand ADHD because his teacher 'doesn't help', he wanted to understand why he has 'frustrated feelings'. He felt these things got in the way of learning at school. Megan wanted her friends and family to understand her 'special needs' and how to 'cope' with her emotions. Billy wanted to know how to manage 'anger better' and similarly, Ryan wanted to learn how he could 'keep calm' but did understand his ADHD medication helps him concentrate and stops his head from 'banging'. Jack wanted to understand what ADHD stands for. He suggested using YouTube to find out. Laura wanted to understand why she had ADHD and how to 'keep calm… in a crisis'. Lastly, Ben was interested in ADHD medication. He wanted to eat during the daytime rather than have his hunger suppressed by the medication and wanted to understand why 'normal Calpol® (painkillers) won't work'.

What types of paper-based tasks do you like and why and which of these paper-based tasks would you like to help teach you about your ADHD?

Answering these questions involved CAYP completing a number of ADHD themed paper-based tasks (see Figure 3).

Figure 3: Example of the gamified learning activities

Participant engagement with the tools above was positive, with CAYP completing each of the activities. Ross stated he enjoyed the true or false questionnaire and marked it 10/10. Megan enjoyed the tasks but felt they were too easy for her, with the exception of the true or false questionnaire (she also expressed an interest for more unicorn themed tasks). Dennis said he enjoyed the tasks and would like to complete them at school. He found the word search challenging but worked with his parents to complete it. It is clear, then, that a key challenge of creating this resource will be striking a balance between making the activities achievable, engaging, and educational.

How workshop findings could feed into intervention development

A number of key learning priorities were raised, which will influence the development of the proposed magazine (Table 3). The suggestions of how these priorities could be addressed are tentative; decisions around this will be made following further co-design work with CAYP with ADHD, families and clinicians.

Key learning points	How it could be addressed in the intervention
Find out what ADHD stands for, what it means, what causes it and how it affects behaviour	Paper-based activity could cement this learning (e.g. true/false questionnaire)
How to teach friends and family about ADHD	Suggestions and key phrases could be introduced in the magazine
How ADHD medication works and what ADHD medications are available	Use of analogies. E.g. a postman working alone and losing messages/letters versus a many postmen working together and not losing letters. This is an analogy for the improvement of working memory when taking ADHD medication.
Techniques to help with routines at home and how to manage difficult emotions	Cartoon strips and scenarios could be presented within the magazine. This could be followed by a quiz.
How to set future goals	The magazine may not set goals for the young person as everybody is different and the goals should be achievable. Advice could be provided about how to think about goal setting and think about what is important to the individual and why.

Table 3. Potential next steps of the intervention

Discussion

Whilst some of the activities aimed to address 5 questions, some aimed to create a positive, creative environment. For example, the first 'superhero' task (Figure 4) drew from previous experience (Wheeler et al. 2018), whereby activities that encouraged self-expression, had no 'right' answers and took an asset-based approach were found to be effective when co-designing with children. This is particularly important in this context, as it is documented that the negative aspects of ADHD are focused on too much (Powell et al. 2019), with further reports demonstrating low self-esteem in CAYP with ADHD (Harpin 2005; Powell et al. 2019).
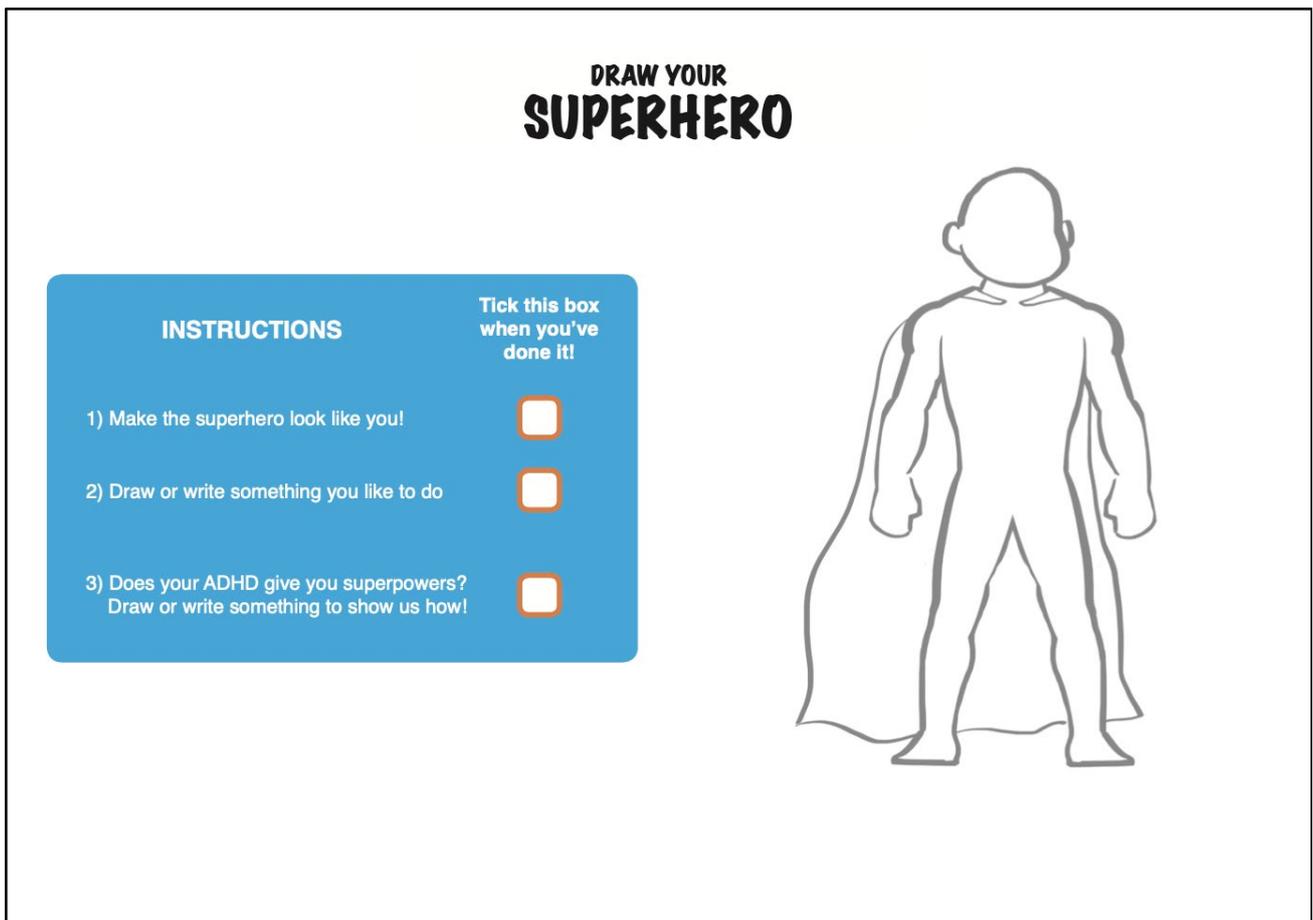
Figure 4: 'Superhero' activity

Working one-to-one with CAYP with ADHD and encouraging 'making' and 'doing' was beneficial. For example, paper-based activities were individually introduced and optional. All CAYP chose to engage with them, also demonstrating feasibility for the 'psychoeducational magazine' concept. The learning benefit of physically doing a task is also supported by John Dewey's Theory of Experiential Learning (Dewey 1997). This is because physical tasks can provide individuals with an experience, and the physical action(s) involved in the task can supplement learning.

It is also important to highlight that CAYP are able to articulate the challenges they face, and therefore should be engaged in co-design processes. For example, CAYP identified difficulties particularly in relation to school, including making and maintaining friendships, managing frustration and feeling of anger. This is important as educational attainment is reported to suffer in CAYP with ADHD (Harpin 2005; Powell et al. 2019). It is encouraging that CAYP could identify their ADHD related difficulties, as one could argue that identification of challenges is necessary to optimally self-manage a condition.

Strengths and Limitations

Given the small sample size, workshop findings should not be generalized to the broader population. However, there is a broader literature base that supports many findings of these workshops (Bussing et al. 2012).

The adapted D4D framework for ADHD (Fekete & Lucero 2019) will be used moving forward to provide a more theoretical basis. However, a number of the recommendations made by this framework have already been implemented during the present workshops e.g. quiet familiar environment, ticking off activities, ability-appropriate content and rewards.

The workshop sample was limited to a male majority. This is arguably not surprising as gender differences in ADHD have been identified with a ratio of 3:1 (male-to-female). The M:F ratio is from clinic populations only. Therefore, it could be concluded that the limited number of female recipients may not make this sample any less representative of the wider paediatric ADHD population.

Conclusion

The aim of these workshops was to begin the iterative co-design process of a psychoeducational magazine for primary aged CAYP with ADHD. The use of this approach is novel with this population as there are few published instances of co-designing with CAYP with ADHD.

Next steps are to design a prototype of the psychoeducational magazine and iteratively co-design is with end users and key stakeholders, with expert clinical input. This intervention will aim to educate primary aged CAYP about their ADHD alongside usual care e.g. ADHD medication, strategies to manage their ADHD at school, parent groups and ADHD clinics.

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GOAL SETTING FOR PHYSICAL ACTIVITY FOR OLDER ADULTS: AN EXPLORATORY CONTEXT RESEARCH

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Abstract

When individuals set the right goal it will improve their performance and motivation. Setting a goal isn't easy as it is personal and needs to be derived from the motivation of the person. Setting goals is already applied in many fitness apps, but there is still a lack of knowledge of how to apply this to specific target groups, like older adults. It is important for them to practise regular exercises as it contributes to healthy aging (Schutzer and Graves 2004; Peel, McClure, and Bartlett 2005). Motivating older adults to exercise more can potentially reduce costs in health care for older adults (Aoyagi and Shephard 2011) and could subsequently reduce work pressure for caregivers. However, some older adults still refrain from exercising because they do not see the benefits, are led by barriers and are insecure about their abilities.

This exploratory research aimed at finding insights in applying goal setting in a motivational tool to help older adults engage in an active lifestyle. It consisted out of two phases: Phase 1 aimed at identifying the relevant characteristics of older adults who might likely benefit from goal setting; Phase 2 examined to what extent goal setting could improve physical activities of these older adults. A group of 7 older adults participated in the study, they filled in questionnaires about their barriers, attitude and motivation regarding physical activity. They also participated in a goal setting workshop where they worked with a goal setting tool that was specifically designed for this research and target group. Additionally, they were interviewed about goal setting and their vision towards physical activity. This data combined gives insights in ways to motivate older adults and their characteristics relevant to goal setting.

Keywords: older adults, goal setting, motivation, physical activity

Introduction

Increasing the quality and years of healthy life is a big societal challenge with the populating ageing trend. Healthy aging includes the process of optimizing opportunities for preserving physical, social and mental health, as well as independence, the quality of life and enhancing successful life-course transitions (Peel, McClure, and Bartlett 2005). Being physically active is important to promote healthy ageing and prevent chronic diseases (Peel, McClure, and Bartlett 2005); (Schutzer and Graves 2004). Unfortunately, activity levels progressively decline while age increases. Knowledge about factors of exercise adherence will help the providers of healthcare solutions to develop interventions to stimulate physical activity (PA) of sedentary elderly (Schutzer and Graves 2004). How to motivate elderly people to remain physically active is the focus of this paper.

Goal setting is one of the commonly applied motivational strategies for behavior change. This research looked at how to apply it to motivate older adults to be physically active. The nature of this research will be exploratory: the context will be assessed together with the barriers and benefits related to goal setting. The results could gain knowledge of applying goal setting to specific target groups for behavior change.

Related Work

The *Goal-Setting Theory of Motivation* (Locke and Latham 2002) states that there is an important relationship between setting goals and performance on a specific task. The goals are used to evaluate the performance and are linked to feedback on the results and they create commitment and acceptance. However, individuals must have sufficient ability, accept the goals and receive feedback related to performance (Lunenburg 2011). Self-efficacy is, next to someone's ability, important for setting successful goals. Within setting goals there is also a distinction between *intrinsic goals* and *extrinsic goals*. The intrinsic goals focus on community contribution, self-acceptance, self-development, affiliation and physical needs: they satisfy basic individual needs. Extrinsic goals focus on social recognition, image, attractiveness, financial success and power (Wilson and Brookfield 2009). The Self-Determination Theory predicts that events that enhance self-determination and competence will facilitate intrinsic motivation (Wilson and Brookfield 2009). Setting a goal could enhance this self-determination and autonomy within the context of PA for older adults.

Goal-setting has been widely used in physical therapy and disease management with older adults where the professional medical staff often defines the goal themselves while the participation of older adults in goal-setting are desired (Brown, Bartholomew, and Naik 2007) (Baker et al. 2001). It has been found effective in encouraging PA among older adults in combination with behavioral self-monitoring and feedback (Gardiner et al. 2011). It has, however, not been widely used by commercial exercise apps in the Netherlands to stimulate physical activities of older adults. These apps (the Beweegapp (Senioren Sport en Bewegen 2019), the FysioFit app (FysioFitApp 2019)and the Fitavie application ('Bloeien Door Bewegen' 2019)) use push messages as reminders for exercising and give visual rewards, but no goal-setting strategy is integrated. This paper focuses to what extend older adults can apply goal setting themselves to become more physically active.

Method

This research adopted an exploratory approach. It was expected that setting the goals would influence the way participants saw and performed physical activities. The approach consisted of the following studies: 1) a qualitative study based on interviews and workshops with a specifically designed tool and 2) a quantitative study

with questionnaires about attitude and barriers. The research was conducted together with Stichting Ontmoet and Groet. This foundation hosts a community centre that provides activities for older adults. For this research the participants of the sports club were targeted. During the sports activities the participants conducted indoor exercises with a sports coach. Targeting the participants at the sports club made sure that people already had a fixed schedule of exercising. 7 people of the sports club participated in this study (2 male, 5 female) with an average age of 83.14 years old.

Probe

A probe specifically for this target group to practice goal setting themselves (see Figure 1) was developed together with an expert at Stichting Ontmoet and Groet. The participants confessed that they were afraid of the mental and physical deficiencies of aging, which made it difficult for them to think about their future, therefore a step by step approach was chosen to slowly work towards a future goal. The goal setting tool is bundled in a small booklet which they worked with during a workshop setting. In a few steps they were asked to look at the past, present and future regarding PA.

Figure 1: The goal setting tool

Deployment and assessment of the Goal Setting Tool

The research took place over a period of 5 weeks with 3 sessions. To assess their attitude the Attitude towards physical activity (ATPA) (Nelson, Benson, and Jensen 2010) was used. This questionnaire assesses the positive and negative attitudes towards physical activity (Nelson, Benson, and Jensen 2010). To gain more insight in

the barriers participants might face the Barriers to being active quiz (BBAQ) was used. The BBAQ gives insight in what refrains someone from being active (What are your barriers to exercise?, 2012). The data gathered in the sessions using the goal setting tool were thematically analysed. An overview of the sessions held with participants can be found in Figure 2.

Session 1	Session 2	Session 3
Participants were asked to fill in the questionnaires, where after a workshop about setting goals with the goal setting tool was held.	Feedback was given on the goals and participants were asked to reflect on their goals to give them the opportunity to work on their goals.	Participants filled in the questionnaires again, after that an in depth group interview was held.

Figure 2: Overview of the sessions with participants

Results

The qualitative and quantitative information generated an overview of the context and future focus points for designers and researchers within this context. Not all participants were able to finish the study due to illness during the test period, 3 of the 7 participants were unable to be there during Session 3.

Goal Setting

The goals set by the goal setting tool were thematical analyzed and coded by a deductive, latent approach. Many *intrinsic goals* (focused on self-development and physical needs) were set, derived from both intrinsic and extrinsic motivation. At the same time these goals had an extrinsic reward: staying active and fit results in a better physique, which is a physical reward. During session 1, it was observed that when they talked about PA in the past they talked about '*I liked participating in sports*' and '*I loved to walk around in nature*'. When they talked about sports in current time or the future participants say things like: '*I have to do it to stay active*' and '*I do it because I have to*' (see Figure 3). There seems to show a shift from being more intrinsically motivated to more influenced by extrinsic factors regarding their goals. During the interviews one older adult kept coming back: the community feeling and the atmosphere of the sports club. They motivated each other by coming together, drinking coffee and eating together. This was the main goal for them to come to the community centre, not the sports itself. They did consciously make the decision for participating in the sports club to stay healthy and fit (intrinsic motivation) but they kept coming back to the club because of the strong social aspects next to the sports (extrinsic motivation).
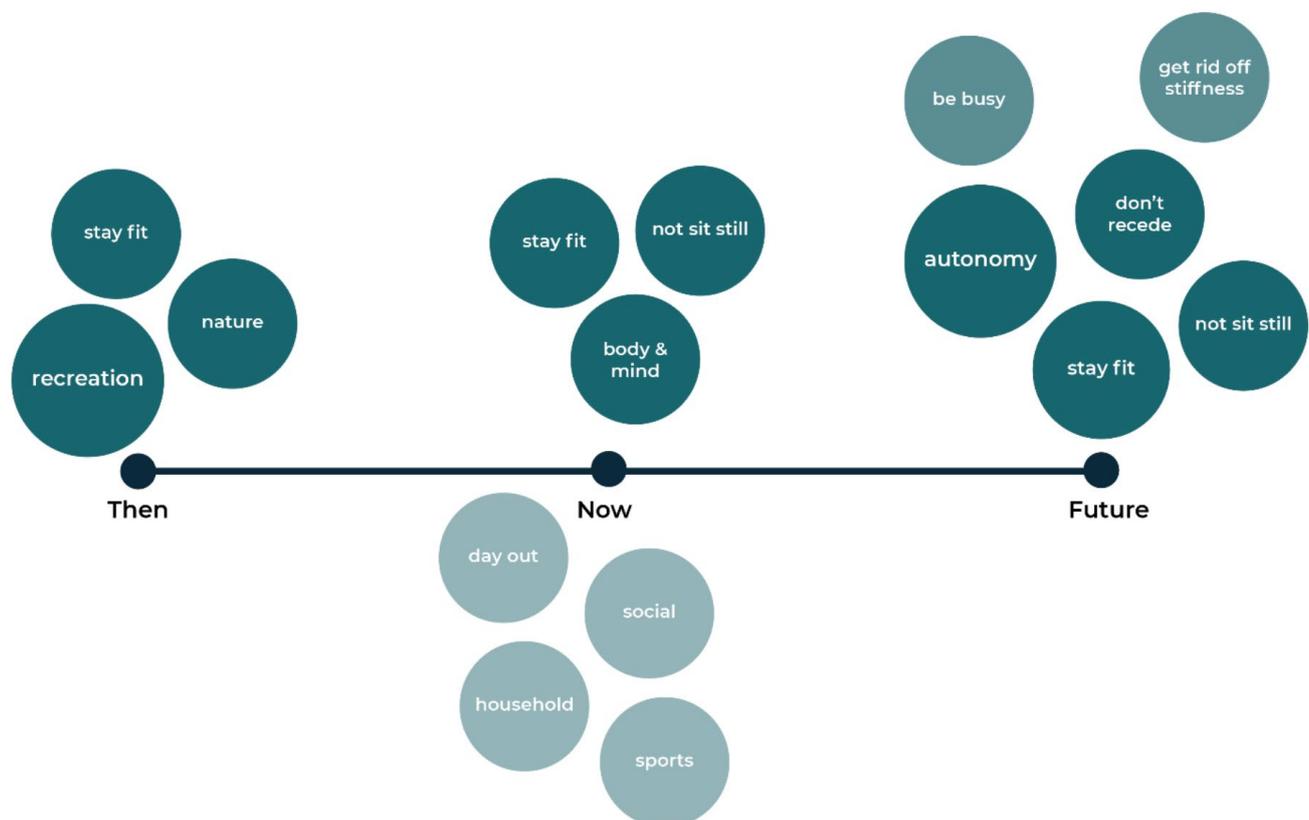

Figure 3: Thematical overview of the goals and motivations in the goal setting tool

During the second session they reset their goals based on feedback of the researcher. This was hard for them as they did not want to change from their current patterns. Some participants did add and changed their goals slightly based on their social motivations, because they influenced them positively. Therefore, they added this to their goal: to work on the social as well as the physical side of the sports club. They saw it as a social commitment and nice social gathering where they looked forward to. Further feedback was not taken into account by the participants.

Barriers

Analysis of the results of the BBAQ in general (Figure 4) showed that the main barriers were a lack of willpower and lack of energy. The questions about the willpower were about commitment of the participants: '*I want to get more exercise,* *but I just can't seem to make myself stick to anything*'. Even though the participants were very committed to the sports club, they experienced a barrier to do more. The overview in figure 5 also shows that some participants experienced more barriers than others. Participant 4 and 5 both perceived multiple barriers during the first measurement, both participants had according to the questionnaire fewer barriers at the second measuring point. Barriers that the participants currently experience related to their declining physical ability. They were constantly measuring their current self with their previous self: 'I am can now do half of what I used to do'. They also had struggles with talking about the future and about future steps. There is hesitance towards PA and talking about the future: '*My body has declined, I cannot do it anymore, so I won't do it anymore*'.

	N	Minimum	Maximum	Mean	Std. Deviation
Lack of time	7	0	5	2.29	1.890
Social Influence	7	0	5	3.00	1.732
Lack of energy	7	0	8	2.71	3.147
Lack of willpower	7	0	8	4.29	2.628
Fear of injury	7	0	7	2.29	2.430
Lack of skill	7	0	5	2.43	1.718
Lack of resources	7	0	4	1.00	1.528

Figure 4: Results of the BBAQ at session 1

Participant	Lack of time		Social Influence		Lack of energy		Lack of willpower		Fear of injury		Lack of skill		Lack of resources	
Session	1	3	1	3	1	3	1	3	1	3	1	3	1	3
1	2	-	4	-	1	-	8	-	3	-	4	-	0	-
2	0	-	4	-	0	-	6	-	1	-	2	-	0	-
3	0	-	0	-	0	-	0	-	0	-	0	-	0	-
4	4	4	5	4	8	4	5	4	7	4	5	3	2	2
5	5	7	2	4	6	2	5	4	2	0	1	2	4	6
6	2	1	4	6	3	1	2	1	3	3	2	4	1	0
7	3	0	2	1	1	0	4	2	0	1	3	3	0	2

Figure 5: Overview BBAQ, score >5 means a barrier on that topic (marked blue)

If I were to be physically active on most days…	N	Mean	Std. Deviation
…it would be painful	6	2.33	1.506
…it would be difficult	6	3.00	1.414
…it would be embarrassing	6	2.00	1.265
…it would make me feel uncomfortable	6	2.83	1.329
…it would make me tired	5	3.20	0.837
…it would make me sore	6	2.67	1.033
…it would be a hassle	6	3.00	1.095
…it would take too much time	6	3.33	1.211
…it would help me cope with stress	6	2.67	1.633
…it would help me make new friends	6	3.67	1.033
…it would get or keep me in shape	6	3.83	0.408
…it would make me more attractive	6	3.83	1.472
…it would give me more energy	6	4.00	0.632
…it would make me better in sports, dance and other activities	6	3.50	1.643

Figure 6: Overview Positive and Negative Attitude towards Physical Activity (Nelson, Benson, and Jensen 2010)

Benefits

The goals that participants set were intrinsic, with both intrinsic and extrinsic motivational factors. Overall, they perceived the sports activity as positive as it was tailored to the physical abilities of each person. The goals the participants created were derived from knowledge of the positive aspects that PA has on their body and their personal motivations to take action upon them. Further social aspects were recognized as the main benefit of participation in the sport group.

Discussion and Conclusion

As an actual change in behavior was not observed during this research it is hard to make claims on what intervention functions will certainly help for active aging. The influence of the environment of the community centre had a positive influence on the participants of the study. They continued coming back to the community centre because of the positive social environment. While designing and researching this context and target group it is impossible to rule out the influences of the aging process and the declining abilities of the bodies. It should be considered that the older adults are inevitably going to face physical and mental struggles while maintaining a healthy lifestyle.

The tool developed in the research did contribute as a means to find motivations and thinking processes of the participants, but it did not influence the way people viewed and participated in PA. It did not show significant differences in the behaviour pattern of the participants. The goals they set about their PA were too broad to be actionable. This observation is in line with earlier research where a collaborative goal-setting with professional medical/care staff was done (Brown, Bartholomew, and Naik 2007)(Baker et al. 2001). The participants were not really receptive for the feedback and changes they had to make during the second session. The goals they wrote down were mainly goals they already worked on for multiple years. The tool might work better for a group who is starting with a physical activity instead of using this tool with a group that is already familiar with sports. The goals that were set and their explanations gave more insight in their motivation and barriers instead of facilitating behavior change.

The group motivated each other and created a positive atmosphere around the sport activities through social support

and peer pressure. Declined mental and physical ability are barriers for people that are already participating in sports activities, as well as for people that want to start with exercising at a later age. Further barriers that were found during the research lie in the lack of willpower, which could also be a result of declined ability. The social aspect is also a benefit according to the participants as they described multiple times how the community feeling motivated them in participating. Another barrier that was identified during the tests is their hesitance to look towards the future, future plans and goal setting. Making plans and setting goals assumes most of the time that they work towards a better physical state, but due to their age they struggle with this because it is inevitable that their physical state will decrease.

In previous work related to goal setting, self-efficacy is found to be one of the factors that influences goal setting, motivation and performance. In this research self-efficacy is not actively taken into account.

This study is conducted with a group of 7 participants; to gain more insights in goal setting for physical activity for older adults a larger group with different levels in physical activity could be researched.

Conclusion

Applying the Goal Setting Theory of Motivation to a small group of older adults to see whether their performance will improve does not work the way it was envisioned with the goal setting tool. The tool did provide knowledge and insights about the target group and their current view on PA; however, it did not motivate people to work more on the goals they had regarding PA. The atmosphere in the group and the community feeling influenced the participants in a positive way and worked as a big motivator for the target group. The inevitable declining physical state did influence the participants in a negative way. The further measured barriers could

also be led back to this as well as the hesitance towards looking at their future. Future research and design could use these findings as a starting point in their process.

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28 DAYS LATER: HOW CAN WE USE HUMOUR AND DESIGN TO HELP YOUNG PEOPLE REFRAME THE 'HORROR' OF PERIOD TABOOS?

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Abstract

This paper reports on recommendations from a successful interdisciplinary pilot using adbusting response activities to address menstrual stigma in educational settings. Both explanatory and participatory, it shares lively practical demonstrations of transferable strategies.

Menstrual wellbeing and the impacts of taboo have been recognised in recent updates to international sex education guidelines along with a call to challenge internalised shame to prevent it becoming an embodied lack of agency. Advertising narratives have been identified as a cumulative negative influence in the discourse, and humour can facilitate young people to re-employ these tropes to satirise and reclaim their fear. Schools have been noted as a powerful point of influence in delivering public health messages around menstruation, providing an opportunity to address historic misinformation and disrupt intergenerational transmission of stigma.

Initially developed in focus groups and learning labs with twenty-four 13-year-old pupils in Sheffield, UK, the materials have now been developed into an education and training toolkit for adults and young people. In post-lab plenaries pupils reported increased knowledge and confidence around menstruation, and six months later reported clear retention of knowledge and confidence and reduction of discomfort.

Despite origins exploring menstruation, it has evolved into a unique and discrete toolkit that can overlay and complement outreach and training on other taboos. Notably, successful strategies for capturing participant comfort levels and providing moments for self-reflection and synthesis offered opportunities to address ethical considerations for supporting the emotional wellbeing of young or vulnerable people while working around difficult topics in a research setting.

These findings have positive implications for anyone dealing with sensitive issues through co-design.

Keywords: action research, advertising, advertising history, adbusting, co-design, craftivism, design approaches, education, forum theatre, graphic design, mantle of the expert, media literacy, menstruation, participatory design, participatory research, periods, public health messages, shame, taboo

THE MINERS' BANNER AS A CONDUIT FOR WELLBEING IN THE POST-INDUSTRIAL MINING VILLAGES OF NORTH EAST ENGLAND

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Abstract

Although the last colliery in North East England closed in 1993, the ceremonial miners' banners remain vital central artefacts in the pit villages stripped of their identity and purpose. These economically disadvantaged communities are using the emblematic power of their miners' banners to represent their resilience. The traditional parade of communities and their banners at the annual Durham Miners' Gala (DMG) becomes a focus for the pit villages' emotional regeneration.

During their working lives, miners' banners were taken to rallies and picket lines and were generally involved in action that left them damaged, or in some cases, completely destroyed. As a result, communities either retired their banners to museums, or were galvanized into action to restore, or make a new banner to re-engage their community around a central artefact. When Norman Emery calls the banners "Graphic messages of hope" (Tallentire 2014), he is referring to their powerful imagery, in which mining communities historically called for social justice and working-class rights. Now, it could be argued, the banners are being used as a 'message of hope' for the wellbeing of the communities themselves.

This paper will report on the creation, pilot use and evaluation of Relic; a tangential object; a design provocation created to distil the elements and essences of what a miners' banner is to its community in order to isolate and then interrogate the individual parts. Relic provides an uncommon lens for post-industrial mining villages in North-East England to draw on their own experiences of their banners; to find a new voice and give new insights into how a banner can promote citizenship, define a collective identity and function as a conduit for emotional wellbeing.

Keywords: banner; community; identity; emotional wellbeing; citizenship; co-creation

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DESIGNING A COMMUNITY-DRIVEN INNITIATIVE TO ENHANCE ADDICTION TREATMENT

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Abstract

The opioid crisis in the United States has had epidemic proportions. In 2018, more than 47.000 people died from an overdose involving opioids, an estimated 7.5 million people had at least one illicit-drug use disorder, and more than 2 million people have an opioid use disorder.

Today, substance abuse can be fought in many ways, like prevention, harm reduction, and treatment. Nevertheless, addiction treatment keeps showing high drop-out rates. Social support is a pivotal factor in relapse prevention. Yet, recovering patients have trouble engaging in new social relationships and communities lack the means to help them. Communities need to work together to help people in treatment, fight the disease of addiction.

The purpose of this paper is to describe the design process of a community-driven initiative, in which the care of patients in addiction treatment is shared by community members, giving the tools and resources for regular citizens to become addiction-treatment sponsors. Using a methodology of participatory design with people in a successful recovery, the result of the research is a toolkit that bridges the gap between patients in treatment and communities to generate the social engagement that can increase the rate of treatment adherence.

As part of this toolkit, there is a digital platform that provides coping tools, and pairs the patient to a community member in a 4-week program of task and rewards. Additionally, different functionalities connect a patient in distress with a member of the community to help them as a sponsor.

The significance of this project is the contribution of bottom-up approaches to social problematics and innovative solutions co-created with a vulnerable population to build caring communities.

Keywords: Co-Design, Social Innovation, Design Research

Introduction

The United States of America is suffering an opioid epidemic that has left an unprecedented number of deaths. 47,600 overdose deaths relate to opioids occurred in the Country in 2017 (67.8% of all drug overdose deaths). Ohio is one of the states that has suffered the hardest in this public crisis. In the same year, Ohio presented 46.3 overdose deaths per 100,000 inhabitants making it the second in the country (Center for Disease Control and Prevention 2018). Moreover, this crisis has also rendered a great number of people struggling with addiction.

There are many ways that this epidemic is being fought, from prevention, harm-reduction approaches, and of course, addiction treatment. However, addiction treatment presents high drop-out rates. These numbers are especially high when detox is not followed by another level of care (Smyth et al. 2010). Medication-Assisted Therapy (MAT) can be helpful for a patient to remain abstinent, but recovery from opioid addiction is a process in where individual motivation and supportive human services are key aspects for success (Marlatt and Donovan 2005).

One of the most important aspects of a successful treatment is social involvement. However, patients face problems engaging in new relationships and society is not involved in the recovery process of patients in our communities.

Even though there are different initiatives to tackle addiction, no effort is too great to fight this public health emergency, and there are still opportunities to build up community engagement with people in recovery as a supportive network. The purpose of this research is to design under collaborative methodologies a tool to bridge people in recovery with caring communities.

Background

Addiction Treatment

The opioid crisis in Ohio has been particularly hard, with the highest rate of overdose deaths in the nation, after Virginia (Center for Disease Control and Prevention 2018). Furthermore, The Substance Abuse and Mental Health Services Administration (SAMHSA) reported that in 2017 in the U.S, an estimated 20.7 million people aged 12 or older needed substance use treatment (This report includes alcohol and marijuana according to federal law), however just approximately 4.0 million people aged 12 or older received any substance use treatment in the past year (SAMHSA 2018).

Lately, Medication Assisted Therapy (MAT) with maintenance opioids such as methadone, have gained a lot of attention in the public opinion, but that is just part of a successful treatment.

George E. Vaillant, in his renowned study of long-term follow up, points to 4 key factor that are present in relapse prevention: 1- Compulsory supervision, 2- Finding a substitute dependency to compete with substance use, 3- Obtaining new social supports, and 4- Inspirational group membership (1988).

Even though MAT has very positive effects on relapse prevention, significantly better than detoxification (Vaillant 1988), patients are navigating through treatment in an unsupportive environment that enables relapse.

According to Vaillant, relapse occurs in someone 'whose daily life is unpatterned by a job, addiction imposes a very definite and gratifying, if rather stereotyped, pattern of behaviour. —addicts finally achieve a means of social reinforcement... Thus, drug addiction provides an ersatz occupation' (1988, 1150) and highlights community interventions as a way to bring structure in the life of a patient who have lost it or who never had it previously.

There are numerous obstacles to effectively drag treatment. For example, there is still a latent stigma around addiction and Medication-assisted therapy in neighbourhoods and even clinicians (Olsen and Sharfstein 2019). Nonetheless, social support can be found in different social spheres.

There is a significant study about the role of community and the patient that established the community assessment inventory (CAI) as a tool to measure the community support of a patient in drug free treatment (Brown et al. 2004). The CAI divides social support in four areas: 1) Partner of family with whom the patient is living 2) Family living outside the home 3) Friends and 4) Community.

The CAI asks 13 questions to assess support from community. These questions not only inquire about recreation programs or safety in the patient's neighbourhood, but also if the patient feels cared by the neighbours, or if the community believe in drug treatment.

> 'that not only family and friends, but also the community itself, or more properly the client's view of that community, could be of support or of impediment to the individual's intent to engage in treatment and seek behavior change.' (Brown et al. 2004, 248)

Social Innovation

The European Commission (2013) defines social innovation as the development of new ways to meet social needs and create social relationships, be that products, services, or models. Moreover, social innovation is not only about improving human well-being and facilitate an individual's capacity to act but also about improving and strengthening society as a whole.

However, not everything that is good for society constitutes a social innovation. Phills, Deiglmeier, and Miller note that

'many innovations tackle social problems or meet social needs, but only for social innovations is the distribution of financial and social value tilted toward society as a whole.' (2008). Thus, their main definition of social innovation weights what stakeholder perceives bigger value. For Phills and colleagues, if a solution to a social problem renders a bigger benefit to a stakeholder different than the society, is not social innovation.

Another approach is to think of social innovation as the ways in which people are creating solution to current problems in more effective ways, as a response to intricate systems, bureaucracy and slow politics (Murray, Caulier-Grice, and Mulgan 2010). This is basically a bottom-up or grassroots approach, where communities, groups, or associations can move and react faster than policy makers, governments, or big stakeholders.

According to the same European Commission report, Social innovation 'rely on the inventiveness of citizens, civil society organizations, local communities, businesses, and public servants and services. They are an opportunity both for the public sector and for the markets, so that the products and services better satisfy individual but also collective aspirations' (2013).

Ezio Manzini moves from the grassroots description towards Collaborative Organizations, companies evolving in highly connected environments characterized by the freedom of choice in their members and open attitude. (Manzini 2015)

There is a lot of commonalities between such collaborative organizations and the sponsor relation in Alcoholic Anonymous. The sponsorship is when 'an alcoholic who has made some progress in the recovery program shares that experience on a continuous, individual basis with another alcoholic who is attempting to attain or maintain sobriety through A.A' (Alcoholics Anonymous World Services 2017)

Also, AA refers to sponsorship as the responsibility that the group, as a whole, has for helping a newcomer.

From the social innovation perspective, there is a great opportunity to bridge the gap between communities and patients in addiction treatment, and to provide platforms in which we share the care of our members that are vulnerable due to addiction and increasing their chances to stay in treatment.

Methods

This exploratory research began with observation in support groups at a local agency that has focused on prevention and treatment of alcohol and drug abuse. Later, interviews and co-creation workshops were held in individual sessions with voluntary participants who had successful recovery stories. The interviews were conducted with the goal of understanding consumption triggers, social and family relations, and community engagement enablers during the treatment.
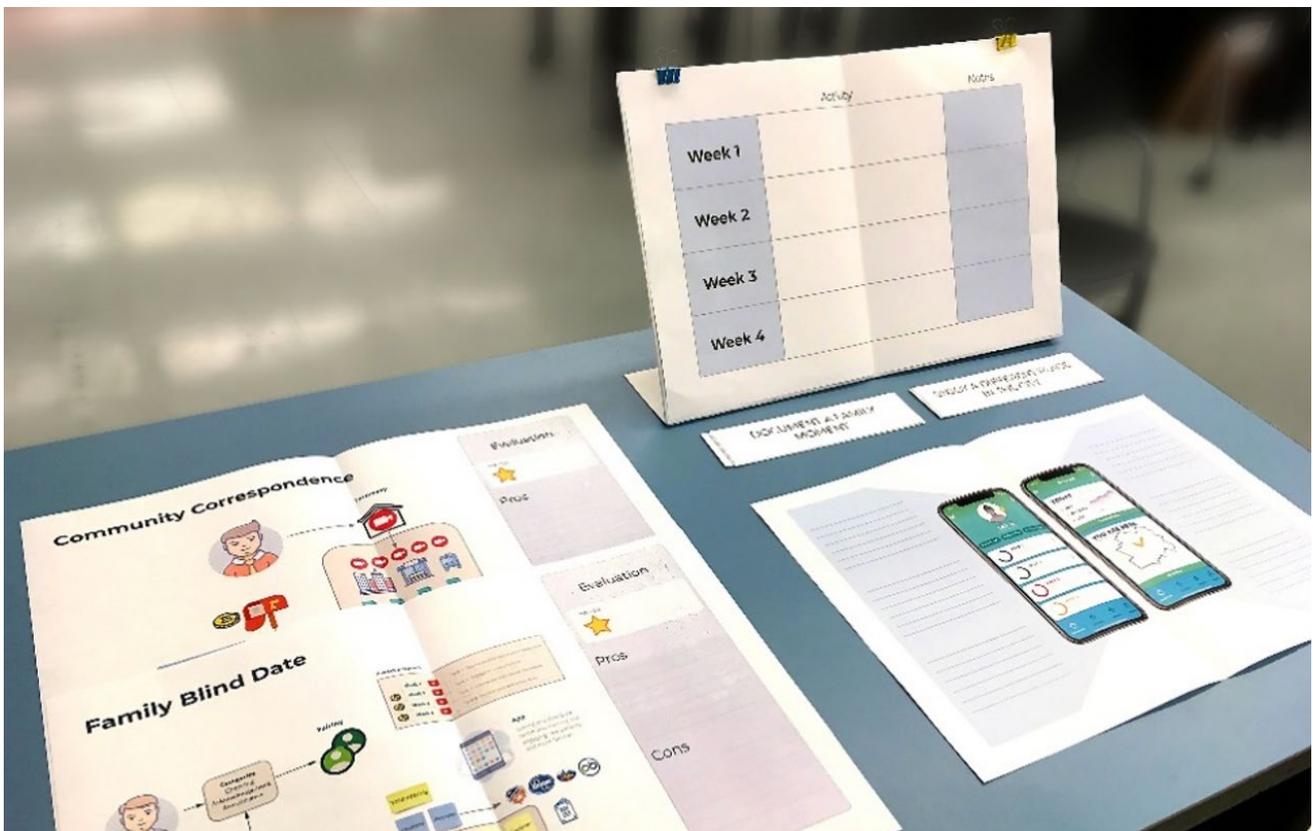
Figure 1: Co-creation toolkit

In the co-design session (Figure 1), the participants evaluated 2 design proposals for systems to engage people in addiction treatment to communities. They described pros and cons of each one. Then, ideated on the activities of a 4-week program based on the interaction of patients with members of the community,

The main objective of using participatory methods for the research is to help ensure that the result will meet the needs of people in addiction treatment and offer solution in areas where the user feels it would have a positive impact.

Lastly, with a pre-structured tool, the participants brainstormed on how technology can help in community engagement and what type of features can support these interactions.

In a similar way, a design concept and 3 main features were presented to the participants. The goal of this stage was to gather valuable insights and possible feedback for the final design, and have validation on the main features and interactions presented.

After presenting the app and introducing the 3 main features, a scenario evaluation tool was used to start provoke conversation with the participants. These scenarios described the use context of the main features to put the participants in the situation of a patient interacting with their sponsor through an app (Figure 2).
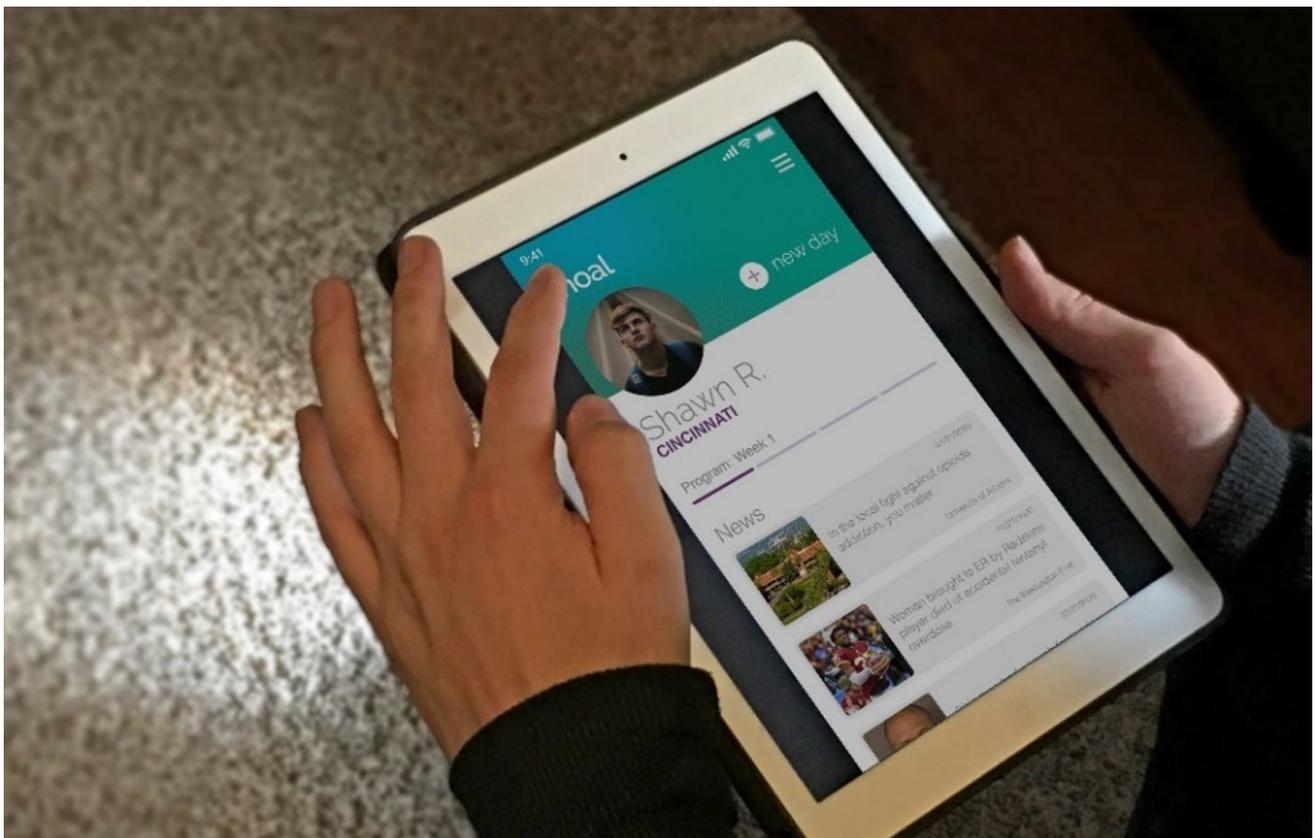
Figure 2: Participant testing the app prototype

Results

The concept of this design proposal was to shift the patients' responsibility of engaging back with the community into a model where community members share that responsibility with the patient (Figure 3).
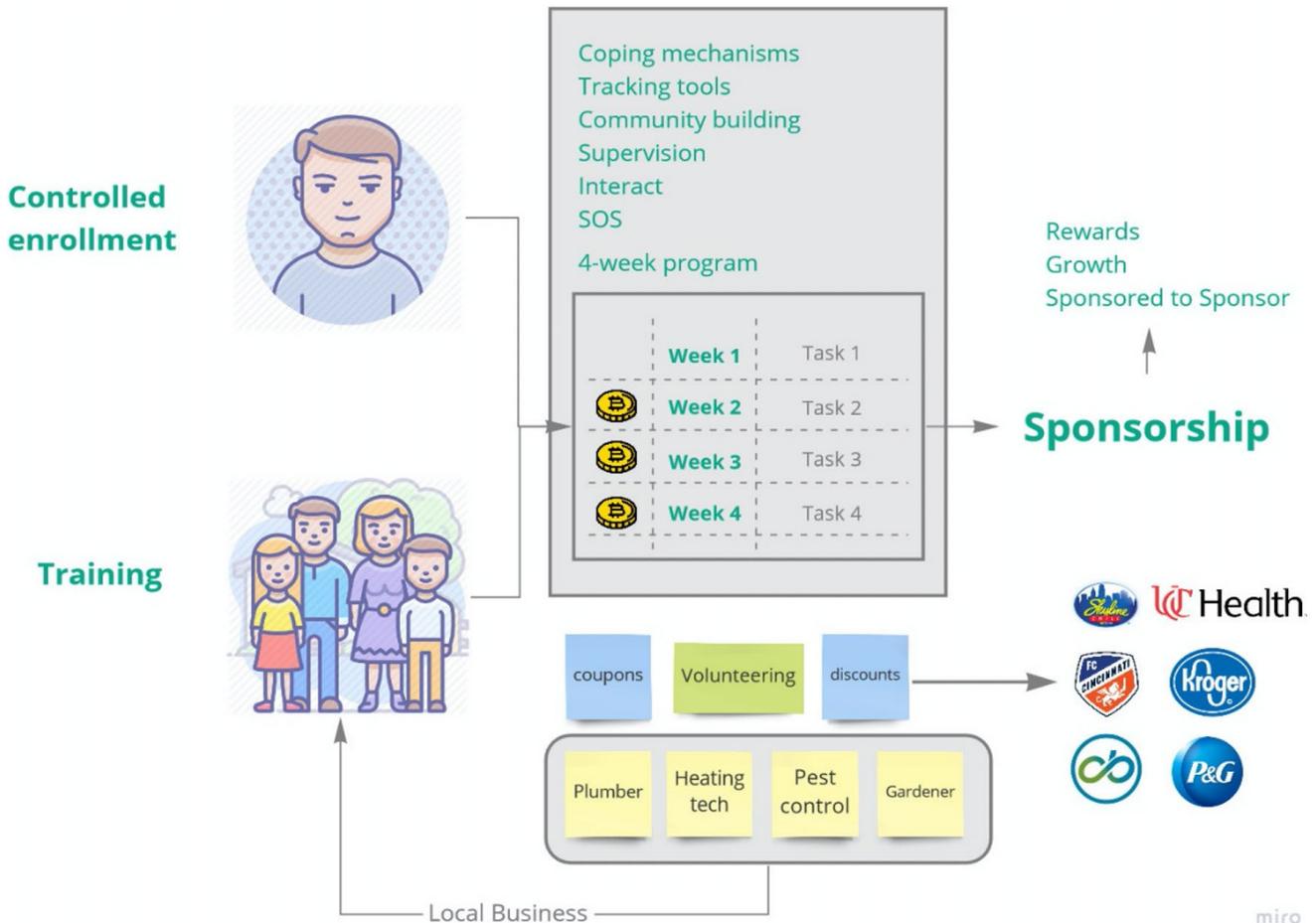
Figure 3: System map

In this proposed community initiative, community members would be trainned and then paired up with patients to undergo a 4-week program that would help with the treatment, self-discovery, and re-establishing bonding skills in the patient. creating at the end, the basis for a sponsor relationship

Additionally, each task in this 4-week program will award the patient with symbolic rewards, to recognize the progress. To sustain the initiative, different companies can be linked in various ways. For example, giving discounts or special coupons to the members or providing rewards to patients who achieve a significant milestone in

their recovery. The initiative itself can recognize publicly the companies for active participation in fighting the opioid crisis.

App

This community initiative would need an application that can be accessed through a website, tablet or smartphone (Figure 4). This facilitates its management and close the gap between people in addiction treatment and sponsors in the community. Furthermore, a mobile app can leverage different capabilities embedded in smartphones to be used in a sponsorship program. For example, Bluetooth connectivity, GPS, fingerprint sensor, etc.
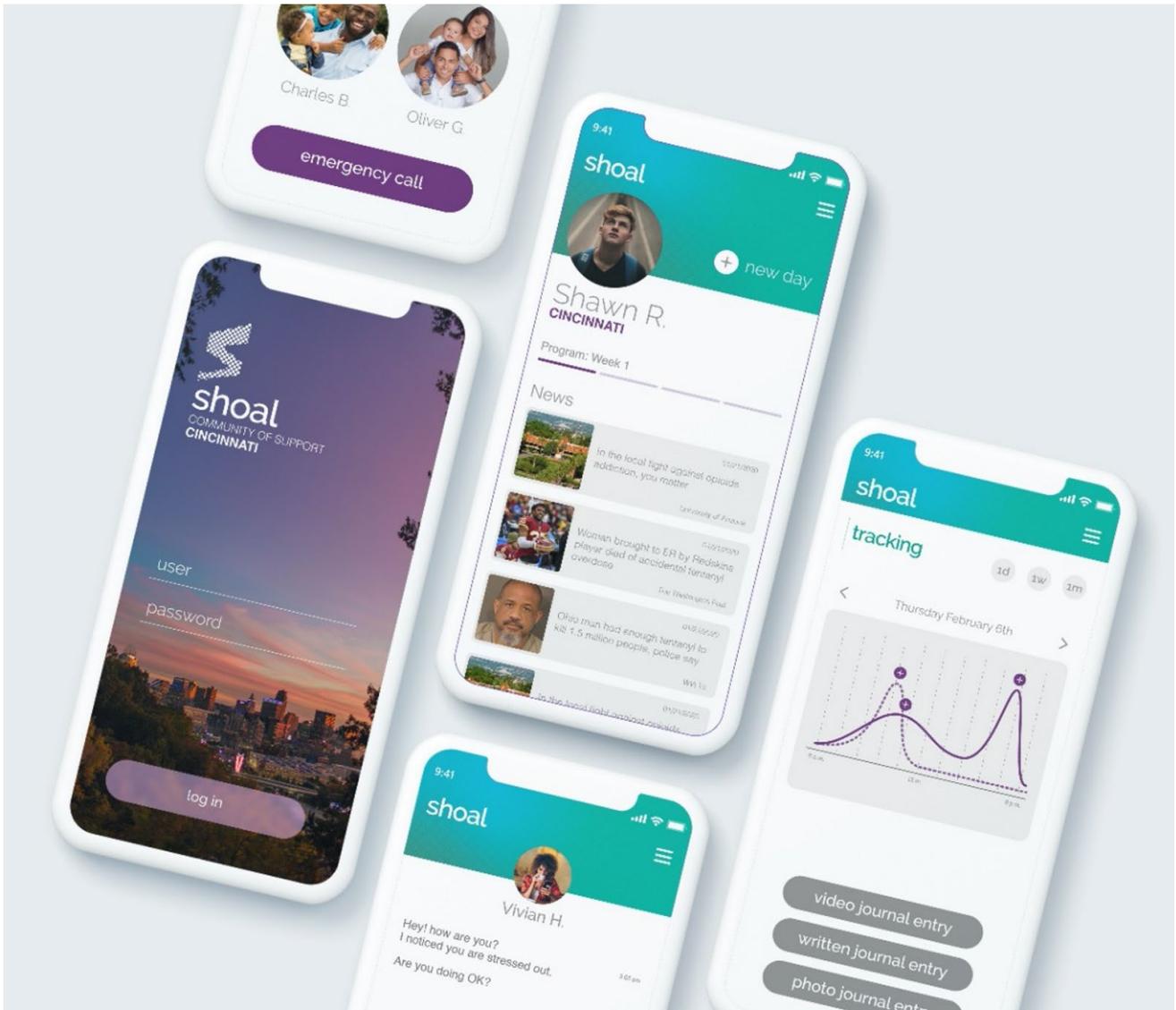
Figure 4: Shoal App UI preview

Special Features

To bridge the gap between sponsors and people in addiction treatment I designed 3 key features to achieve a different level of care. These features aim to impact the effectiveness of the sponsorship program providing a different intake on the supervision, communication and support. These features were tested in interactions with participants.

Emergency Call

It is a phone call that the person in treatment would make during a moment of extreme struggle of triggers and cravings. The phone call would be directed to the main sponsor. It that person does not answer, the call is re-directed to other sponsors. In case there is no answer, the call is re-directed to other members of the initiative that can serve as temporary sponsors. The last resource is there is no answer in the call, would be a 24-hour helpline, like the SAMHSA's National Helpline.

Anxiety Tracking

A fidget element to cope with stress and anxiety that is paired with the patient's cell phone and tracks the daily activity. Sudden spikes in the activity of the fidget activate a notification on the sponsor's end, that encourages to contact the person in treatment and ask about the anxiety.

Geofence

Geofence is a capability in an app that can recognize a perimeter in a real-world area. Sponsors and sponsored can establish geofences around the places in the city that produce triggers. When a person in addiction treatment crosses a geofence, it activates a notification to the sponsor to call the person and ask about their location and how they feel about it.

Discussion

"More comfortable pursuing support"

"Reduce stigma attached to addiction"

"More awareness in the community"

"Spark something in the people"

"People assume they are not qualified"

"They need to understand addiction and the illness"
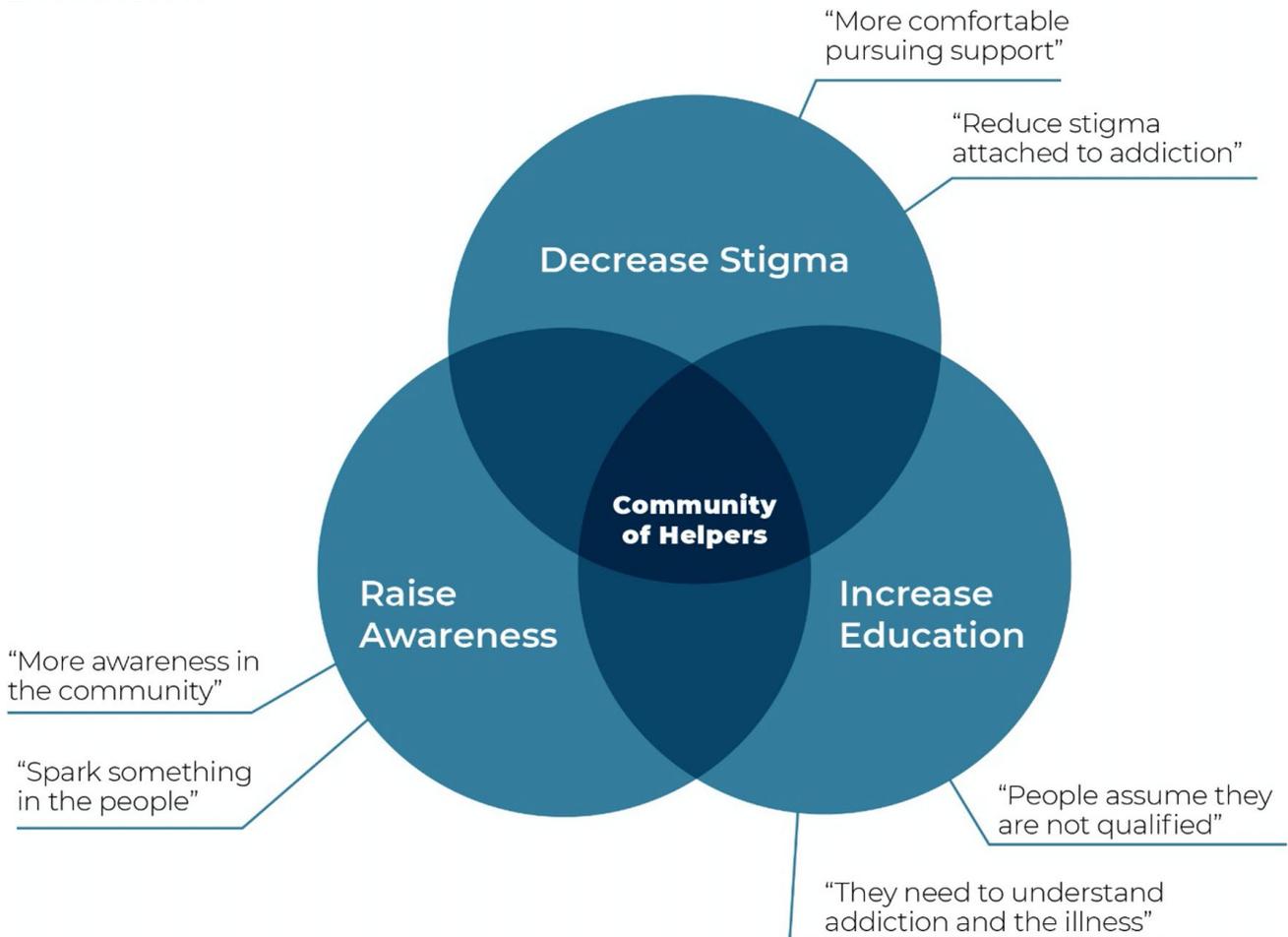
Figure 5: Areas needed in a community of helpers related to participant insights

There are 3 major elements to consider when designing solution to improve social engagement in addiction treatment patients (Figure 5). Raise awareness, decrease stigma and increase education.

Raising awareness alone has a low impact. However, it is important to increase the general information in the community and raising awareness opens the gates of the larger goal. It is not an easy task to share responsibility when you have a community that is not informed in the current state of a situation (such as addiction) especially, when they don't understand the necessity and the benefits in the long term.

The second step is to decrease stigma both in communities and patients. Communities need to provide a caring atmosphere that encourages patients to stay on treatment.

Lastly, to effectively help patients in treatment, all the parties involved need education before being involved and sustained education while enrolled in a program like a community initiative.

The people in treatment need to have resources that help navigate through life after recovery and how to fight triggers and cravings as much as the community members need to know how to help.

Additionally, to create social support, it is imperative to generate bridges that close the gap between these stakeholders. In the case of my proposal, an app was the platform that provided 3 interactions between patient and sponsor (Figure 6).

The app and the interaction were positively evaluated by the research participants, but where the need really lies is in enablers of care.

The three interactions looked for a proactive demonstration of care from the sponsor, in a phone call or a text message, even anticipating the craving like the geofence and the anxiety tracking interaction, where the sponsor reaches out to the sponsored.
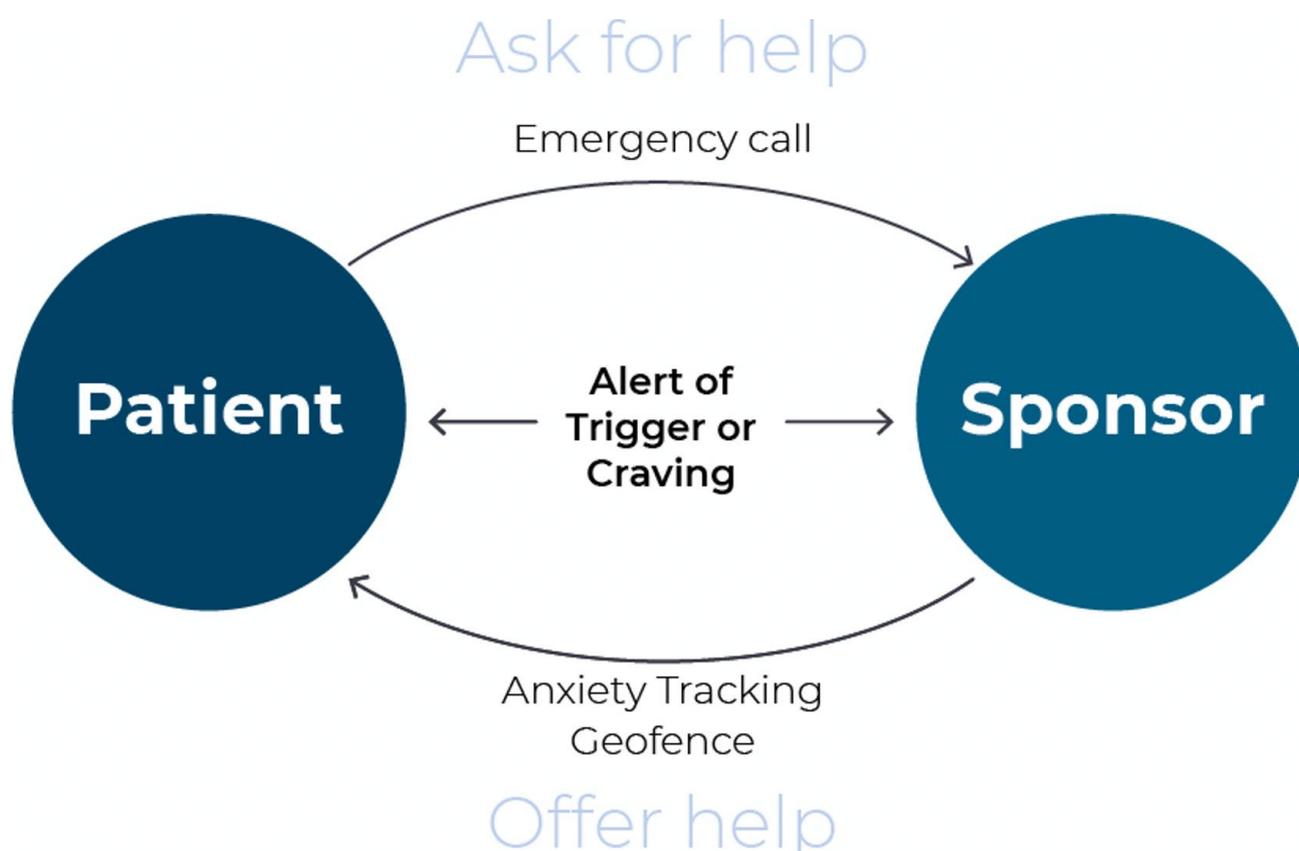
Figure 6: Patient and Sponsor interactions

Finally, it is important to highlight the value collaborative methods of design added to this research, and how it helped the project move forward. It is widely known how these methods establish a closer relationship designer-user, and achieve a better understanding of challenges and hurdles. Moreover, in this exploratory research, co-designing with the participants was a powerful vehicle for they to talk openly about difficult moments in their life when they struggled with addiction and its effect in social relationships.

During interviews, workshops, and validation sessions, it was clear for the participants the importance of their participation and how determinant it was in the design outcome. In the end, the rewarding experience of helping to design a solution for other patients, enabled conversation, experience sharing, and sincere insights.

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CRITICAL ANALYSIS OF THE NEW INDIAN CURRENCY DESIGN FROM THE PERSPECTIVE OF VISUALLY IMPAIRED

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Abstract

India is a cash-rich economy where 90% of day-to-day transactions are conducted in cash (Chowdhury and Hosain 2018). In 2016, following a demonetization drive, the Government of India launched a set of 7 new banknotes, eliminating INR 500 and 1000 from the system to introduce two new denominations of INR 200 and INR 2000. This resulted in a mix of new and old banknotes in circulation for the same denominations.
At present, India has approximately 4.8 million people with visual impairments (PVI). This paper presents the study done in two phases. In part one, the design of the new currency was critically analysed and compared with the recommendations of DNB. The second part of the study reveals the findings of the investigation done on the various difficulties faced by the PVI in identifying and transacting with the new banknotes. The situation became complex when the mix of new and old banknotes started coexisting.

Phase-2 presents the learning from the tasks of identifying the banknotes by PVI participants. Findings were drawn from the observations and semi-structured interviews with participants. Surprisingly no participant could identify the new currency denominations even after two years of being in circulation. All the denominations below INR 100 have no tactile marks. Therefore, the variation in the size remains the only identifying feature for the PVI. The size differences of the banknotes were found insufficient to make them distinguishable.
The findings indicate that the design of new currency introduces evident visual changes with vibrant colours, facilitating quick identification for people with vision. However, the unrecognizable change in dimensions and unimproved tactile cues raises issues about the concerns towards inclusiveness in the design of currency for the PVI population.

Keywords: currency design, inclusive design, design for visually impaired

Introduction

November 2016, Indian government banned INR1000 and INR500 banknotes. Following this, the Reserve Bank of India (RBI) launched Mahatma Gandhi (MG) new series of banknotes in seven denominations of Indian Rupee (INR) 10, 20, 50, 100, 200, 500, and 2000, gradually over 2 years. However, the old banknotes in five denominations of INR 5, 10, 20, 50, 100 continued to exist in circulation. This created a unique mix of 12 types of banknotes in circulation (Figure 1).

Defining PVI and scope of the study

After India changed its four-decade-old definition of blindness in 2017 from 6/60 to WHO criteria of 3/60 in the better eye, the blind population in country reduced to 4.8 million (2019) from 12 million (2006-07) (N. C. Sharma 2019). De Heij (2009) categorised the PVI into three sub-groups, colour blind, partially sighted and the blind. Our study was limited to identifying the denomination of new and old banknotes with partially sighted and blind. The design of the coins is not covered in this study.

New banknotes and the PVI population

The design of new banknotes was well received by people with normal vision but was found unsatisfactory by the PVI population. Multiple articles in media voiced this issue. In response, National Association of Blind (NAB) filed a petition in Bombay high court stating that the new currency is difficult to identify and distinguish for the PVI (The Wire 2019).

Structure of enquiry

The concern regarding dissatisfaction among the PVI populations led this study into two parts. The first part focuses on the critical analysis of the design of new MG banknotes by comparing it to the recommendations by De Heij (2009) for 'Banknote design for the PVI'. The second section of the paper describes study conducted with the PVI participants regarding the accessibility features of the new and the old banknotes through semi-structured interviews and observations drawn during the identification task.

Figure-1: Left- 7 denominations of the MG banknotes; Right- old banknotes in circulation

Critical analysis of the design of new MG notes

This section analyses the design of new MG notes with respect to available international guidelines.

Accessibility features for the partially sighted and the blind

Sight plays a significant role in transacting money. Well-designed accessibility features in a currency can ease the identification of denomination for the PVI population. However, the PVI is not a homogenous population. It includes people who are born blind, have lost sight due to various reasons at a later age or turned blind in childhood, have limited visual acuity or acquired visual problems with growing age. In India, untreated cataract is a significant cause for blindness in the aging population. Moreover, most people cannot read braille. Therefore, designing the currency for a country is a challenging task and requires a universal design approach (De Heij 2016).

The designing of any currency is striking a delicate balance of art, science, and economics (Williams and Anderson 2007). Accessibility features must compensate the absence of sight or poor vision. The recommendations to facilitate blinds in identifying denominations include; variation in note length as per denomination, tactile patterns of dots or lines on the short or long edges, and symbols with intaglio printing. For the partially sighted, a considerable numeral denomination height at the same location across denominations, numerals on the front and reverse with clear contrasts are recommended (De Heij 2009). BEP 1983 and NRC 1995 reports that change in size with denomination is the most valuable feature for the PVI (De Heij 2009).

Design of new MG series banknotes

RBI promotes the new currency through its interactive posters (RBI n.d.) on its website.

The essential features incorporated in the MG banknotes include variation in colour and note size across denominations, tactile patterns on both the short edges and symbols with intaglio printing for all notes of denominations above INR 100 (Figure 2).

Figure-2: The new MG banknote INR 500 with features for PVI (RBI n.d.)
1. MG Portrait in intaglio printing. 2. Ashoka pillar emblem- intaglio printing.
3. Tactile pattern on both short edges and tactile identification symbol.

Analysis of currency design for the partially sighted

The denomination on MG banknotes is mentioned in words and numerals. Numerals are mentioned in English (oriented horizontally) and in Devanagari script (oriented vertically) on the obverse and the reverse of the banknote. All numerals are placed at the same location for all denominations (Figure 1). They are repeated thrice or more on each side. The height of the largest denomination numeral (LDN) on the MG banknote is 8.34 mm (Figure 3). However, it is much smaller in comparison to the recommended height of minimum 15mm or preferred height of 22mm for the partially sighted (De Heij 2009).

Figure-3: Scaling the LDN for INR 2000 (8.34mm height) to the recommended size of 22mm without rupee symbol

Use of Rupee symbol as prefix with the LDN

MG banknotes use the rupee symbol as prefix with all DN. Other countries studied (USA, European Union, Japan, Australia, Sweden, Singapore, Hong Kong, Switzerland) do not use currency symbols as prefixes, especially with the LDN except for the British pound. Authors suggest that MG notes should drop the use of rupee symbol prefixing the LDN across all banknotes and increase the height of the LDN to more than 15mm. This will ease the identification of the LDN for the partially blind. The smaller size numerals repeated on other locations could continue using rupee symbol.

Position and colour contrast of LDN

The numeral location is consistent in its position across all denominations. The plain background behind LDN results in acceptable contrast (Figure 1). The position and colour contrast for the LDN meet the recommendations in the MG banknotes.

Analysis of currency design for blind

Variation in banknote length

In the absence of visual clues, the variation in the banknote length is the most valuable feature for the blind. De Heij (2009) recommends incremental increase in the length of the banknote with the increasing denomination keeping height constant. The MG banknotes are not consistent with this recommendation. INR 10 and 20 of MG banknotes differ in height as compared to other denominations. INR 50, 100, 200, 500, and 2000 have the same height, but the difference in length is not incremental. The marginal difference of 4mm in the denominations of INR 100 (142mm), 200 (146mm), and 500 (150mm), is insufficient for identification. The mixture of the new MG notes sizes with the old note sizes adds to confusion. 1mm difference in length of MG INR 200 and old INR 20 note and 2 mm difference in old 10 with MG 50 is almost impossible for a blind to differentiate (Figure 4). The old series INR 100 is significantly rger than the MG INR 500 note. (Figure 5).

Figure-4: Above: New 200 1mm shorter in length and 3mm taller as compared to old 20
Below: New 50 2mm shorter and 3mm taller as compared to old 10

Figure-5: Old 100 157mm long and 73mm tall is larger than new 500 of 150mm x 66mm

The National Research Council (NRC 1995) has prescribed the minimum value of Weber fraction for banknotes as 0.03. However, De Heij's (2009) study finds it to be ineffective and recommends 0.06 value. In an ideal scenario, the Weber fraction throughout the banknote series across consecutive denominations should remain constant (De Heij 2009).

In the MG banknotes, with rounding-off, the Weber fraction is 0.05 for the denominations up to 100 (Table 1). However, the fraction suddenly drops to 0.03 for INR 200 and 500, making it difficult to distinguish between INR 100, 200 and 500 banknotes.

Table-1: Weber fraction for new MG and old banknotes

Value	New MG banknotes					Old banknotes in circulation				
	Length	Height	ΔL	Weber Fraction	Remark	Length	Height	ΔL	Weber Fraction	Remark
5					Replaced by coin	117	63			
10	123	63				137	63	20	0.17	
20	129	63	6	0.05		147	63	10	0.07	
50	135	66	6	0.05		147	73	0	0.00	Change in Height
100	142	66	7	0.05	3 mm height difference	157	73	10	0.07	
200	146	66	4	0.03	Fraction reduced to 0.03.					Didn't exist
500	150	66	4	0.03						Discontinued
2000	166	66	16	0.11						Didn't exist

Use of tactile patterns and high raised intaglio printing

In MG Banknotes the tactile patterns and intaglio printed symbols on the front of the banknotes on short edges. However, denominations below INR100 do not have tactile patterns or embossments. De Heij (2009) suggests midpoint on the edge as the most active area for tactile pattern. In the older banknotes, the tactile marks are placed slightly below the midline and for MG, slightly above the midline.

The tactile patterns and codification

The tactile patterns are a combination of angular bleed lines. For INR200, it is a combination of lines and circles (Figure 6). A simpler and visually consistent logic for codification could have been devised, as seen in Canadian banknotes. They use raised dots as a tactile feature with simple codification (Figure-6) (Bank of Canada 2012). Interestingly this is not in braille as their research with the blind or partially sighted people in Canada indicated that all users cannot read braille (Bank of Canada 2012).
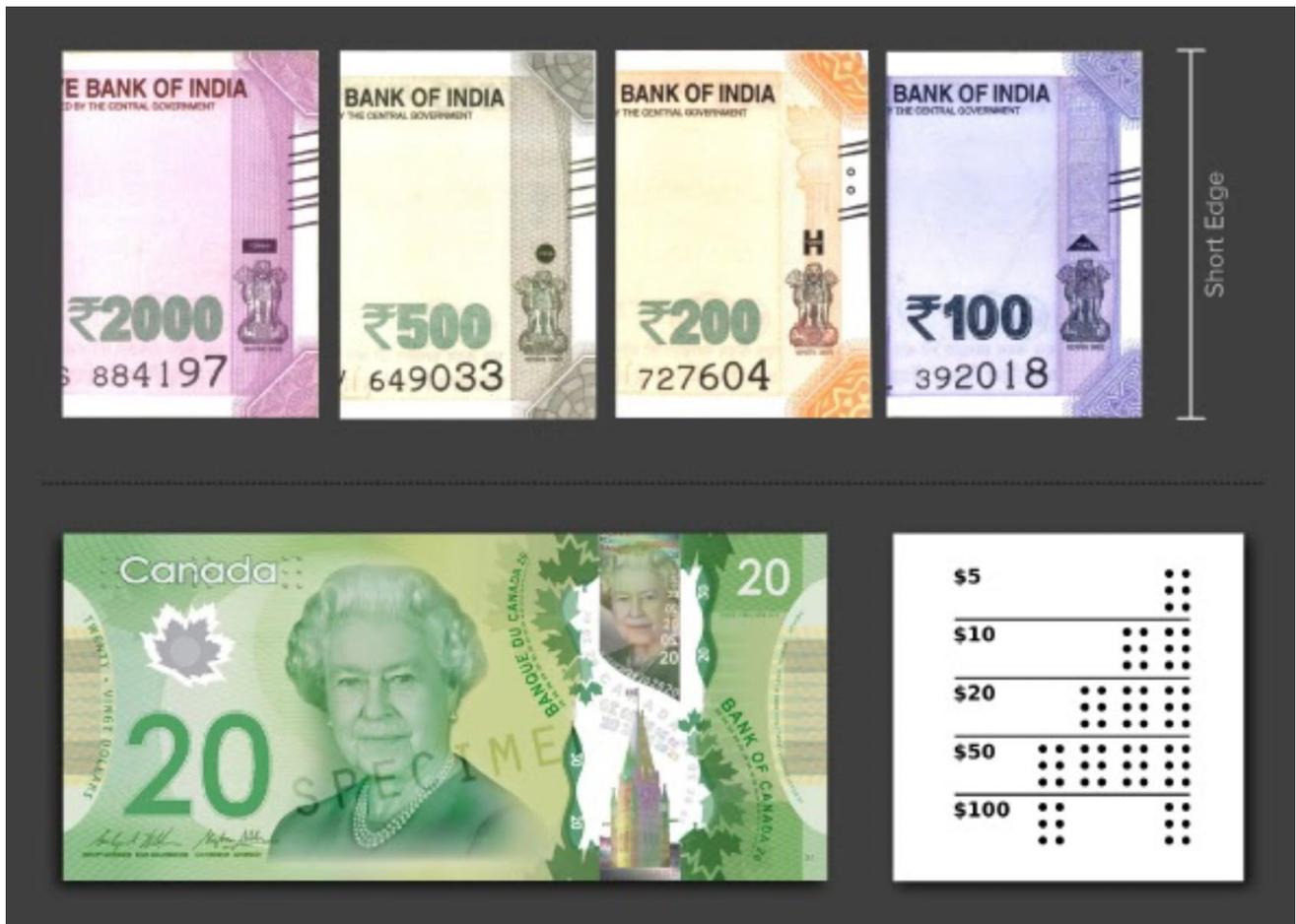
Figure-6: Tactile markers on the new MG Banknotes along the short edges with intaglio printed symbols of various shapes (top). Raised dots as tactile markers on the Canadian polymer banknotes (bottom-left). A simple codification method (bottom-right)

Limitations of the analysis

We could not analyze certain features of the banknotes, such as the reason for the choice of font, frequency of denomination numerals, space between the tactile patterns, height of the tactile pattern, choice and shape of symbols for intaglio printing. RBI has not published any document stating the rationale for the design decisions of the new MG notes.

Study with the PVI users to identify banknotes

The second phase of the study explores how PVI manage transactions with a mix of old and new banknotes and identify the challenges faced. Participants were presented with banknotes and asked to identify the denomination. The task was followed by the interview to understand the various methods they use and the scope for errors.

Methodology

Semi-structured interviews and observations were used to collect data. Participation was voluntary with prior consent and no monetary compensation was offered. The interview responses were voice-recorded and transcribed. Participants were provided with new and old banknotes and requested to identify its denominations. Some tasks were video recorded with prior approval to facilitate re-looking.

Participants

Eleven participants, 3 female and 8 male in the age-group of 35 - 60 years were interviewed for the study. Two of them (one male and one female) were partially blind

with 5% vision and nine were completely blind. Four participants work in banks, 2 in government offices, 2 street vendors, one runs an NGO for blinds, one is a music teacher, and 1 is a housewife. 8 participants out of the 9 were blind from birth, and one of them turned blind at the age of 25.

Identifications task

Participants were handed over the banknotes one after the other and later in a bunch and asked to identify the denominations.

Various ways to identify the denomination of a banknote

The accessibility features in the MG banknotes for the partially blind and the blind include tactile patterns, intaglio printed embossments, and variation in the colour and length of the banknotes (Table 2). However, their implementation is inadequate in two columns, the size and tactile markers, which are crucial for the blind.

Table-2: Currency design features for visually impaired (Williams and Anderson 2007)

Issuing Authority	Primary colours that differ by denomination	Size that differs by denomination	Tactile recognition symbols	Certain oversize numerals	Machine readable features for banknote readers
India	Y	Y*	Y*	N*	Y

Y* They are present but with problems in implementation.
N* Largest numeral height is 8.34mm against recommendation of 15-22mm

Methods the participants use when the tactile feature fails

Estimation using length for single banknote identification

Since the tactile features are not adequately perceived, the difference in length of the banknote is the only reliable feature for the blind. When a single banknote was presented for identification, the participants tried to estimate the length by measuring it with their hands by aligning it with the base of palm or fingertips (Figure- top) or by measuring from the center and travel to edges (Figure 7 bottom). This estimation is verified against their stored memory of the prior experience.
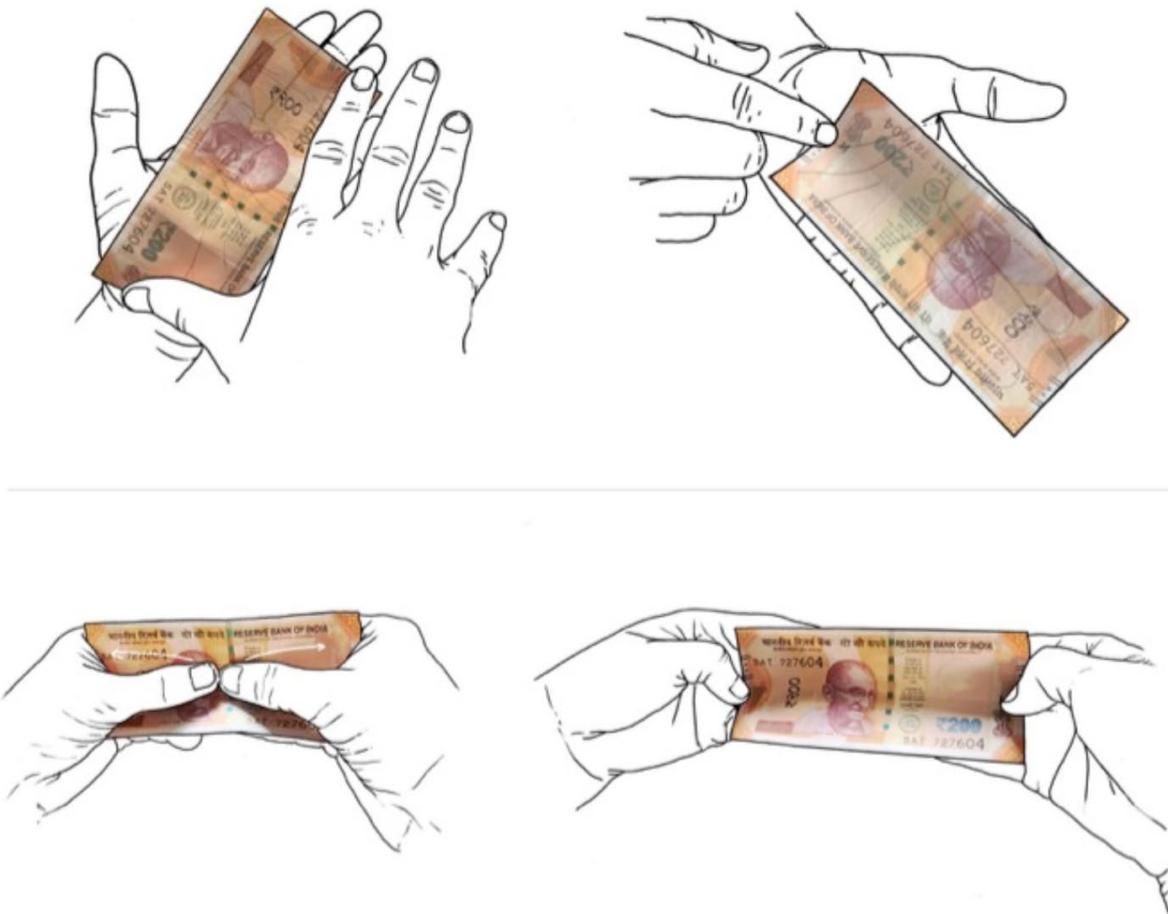
Figure7: Estimation technique to identify single note denomination

The folding technique to identify single banknote denomination

The participant folds the banknote into half and aligns it from the base of the fingers and measures with respect to the fingers (Figure 8).

Figure-8: Estimation technique with folded note

Comparison technique to identify denomination

When the participants were handed two banknotes they try to compare the difference in length by touch (Figure 9). If the difference is not discernable, then it is difficult to identify the denomination. In MG banknotes, the lengths difference of 4mm for INR 100, 200 and 500, is too subtle for identification by the sense of touch. Whereas, the difference of 10mm across all denominations in old notes makes them easier to identify.

Problems in identification due to mix of old and new

When participants were given a mix of the new MG and old notes, they were unable to identify the denominations using the length of the long edge. One group of banknotes given for identification included old INR 100 (157mm length), new MG banknotes of 100 (142 mm) and 500 (150mm). Participants were familiar with old INR 100, but since the new INR 500 was smaller in size, it confused. The participants also failed to differentiate the MG note of INR 200 (146 mm) and old INR 20 (147 mm); MG note of INR 50 (135mm) and old INR 10 (137mm) as the differences were subtle.

Other ways to identify banknotes

All participants knew about signature guides, which help the blind to identify denominations. A signature guide Notex made by the National Association of Blind (NAB) was used by 60% of the participants. It is a small plastic strip with indentations, where they fold the banknote and match the indentation to identify its denomination. The new notes cannot be identified with the device because of changes in lengths. To compensate for the failure of tactile markers, RBI launched MANI (Mobile Aided Note Identifier), a free mobile app for android and apple in January 2020. It works without an active Internet connection. It announces the denomination when the note is held in front of the camera, in Hindi and English.

Digital payments and hassles of transactions with new and old currency

All participants had a mobile phone and made digital payments using the talkback feature within apps. However, at certain occasions digital payments were not possible and one has to transact with cash. The common scenarios they quoted were shopping for vegetables from a street vendor, hiring an auto-rickshaw, or receiving money from an ATM. Participants reported that they have got accustomed to the old currency, but the mix of old and new makes transacting difficult. Participants reported being short-changed while paying off for a taxi ride as there is less time to check the returned money. The overall feedback summarized that the new currency is difficult to decipher with touch and the feeling of being dependent on others to identify a denomination is frustrating. The use of a mobile app is possible, but it is time-consuming.

Conclusion

In summary, the new MG banknotes incorporate the recommendations mentioned by DNB (De Heij 2009) for the PVI population but inadequately. The tactile markers and embossments appear on higher denominations and not on the frequently used lower denominations. The next reliable feature of identifying a banknote was to compare the length of the banknote within denominations. It was hampered by a mix of various lengths of the old and new banknotes in circulation. As a result, the day-to-day transactions became stressful for the PVI.

Blinds have resorted to their ways of guessing the denominations by measuring the banknotes against their palm and fingers. Very few manage to guess it correctly and often fail. This method is time-consuming. Signature guides and mobile apps launched by RBI are other ways of identification and were used by participants. Nevertheless, all participants desired accessibility features, as they are more convenient and accessible than to be device-dependent.

The change in the length and colour of the banknotes with the increasing denomination is a valuable feature, as it benefits everyone, the normal sighted as well as the PVI. The MG banknotes can be improved if the difference in length is increased and made more apparent to the blind by touch. For the PVI, sense of touch is their way of seeing the world. Treating PVI as a special group

and providing alternative ways for them to access currency, does not pronounce equitable access and well-being. The ease with which a sighted person performs his daily transactions, the PVI should also be able to transact with such ease using touch and feel. Currency is to be understood by designers as a product of frequent and mass use; errors in decision-making are long-lasting and difficult to repair. Therefore, the design of currency must exercise a rationale and an inclusive approach.

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CONTEXTUAL STUDIES TO UNDERSTAND THE PROBLEMS AND NEEDS OF PEOPLE LIVING WITH ALS/MND THROUGH STAKEHOLDER WORKSHOPS IN INDIA

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Abstract

ALS/MND (amyotrophic lateral sclerosis/motor neurone disease) are currently incurable, progressive neurodegenerative disorder of nerve cells in the brain and spinal cord. Needs of people who have ALS/MND differ, in part as per their disease progression stage. To understand concerns of patients and allied stakeholders, Lab4Living(L4L), School of Design at IDC, IIT Bombay, and Neurogen, a clinic with dedicated Neurorehabilitation resources, collaborated with a focus on developing new assistive technology (AT) and inclusive designs for people living with ALS/MND in India. The research comprised local contextual investigations through two participatory workshops with support of Asha Ek Hope Foundation, and involved people living with ALS/MND, their caregivers, Occupational Therapists and Design Researchers. The paper describes methods used, insights built, and outcomes to date including concept designs for new AT and inclusive designs, impacting on the Design curriculum in India ,

informed by this study, that have since progressed to user evaluation stages of R&D processes.
Authors gained insights about why the design of products, and their facilitating services, for ALS/MND patients may differ from a standard product/service development process. We suggest products designed for ALS/MND should co-exist as a part of a designed ecosystem. This ecosystem could facilitate sharing of products amongst patient populations, while addressing concerns of manufacturing low volumes of batch production items at an affordable cost for all socio-economic groups. The design of this ecosystem and its interconnectedness may be a critical factor in making products feasible and sustainable. The project was funded by Sheffield Hallam University (SHU) Global Challenge Research Fund (GCRF) and Expanding Excellence England ('E3 Research England').

Keywords: human centred design, MND/ALS, participatory research, design approaches, rehabilitation

Introduction

This project forms a part of a wider study seeking to investigate and provide responses to social, sustainability, health inequality or economic issues faced by countries on OECD (Organisation for Economic Co-operation and Development) forum's DAC (Development Assistance Committee) country list. Specifically, this branch of SHU GCRF activity is framed around uncovering challenges and barriers people living with MND/ALS experience in India, given 1. Size of population (compared with EU nations), 2. Relative lack, with respect to population size, of assistive technology (AT) infrastructure and 3. Given comparatively low levels of income in relation to AT provision. Design responses therefore are required to be 'frugal' in this context. The project was delivered by Design Researchers working with L4L, industry based Design partners in India, Ativa, and Design academics from Industrial Design Centre (IDC), School of Design, Indian Institute of Technology Bombay (IITB), crucially, people living with ALS/MND, patients of Health Care Practitioners based at NeuroGen, Centre for Stem Cell Therapy and Neurorehabilitation, Mumbai, and their carers.

Our interest and motivation in undertaking this work was driven by technical and quality of life understanding of this debilitating disease from a developed country perspective, gained through a previous L4L project named 'Head Up', and to apply creative strategies to explore challenges and potential solutions in 'frugal' ways, in the context of India. Whereas the Head Up project specifically considered head drop, a project that successfully delivered a new type of commercially available orthotic to improve quality of life for people across the world ('Revolutionary neck support collar now available on the NHS for people with motor neurone disease'), this study investigated some of the wider issues of daily living with ALS/

MND, in India. It aimed to extend the range and reach of these kinds of products, and to maintain functional benefits at local cost effectiveness levels. Many product concepts were derived from these sessions. The following captures key methods and findings, and illustrates and describes some outcomes, but many are not disclosed for reasons of IP. Based on this initial study we plan to progress this work, subject to further funding.

Methods

With consent of NeuroGen, through which participants were recruited, the team produced materials in paper format to inform and raise awareness of this research, distributed approximately three weeks prior to the events. One document asked people interested in contributing on the day to think and record their daily challenges. This was presented as a daily timeline identifying what they did, when, and any challenges they encountered. People living with ALS/MND were asked to include their care givers in this insight capture. The daily timelines were reviewed and contributed to insights and understanding reported here, despite the fact the exercise was intended more to allow participants to think about/help in preparation for workshop discussions. Invitation and timeline documents were produced in English and translated into Hindi and Marathi, these three languages believed to cover a significant percentage of the anticipated group attending (Figures 1&2). Consent to take part information and participant rights were integrated within these two documents, alongside agreements for photographic/audio recording. From previous experience the team felt strongly that persons at different stages of disease progression would not attend at same times, to avoid possible stress of potential early stage patients observing late progression patients. Following the workshops, audio recording were transcribed, reviewed, and key considerations extracted.

The workshop comprised two main sessions. Firstly, approximately one hour involved the design research team and seven Occupational Therapists (OT). This session focused primarily on challenges of existing AT and its provision. A number of OT's from the team also reported as having been diagnosed with ALS themselves. Secondly, the group reconvened with seven ALS patients for approximately two hours.

Some patients were accompanied by their family carer, who also contributed to loosely structured and conversational (by intent) discussions. Following an introduction and outline of aims, the group divided into 'one-on-one' sub-groups. The final one-half hour of session comprised whole group discussions. Insights were recorded in note form.

Figure 1: English version of Timeline

Figure 2: Marathi version of timeline

OT viewpoint summary

The session format was 'roundtable', with the design research team and OTs exchanging insights based on what existing AT is available, and its limitations. Conversation then led into challenges for carers, and provision in India. During the task it was felt that the first priority was eating and addressing poor hand function, often a result of the disease.

One existing product, the 'universal cuff', a Velcro hand 'wrap' for holding implements (spoons, forks, hairbrushes) was demonstrated by OTs. A shortcoming highlighted was the limited number of tools it could accept and the design of the cuff's, tool accepting pocket. It was felt to be in the wrong position for many people resulting in the wrong angle of implement hold for different tasks. It was further highlighted that eating with a spoon was not a 'traditional' method in India. It was noted that, depending on body region affected, hand-based aids could be less useful if function is impaired simultaneously with limitations higher up the arm/shoulder. It was regularly highlighted that the disease affected individual patients differently, and it could affect different parts of the body at varying rates, either rapidly or more slowly. There was some debate between OT's as to where the disease manifests first, either in the shoulder or in the hand. It was agreed however that even though many people can have different manifestations, the effects eventually and generally are common as it progresses.

There was debate about how stigmatizing AT was, with some reporting that patients did not 'want to wear it and use it in the community'. A general consensus amongst ATs was as long as it worked easily, and well enough to provide greater independence, then look (appearance?) and associations with AT become secondary. However, devices that were both visibly and functionally 'lightweight' are preferable.

Issues around the complexity of body movements during tasks, and if designs should focus on supporting either specific or more complex movements (wrist and whole arm for example) were discussed in terms of where new designs should concentrate. As a complex problem (individual's condition, stage and regions affected) it was agreed as many options as possible should be integrated. This suggested consideration of a modular, lightweight, literal 'suite' of interchangeable device options. Importantly, for the design research team, realisation that motion is affected most where the person needs to 'fight' against gravity was established. The team began to consider how gravity may be used to support rather than hinder specific actions. It was proposed a next step of this research could start with an analysis of common task related body movements, from which means of utilising gravity or 'movement boosters', to aid those tasks, may be derived. This was seen as important to conserving energy where physical fatigue can be a major factor. Principles of clothing that helped blood flow were also raised in relation to the 'suite' of interchangeable device options.

All AT available, with few exceptions, was deemed to be prohibitively expensive in India, and as such unlikely to be taken up. For example, larger installed body moving hoists were deemed not to be in widespread use because of limitations of cost and fit in/at home. In terms of 'manual handling' comments were made about India's large population and possibilities that more carers may be available, subject to training. Conversation moved to manual handling of people to and from bed. This is not only physically challenging but psychologically also, as, where people need turning at night, it is a carer who is required to help, who 'often lift them', to move or transfer. Specialist equipment to aid this process is available, but again its availability is limited due to cost and space in the domestic situation. Devices to aid turning in bed, to

avoid discomfort, and eventual pressure sore onset, and getting up from bed were discussed, and were also described as problematic.

The OT group felt a significant barrier to physical fitness was exercise, explaining it was very difficult to simply get people to walk. Ideas and examples of 'passive movement machines' were discussed but that current provision was limited in what kinds of exercise they offered. In many cases needs change often, so every product investment could become redundant very quickly. One OT commented, 'that is the biggest challenge. As the disease progresses the number of devices required goes on increasing and you have a pile of devices which are useless'. However, regarding beds it was agreed investment here may be longer lasting. Questions of access to

AT were discussed and ideas about sharing certain types of AT between patients tabled. Hospital representatives confirmed they do pass redundant equipment to others in need, but there was no 'system' in place to manage that.

A specific condition was highlighted as very painful, distressing and functionally debilitating, known as subluxation, whereby upper arm dislocates from shoulder. Design Researchers were advised that there are products that attempt to address this but that they 'work in the wrong way', and they don't work at all when both shoulders are affected/bilaterally (more about this in patient group discussion). The session also covered aspects of communication, although this was limited, and around a lack of equipment for aqua therapy.

Figure 3: OT lively roundtable discussion at NeuroGen

Summary of Patient and carer workshop

Of particular interest in this session were notions of who we were designing for. Of course, ultimately, we are concerned with provision of solutions that meet often complex needs of the patient, to ensure they can live full, happy and as independently as possible. But the design briefs (design requirements) we develop can equally have drivers powered by other foci, on the specific needs of the carer, for example.

When demonstrating how a physically smaller primary carer for a physically heavier ALS patient undertook his transfer from chair to bed, she expressed concern that she didn't have strength to hold his weight high enough such that no load was placed on his feet, that she may slip, lose grip, or otherwise injure her husband during process. Breaking the ankle was of particular concern to her. This physical strength issue is compounded where the patient lacks physical control and is unable to assist maneuvering. An example demonstrated by the couple was of 'foot drop', and peripheral neuropathy. These conditions result in a lack of self-control of the position of the foot/where the ankle will not support the foot parallel to the floor, and a lack of sensation informing what the foot is coming into contact with (floor, objects etc.).

The carer demonstrated how when handling their partner's mass, stood face to face, she would stand on one leg, using her free foot one to 'kick' the patients foot into an appropriate position as not to cause injury when load bearing. This combination of control and feedback problems may be able to be addressed through AT provision focused on the needs of the carer, rather than patient. For example, an ankle orthotic that is designed to help patients' feet stay parallel with the floor would certainly help the carer, but may be further augmented with features enabling the carer to more easily reposition feet such that it reduced potential for injury during transfer, and importantly reduce carer anxiety about causing damage through accidental falls.

Whether an ALS/MND patient maneuvers themself out of bed alone or has assistance, it was highlighted that this act is a particular challenge. People described varying amounts of body pain following longer sleeps, some very severe. Mainly, it was speculated this was a result of not being able to move or reposition frequently during sleep. If laying supine (face upwards) persons described firstly 'flinging' an arm, from the shoulder, over their body so they could role onto one side. Secondly, legs would be controlled over bed edge until above or on floor. If an over bed handle was available, it could then be grasped to pull body upright. If not, they may bend the torso forward until stomach muscles could be used to become upright, as well as employing various other coping strategies. From this sitting on bed edge position, the person could, depending on severity of their condition, move forward to a standing and/or ambulant situation. Points of intervention discussed around these scenarios included how we might decrease discomfort through design of sleeping surfaces, how to facilitate more accessible over bed grab handles and how might we provide systems that assist transitions from supine to standing/walking. The design team recognized it is not possible to procure and install 'developed' country type AT (hospital beds and the like) into, what are often very low-income situations, and considered 'frugal' adaptations to existing furniture.

A further area of what we have come to call 'arm drop', (aforementioned subluxation), was discussed. This manifests, as described by patients, as the top of the arm (humeral head; the 'ball' of the ball and 'socket' joint within the shoulder) dislocating as, it is thought, a result of gravity and a loss of muscle mass holding the shoulder joint in place (a union of scapula features (acromion and coracoid process), and clavicle, holding

the humeral head in place). The condition effectively renders the patients' arms useless/with very limited function. There was a high proportion of Indian patients in the group with the condition, the reason for which was not established. Figure 4. shows one of the patients attending the session posture (center image, gentleman in pink shirt). It can be seen that his arms are 'dangling' by his side and appear over long. Existing aids to help keep the shoulder joint intact were discussed as largely, mechanically inadequate.

Figure 4: Examples of subluxation in the patient group

Summary of findings

A finding of both workshops was AT items should be cost effective such that they can be available to the majority of those that would benefit from them. This is a multifaceted problem, one involving many aspects of products being 'fit for purpose', including device functional specifications, materials selection and processing/ fabrication, product life cycle, repair, manufacturer, marketer and distributor mark ups, not to mention research and design development costs. In discussion with the groups the design team connected many of these issues into a potential, single 'simplification' of said complexities. Requiring further investigation, and subject to regulatory and other compliance criteria, the idea revolves around the notion that it could be the hospital (or clinic) that would procure, own, develop and distribute AT items. The clinic may then offer continuous and bespoke support to its patients, issue, collect, service, and re-issue devices to new patients. This sharing of equipment concept would be seen as an essential component of a product-service ecosystem, and design of these devices would need to take new product use life cycles into account. The approach could allow for continuous, iterative product improvements, and for

new AT opportunities to be identified. Many barriers to this approach would need to be overcome to enable facilitation, in particular those concerning economy and operationalization, but if those could be overcome the benefits may be significant.

- Needs are highly complex with at least four primary multipliers, summarised as 1. personal situation (social/economic), 2. personal routines/tasks undertaken 3. Nature/locality of affliction, 4. stage of disease progression.

- Consideration must be made towards cost and new methods of distribution and ownership explored.

- There are many, many new product opportunities. Lack of investment in these areas is key to current overprice and undersupply.

- General themes for development of new AT products include

    - Moving (oneself around an environment) and handling/transfers (by others)

    - Supporting body movements (against gravity) and integrating physiotherapy

    - Dexterity/specific hand aids

    - Product service/supply

- Designs need to be adaptable to accommodate disease progression.

In respect to the context of India, the research revealed important and valuable factors to inform potential solutions but highlighted the need for a more extensive national study. However, the work did open some avenues for further investigation, for example, that eating cultures needed addressing with designs reflecting local practices. Generally, economies of scale need addressing through AT designs in line with peoples means. It would be beneficial for people around the world to have more affordable products, this is particularly true of economically 'poorer' societies. It is recognised that India has a very large population and as such may be able to provide a larger number of carers, subject to adequate higher volume training programmes.

Outcomes

Figure 5 and 6: Universal Cuff prototype(left) by Nikhil Dhamnaskar and Gaurav Nandan's Foot Orthotic prototype(right)

While many of the potential interventions this study presents remain simply 'ideas' and concepts, the research helped the design team grasp what the real, on the ground issues are, and opened avenues for future investigation, subject to funding. However, two areas of the debate have evolved into new product developments. Use issues with the 'universal cuff' and those associated with 'foot drop' were translated to student design briefs by the IDC team. Two students, Nikhil Dhamnaskar–Universal Cuff prototype and Gaurav Nandan–Foot Orthotic prototype (figures 5&6.) undertook these briefs as part of their IDC Masters in Design, 2019. Embedding and supporting projects such as this within the Design curriculum in India has potentially long-term benefits in further raising and in developing the next generation of designers working within the field of design for health, and in improving the practice and manufacture of AT in India.

Acknowledgements

THE WALL OF CHANGE: INCLUSIVE FUTURES DESIGNED BY PEOPLE WITH LEARNING DISABILITIES AND AUTISTIC PEOPLE

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Abstract

This paper discusses a speculative design research project called Inclusive Futures. The project aims to imagine alternative versions of the future based on what people with learning disabilities and autistic people would most like to change about the world. Inclusive Futures is part of an interdisciplinary research project called 'Heart n Soul at the Hub', funded by the Wellcome Trust. The paper provides an overview of two key phases of the Inclusive Futures project: a public exhibition and two 'futuring' workshops. An analysis of the data generated during these phases was undertaken in order to better understand what disabled and non-disabled participants believe are the most important things to change within the development of a more inclusive future. In sharing our approach, we aim to advance the established practice of speculative design and position people with learning disabilities and autistic people at the centre of the expanding understanding of speculative design as a catalyst for social change.

Keywords: human-centred design, speculative design, learning disability, autism.

Introduction to the Authors

The Inclusive Futures project is led by a team of eight people. Two are researchers from the Helen Hamlyn Centre for Design (Will and Chris) and six are co-designers with learning disabilities and/or autistic people (Aysen, Bobby, Castro, Rajah, Robyn and Thomas). The authors' names are used throughout this paper to highlight passages written directly by a specific member of the team.

Introduction

'Inclusive Futures is an example of when people really listen to you. Camaraderie - we all work together . . . it's really important that disabled people are empowered to do things and know that they can change things.'

(Robyn)

Inclusive Futures is a speculative design research project that aims to create alternative versions of the future based on what people with learning disabilities and autistic people would like to change about the world. Inclusive Futures is part of Heart n Soul at the Hub – an interdisciplinary research project that brings together disabled and non-disabled artists, scientists, researchers and clinicians. The project is led by Heart n Soul, a creative arts company and charity that believes in the power and talents of people with learning disabilities and autistic people. At its core, Heart n Soul at the Hub understands that research processes that relate to disabled people are inherently political with the potential to either exploit or empower those involved. The project builds on emancipatory and participatory approaches within the field of Disability Studies that have '(re)positioned disabled people as social actors with rights, and research as a potentially democratizing activity aligned to disability politics' (Liddiard et al. 2018). Pino Frumiento, co-founder of Heart n Soul, notes:

'All our lives people ask us questions, from benefits interviews to doctors' appointments – we are under the microscope. Now with this research project we are in charge, and we are the ones asking you questions.'

(Frumiento and Collins 2019)

Inclusive Futures addresses the concern raised by Gieben-Gamal and Matos (2017) that although the field of Disability Studies has created a significant increase in theoretical and practical understandings of disabled people's lives, there has been little crossover between this and the field of design.

Imagining Futures

Speculative design is the use of design to imagine how things could be different. Speculative design 'can give form to the multiverse of worlds our world could be. Whereas it is accepted that the present is caused by the past it is also possible to think of it being shaped by the future, by our hopes and dreams for tomorrow' (Dunne and Raby 2013, 160). However, the perspectives of people with learning disabilities and autistic people are notably absent in existing literature and practice concerning speculative design (see Tharp and Tharp 2018; Dunne and Raby 2013). This lack of representation is discussed more broadly within the fields of Critical Disability Studies (Goodley 2017) and Inclusive Design (Hamraie 2017). In response, Inclusive Futures aims to position people with learning disabilities and autistic people at the centre of imagining new possibilities and possible futures. 'The most important thing about Inclusive Futures is getting to say what we want to do. Coming up with our own ideas on what we want to change' (Thomas).

There are a number of speculative design approaches that have informed the project. These include the Royal College of Art's Gateway project (Harrow et al. 2018) which visualizes future cities where driverless vehicles have changed how people live, and Madlove - a collaborative project led by artist and activist the vacuum cleaner which reimagines the asylum as 'a safe place to go mad'.

Figure 1: The Vacuum Cleaner and Hannah Hull's Madlove - Wellcome Images

The following sections detail two key phases undertaken during the Inclusive Futures project: an exhibition titled 'The Wall of Change' and two 'futuring' workshops.

The Wall of Change

The initial stage of the Inclusive Futures project was the design of a participatory exhibition titled The Wall of Change (figure 2), open to the public at the Wellcome Collection in London between June and August 2019. The exhibition presented a series of speculative ideas illustrating what people with learning disabilities and autistic people would like to change about the world. The intention was to encourage the public to imagine and respond to a more inclusive version of the future. Four people with learning disabilities were recruited through the existing networks of Heart n Soul to join the exhibition team as co-designers. The co-designers were introduced to the Gateway and Madlove projects detailed above to familiarize them the speculative design process. Through a co-creation workshop (Marlow 2013; Liddiard et al. 2018), working with artist Ben Connors, the group visualized objects, environments and services that they would like to change. Each co-designer selected one idea to present to the public. These included a multifunctional electric can opener that works at the push of a

button, an accessible tube station that better supports the needs of people with sight loss, a universal freedom pass that enables disabled people to travel where and when they want, and a proposition for a hospital that makes people with learning disabilities feel comfortable and welcome. Audio description was made available via a QR code next to each image, increasing the accessibility of the exhibition for people with sight loss. The descriptions were written and read by the co-designers - placing their voices at the heart of the exhibition.

Figure 2: The Wall of Change Exhibition - Wellcome Images

The public were invited to consider the artworks and respond by describing or illustrating what they would like to change. 'Ideas templates' (figure 3) were provided, encouraging people to write or draw their ideas and add them to the exhibition. In total, 245 contributions were added by members of the public of which 71 (29%) self-identified as disabled, 57 (24%) as non-disabled and 117 (47%) did not specify.
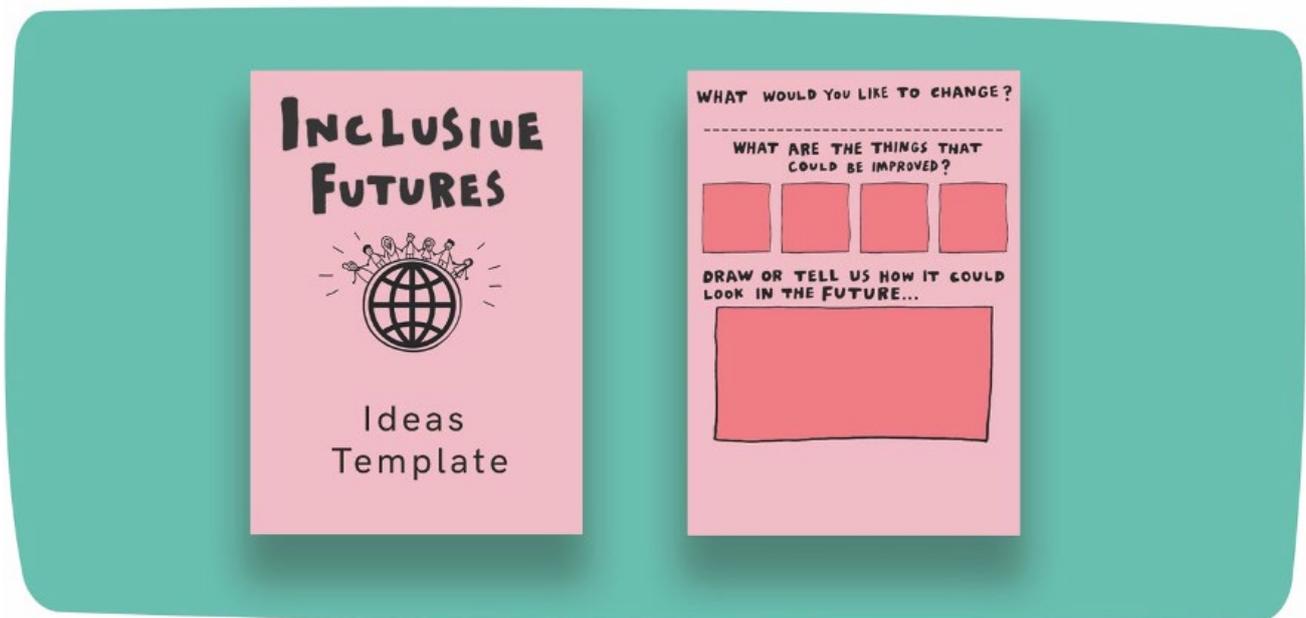
Figure 3: Ideas Template

Futuring Workshops

'We are making something not just sitting around talking about it . . . it's not non-disabled people making something for you, it's disabled people making things for other disabled people.'

(Robyn)

In August 2019, two futuring workshops were hosted at the Wellcome Collection to develop the previous speculative design process with a larger group. 33 participants with learning disabilities and/or autistic people were recruited through the networks of Heart n Soul, charity Artbox and Westminster Learning Disability Partnership. A visual story (figure 4) was created for each event, providing a clear understanding of what to expect. This included information such as:

- The location, date and time of the workshop as text and easy-read symbols

- Sensory information about the workshop environment including lighting, acoustics and available furniture

- The anticipated number of attendees

- Photographs of the workshop team

- A list of accessibility provisions that were and were not available, such as accessible toilets and a chill-out space

Figure 4: Workshop Visual Story

The visual stories were an important component in making sure participants felt comfortable during the design process. 'Working inclusively isn't just about what happens in the room (although that's important too), it's thinking about how people will get to the room or if they need to know about stuff like lighting before they come in' (Robyn). During the futuring workshops participants used ideas templates (figure 3) to share what they would like to change, what elements of that choice could be improved and how their idea might look in the future.

Participants worked individually and in small groups to complete their templates and attach them to a large cork wall. Participants could complete multiple templates for multiple ideas and mark connections between them on the wall using coloured string. With a map of ideas in place, three artist-led spaces were created focusing on 2D, 3D and sonic materials. Each space was designed to support the participants to discuss their ideas in more detail from different sensory perspectives. Participants could remain in one space or move between all three. The 2D area focused on materials such as paper, card, pens, pencils and crayons. Participants created drawings, illustrations and newspapers that were displayed on the cork wall. The 3D area used tactile materials such as cardboard boxes, plasticine, pipe cleaners and stickers. Participants created speculative models of objects, vehicles and buildings (figure 5). The sound area was located within the Wellcome Collection radio studio. In this space informal conversations were recorded during which participants discussed their ideas for change with other members of the group. An edited video of these conversations is available online (https://vimeo.com/399873009).

Figure 5: 'The Perfect Job Centre' (Thomas)

Having presented two key phases of the Inclusive Futures project, the following section will provide a brief analysis of the data collected.

Analysis

The following analysis focuses on 304 responses to the question 'what would you like to change'. 245 were submitted by members of the public via the Wall of Change (public) and 59 were submitted by people with learning disabilities and autistic people during the futuring workshops (workshop). The analysis uses a topic modelling tool Text2Speech (https://github.com/ual-cci/Text2Analysis) developed at the Creative Computing Institute at University Arts London. Text2Speech uses the Machine Learning capabilities of a variety of sources including the Python Genism package (Rehurek and Sojka 2010)

and the LDAViz visualization system (Sievert and Shirley 2014), based on Latent Dirichlet Allocation modelling (Blei et al. 2003). The tool applies heuristics to make these sources more accessible via a web application framework.

Initially the most common terms were extracted from the data along with the percentage of the overall corpus that each of these terms represents, listed below.

Top five terms (workshop):

1. People (3.62%)
2. Disabled (2.71%)
3. Accessible (2.1%)
4. Change (1.44%)
5. Jobs (1.08%)

Top five terms (public):

1. People (2.84%)
2. Mental health (1%)
3. Better (0.82%)
4. World (0.73%)
5. Access (0.64%)
6. Significantly, the most common term in both data sets is 'people', suggesting that disabled and non-disabled participants in both settings were primarily concerned with change related to people. Both lists include a specific theme and word for transformation: 'jobs/change' for the workshop data and 'mental health/better' for the public.

Building on the above, a 10-part topic model analysis was undertaken for each data set to identify;

a) prominent topics within the participant responses

b) key terms associated with each topic

c) how the topics relate

The topics were assigned a title based on a topic ranking system proposed by Bischof and Airoldi (2012) which looks at the frequency of the terms within each topic and their exclusivity (i.e. the extent to which each term exists in one or multiple topics). Figures 6 and 7 present two visualizations based on the analysis. Topics are represented by coloured circles, the size of which represents the prevalence of topic and the percentage of the corpus it uses. The distance between circles highlights the inter-topic similarity – the closer the circles are to each other, the greater the similarity.

What would you like to change?

1. Disabled people (16.5%)
2. Hospitals & safety (15.3%)
3. Accessibility (13.9%)
4. Opportunities & wellbeing (12.5%)
5. The council & the law (8.7%)
6. Listening, pride & friendship (8.3%)
7. 'Would like' (real) (8.2%)
8. 'Would like' (abstract) (7%)
9. Music & communication (6%)
10. Freedom & treatment of people (3.7%)

10-part topic model analysis (workshop)
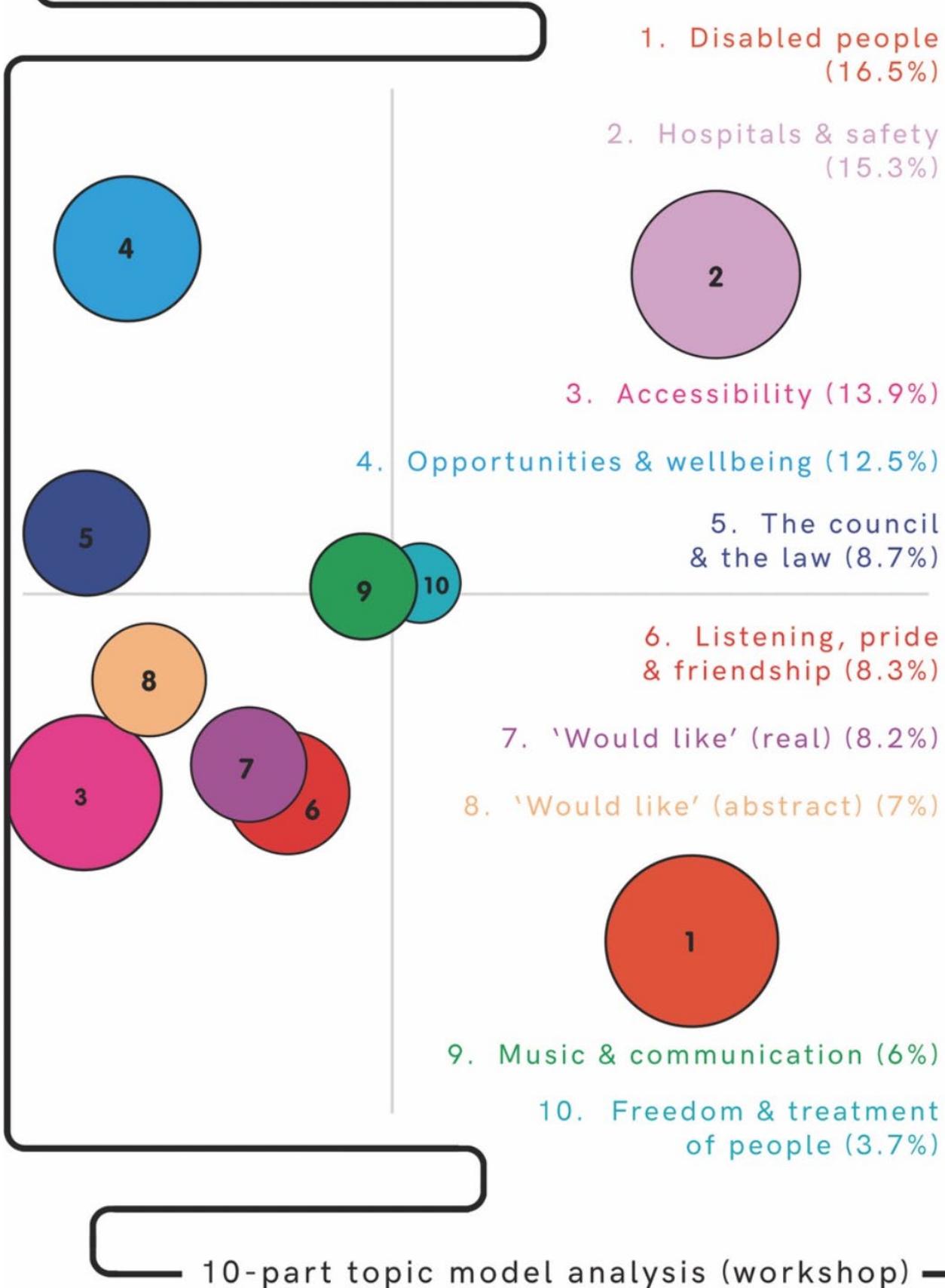
Figure 6: topic model analysis of workshop data using *Text2Speech* tool

What would you like to change?

1. People, disability & accessibility (15.8%)
2. Spaces & environments (11.8%)
3. Pollution (11.5%)
4. Love & language (10.9%)
5. Climate change (10.2%)
6. Awareness & compassion (10%)
7. Things that could be better (8.3%)
8. Attitudes, education & jobs (8%)
9. Mental health (7.4%)
10. Cities & housing (6%)
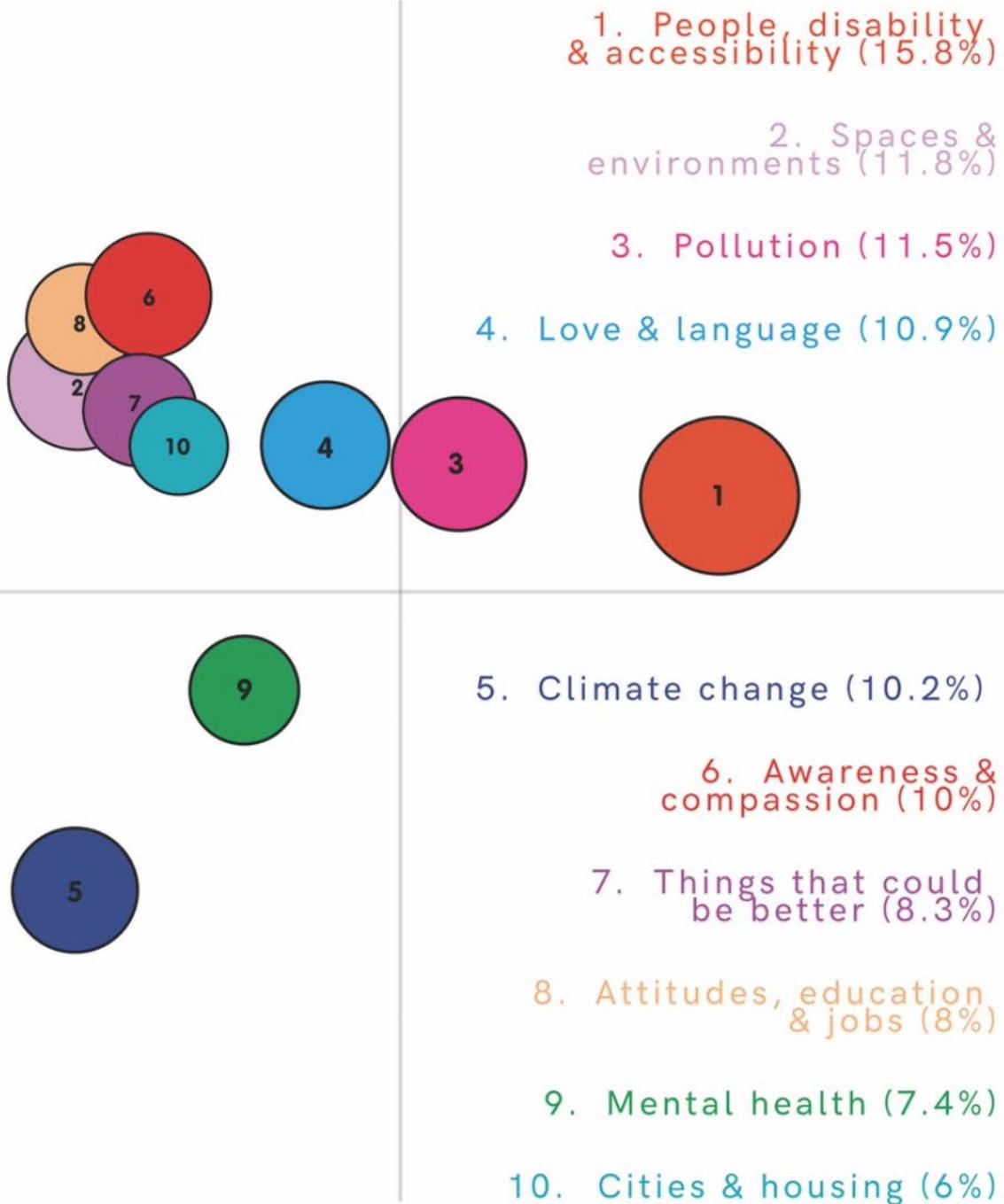
10-part topic model analysis (public)

Figure 7: topic model analysis of public data using Text2Speech tool

Within the workshop data there are 3 distinct topics: 1.' disabled people', 2. 'hospitals & safety' and 4. 'opportunities & wellbeing'. Collectively, these use 44.3% of the overall text corpus. The remaining 7 topics use 55.7% of the corpus and are much closer together. This suggests that just under 50% of the responses from workshop participants related to three distinct topics, with the other half addressing similar themes and/or using similar words. Each topic contains a number of associated key words used frequently by participants in relation to each theme. Topic 1 - disabled people - contains key words including positive, access, toilet and story. Topic 2 - hospitals and safety - includes words such as bullying and stress. Topic 4 - opportunity and wellbeing - includes key words such as artist, salary and single.

Within the public data there are also 3 distinct topics: 1. 'people, disability and accessibility', 5. 'climate change' and 9. 'mental health' which collectively use 35% of the corpus. These are more closely related to the other topics than in the workshop data. The close proximity of the remaining 7 topics suggests that 65% of the public responses used similar words and/or related to similar themes, particularly topics 2, 6, 7, 8 and 10 which are tightly connected within the visualization. Topic 1 - people, disability and accessibility - includes key words such as selfish, other and norms. Topic 5 - climate change - includes words such as government, environment and world. Topic 9 - mental health - includes key words such as public and support. The proximity of topics 5 and 9 highlights the similarities between responses relating to mental health and climate change.

This analysis considers the similarities between the two data sets – they both foreground people, use comparable terms for transformation and, fundamentally, address issues relating to disabled people and accessibility. The analysis reveals several key themes from each data set. The public responses are particularly concerned with pollution, climate change and mental health, whilst the workshop data considers hospitals, safety, opportunities and the law.

Conclusion

The Inclusive Futures project goes beyond simply creating designed outputs. It strives to demystify the design process and focuses on how the imaginations of people with learning disabilities and autistic people might raise critical questions about everyday life. 'Use the information (Aysen) . . . it's a good project (Bobby) . . . helping to make things better for everyone' (Thomas). As Dunne and Raby (2013, 189) suggest, speculative design can act as a catalyst for social change 'adding to what life could be, challenging what it is, and providing alternatives that loosen the ties reality has on our ability to dream'. 'We need to give people ideas and tell them what's important for people with disabilities' (Rajah). During the project, a strong sense of collective agency emerged, with the co-designers sharing their lived experiences of in/exclusion openly and having the confidence and support to propose positive alternatives. The designed outputs to date represent a core set of values about a world designed with disabled people in mind, and the data highlights clear connections between people and a shared desire for change. 'Inclusive Futures is about disabled people designing things that work for them and hopefully for other people so that we can all be included in the world' (Robyn). 'Check it out and see the work that we have done. It gives me the idea that we can change things for the better' (Castro). In a world that is increasingly designed around specific ways of being and doing that gives priority to particular bodies and minds, it feels more important than ever to imagine genuine alternatives that consider divergent experiences. We believe that by using design as a way to consider a diversity of hopes and fears about the world, the proposition of a more inclusive future can begin to evolve from a speculation into a reality.

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BIRDS OF A FEATHER SEW TOGETHER: A MIXED METHODS APPROACH TO MEASURING THE IMPACT OF TEXTILE AND E-TEXTILE CRAFTING UPON WELLBEING USING WARWICK-EDINBURGH MENTAL WELLBEING SCALE (WEMWBS)

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Abstract

In this paper two textile-based craft workshops focused on constructing and personalising 3D fabric birds are presented; one using traditional textile materials and another also incorporating electronic components. Working with the public, we employed a mixed methods approach measuring social and mental wellbeing factors using the Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS) and conducted semi-structured 'conversations' throughout the crafting sessions. Our findings showed a statistically significant increase in wellbeing following both sessions, with no significant difference between the traditional or e-textile workshops. We contribute findings relating to the quantitative evidence of an increase in wellbeing during crafting sessions and the learning associated with e-textiles crafting in comparison to traditional textile crafting. Although previous textile craft studies have shown benefits to wellbeing, the approach has been qualitative and e-textile crafting is underexplored for its impact upon wellbeing.

Keywords: craft; textiles; e-textiles, wellbeing scales; WEMWBS

Introduction

Increasingly textile making is employed to improve and support good health and wellbeing (Riley, Corkhill, and Morris 2013), by alleviating symptoms of physical and mental health conditions (Bedding and Sadlo 2008). Yair (2011) reported that crafting can support individuals in building relationships as it encourages collaboration and shared experiences. Additionally, makers described the immersive effects of making as:

> 'the feeling of being lost in the "flow" of things' (Yair 2011)

Csikszentmihalyi (2002) describes flow as where both body and mind work in sync.

As a material, textiles are sensory objects that

> "help us communicate and learn, add beauty and stimulation to our days, and make our lives richer' (Gordon 2011).

The naturally tactile qualities of textiles have been extended further as traditional textiles are combined with electronic components like power, light, sound and small computers to create smart or e-textiles (Posch 2017).

Several qualitative studies in both traditional and e-textiles (e.g.; Burt and Atkinson 2011; Kettley, Sadkowska, and Lucas 2016; Yair 2011) suggest that crafting in general has a positive impact on wellbeing. In the context of this research, wellbeing, which is broadly defined as

> 'feeling good and functioning well' (Huppert 2009)

is measured quantitatively through the Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS; Tennant et al., 2007). An evidence-based or scientific approach allows inspection of design activities and associated wellbeing claims and provides another way for designers to evaluate their own practice.

In this paper we discuss related work, our methodology, and findings which demonstrate a statistically significant increase in wellbeing following both the traditional and e-textile crafting sessions, with no significant differences between the workshops. Qualitative data revealed several themes providing a better understanding of participants' relationship between crafting and wellbeing.

The Gap

Previous studies have explored the benefits of traditional textile craft for health and wellbeing (Corkhill et al. 2014; Green 2017; Katz-Frieberg 2010; Kenning 2015; Nevay et al. 2019; Reynolds 2000). Predominantly these have employed qualitative methods including surveys, interviews and written exchange. Until recently, when a pilot study was conducted and reported by the authors of this paper in 2019, the use of both qualitative and quantitative methods to capture the effect making with e-textiles has on wellbeing had not been explored (Nevay et al. 2019). Additionally, while previous studies have focused on specific groups including people living with dementia (e.g. Treadway et al. 2019, Robertson et al. 2019) this study employed a self-recruitment method inviting the general public to participate in textile workshops for a research project.

The research reported in this paper builds on previous studies by examining both traditional and electronic textile crafting. Data on participants' wellbeing states were gathered in conversation and by employing WEMWBS scales pre and post crafting. The research questions explored were:

1. Is there any quantitative difference in wellbeing between traditional and e-textile crafting?

2. What are the wellbeing experiences of traditional and e-textile crafting?

Methodology

A mixed-methods approach was used to gather qualitative and quantitative data during textile and e-textile workshops. Conversations were recorded, transcribed and thematically analysed, whilst quantitative wellbeing data was gathered using the Warwick-Edinburgh Mental Wellbeing scale (WEMWBS) before and after crafting activities. This data was used to establish relationships between both textile and e-textile crafting and wellbeing.

Process

Both workshops followed the procedure outlined in Figure.1 and Table 1. In response to the different stages throughout the workshop the researchers took on a range of roles; observer, facilitator and instructor.
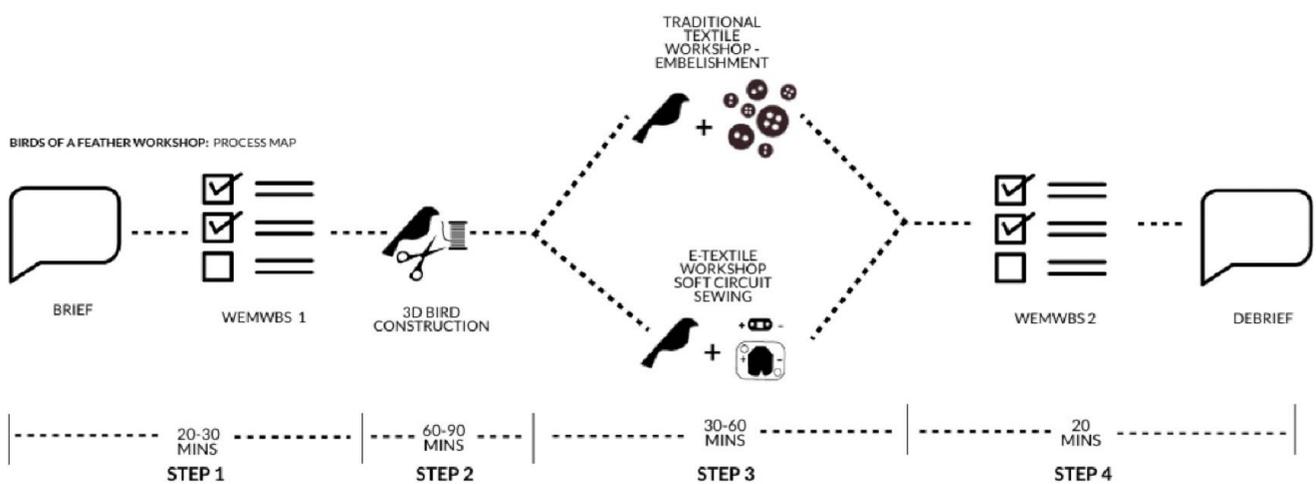

Figure 1: Workshop Process.

Figure 2: Left to right; Storyboard e-textile guide; Sewing patterns; E-textile sewing kits.

Table 1. Workshop Process Step by Step.

Step	Task	Detail
1	Briefing, Consent and WEMWBS	Briefing about the workshop and research, consent forms and WEMWBS completed.
2	3D Bird Making	Create a 3d textile bird with the provided template (Figure 2). This activity included picking their fabric cutting the pattern shapes, sewing them together and stuffing the bird to make it 3D.
3 Traditional Textile workshop only	Embellishment	The traditional textile participants were given the rest of their time (30-60 minutes) to embellish their bird using buttons, feathers, ribbons, sequins, other fabrics and bells.
3 E-Textile workshop only	Soft Circuit Sewing	The E-textile participants used the storyboards to sew their soft circuit and create their light up bird. (Figure 2)
4	Debrief, Feedback and WEMWBS 2	Participants were invited to complete a second WEMWBS survey and provide any feedback about the workshop itself.

Data Collation

Cronbach's alpha was calculated for the WEMWBS responses across both workshops before (α = .87) and after (α = .90) the activity and was found to be good. Sum scores were generated for each participant based on their responses to the WEBWMS scale pre- and post-participation in the workshop. In addition, a wellbeing change score was generated. Based on simple non-differentiation analysis, one participant showed evidence of giving the same response to all questions and so their data was removed from the analysis. There were two participants in the pre- responses and one in the post-responses who missed a question on the scale, and so a mean value was calculated based on their other responses to replace the missing value. Further to this, extreme outliers for each of the measures were removed from the analysis (wellbeing score pre-, N = 4; wellbeing score post-, N = 2; wellbeing change score, N = 2).

Participants

Participants were recruited via University, craft and community networks. 65 participants were recruited overall (Table 2). Whilst we acknowledge that the gender balance within our sample is unequal, we followed the same recruitment approach as previous related studies (e.g. Corkhill et al. 2014; Kenning 2015) who similarly found that self-selection resulted in more female participants. Across both workshops there was a range of sewing abilities, but no experience of e-textiles.

Table 2. Workshop Participant demographics.

	Female	Male	Gender not disclosed	Total
E-Textile Workshop	27	4	2	33
Traditional Textile Workshop	27	4	1	32
				65

Ethics

This research was conducted with the ethical approval of Duncan of Jordanstone College of Art and Design, University of Dundee Research Ethics Committee.

Findings, Results and Analysis

Quantitative Findings

An independent t-test demonstrated that there was no significant difference in wellbeing change scores between the traditional and e-textile workshops, $t(60) = 0.70$, $p = .49$. Based on this, the two workshop types were analysed collectively to explore the difference in wellbeing scores pre- and post- participating in the workshops. A paired-samples t-test demonstrated an overall significant change in wellbeing, with mean values shown in Table 3 suggesting an increase following participation, $t(59) = -6.72$, $p < .001$, $d = .87$.

Table 3. Means (and SD) for measures of wellbeing change following participation in both workshops.

	WEBWMS Pre-	WEMWBS Post-	Difference score
E-Textile Workshop	50.42 (4.75)	54.91 (6.27)	23.61 (3.93)
Traditional Textile Workshop	51.61 (6.60)	54.65 (6.68)	2.94 (3.60)
Total	51.02 (5.73)	54.78 (6.42)	3.26 (3.75)

Qualitative Findings

Thematic analysis identified five themes: Textile Relationships; Textiles and Wellbeing; Identity and Self Expression; Sharing Life Experience; and Learning and Skill Sharing. Participants are identified by number and workshop with 'E' for e-textiles and 'T' for traditional e.g. P1E is Participant 1 from the e-textile workshop.

Textile Relationships

Similar to Kenning (2015), participants explored sharing and the passing down of skills through generations, describing family members who had influenced their interest and knowledge of textile processes i.e. sewing and knitting. Birds were personalized in representation of significant relationships, for example, P6E:

'I've chosen this lovely map fabric... showing France as my sister lives there and I want my bird to symbolise my connection with her'.

In identifying the people or places that they associate with textile crafting participants were able to reflect upon their relationship with making textiles.

Textile and Wellbeing

Participants with previous textile experience expressed awareness of existing cognitive and emotional benefits: P5T:

'I am very aware that doing crafting is something I just enjoy, it is like escapism – I suppose a lot of the time I am quite stressed at work so [craft is] a good thing to do for your health...because it makes me focus not on work'.

and P1E expressed that textile crafting makes them:

> 'feel happy ... I want to say it ignites something, it gives you a little bit of excitement...you are taking flat things and making something 3D'.

Further, P2E highlighted:

> 'I think it's good for your brain to be really focused on something and wanting to make a good job of it – it's good for your emotional wellbeing'.

Identity and Self Expression

Participants used their creations as vehicles for expressing themselves (e.g. elements of their own identity, histories and personality) by using resonant fabrics and material: P7E:

> 'I've chosen these materials as the clash reminds me of my favourite jumper.'

Thus participants were able to quickly communicate aspects of their character and their lives. This prompted further conversation and bonding as they established parallels between each other's' lives. Possibly reflecting their new connections, participants were influenced by and echoed peer design choices including embellishments with feathers, bells and buttons (Figure. 3).

Figure 3: Left to right; Storyboard e-textile guide; Sewing patterns; E-textile sewing kits.

Whilst identity is also highlighted in previous works, (e.g. as crafter/maker in Kenning (2015)) in this study, participants' various personal identities were expressed through the fabric and embellishments they used to construct their birds.

Sharing Life Experiences

While reflecting upon their individual motivations for engaging in textile crafts during the workshops, participants broached some highly personal and potentially sensitive or difficult subjects. The researchers observed an exchange between two participants concerning retirement and ill-health, P4T chatted to P7T:

> 'I had to retire for medical reasons earlier than anticipated – I went with a bit of a grudge.'

Despite not being previously known to one another, their shared participation and interests (i.e. textile crafting) enabled conversations about wider issues within their lives. This suggests that the workshop activities facilitated both social activity and connections with like-minded people, fostering mutual understanding and confidence between participants as they worked.

Learning and Skill Sharing

Both workshops presented challenges around bird construction (e.g. manipulating fabrics of different weights and textures and using the sewing pattern) but the e-textile workshop, combining familiar hand-sewing skills with less familiar rules of electronic circuitry presented difficulties for several participants. Other participants who did not encounter difficulties offered practical advice and encouragement to their peers evidencing group cohesion, inspecting birds for circuitry problems and giving verbal support.

Across both workshops, participants supported each other by sharing skills and knowledge such as pinning and button-sewing techniques and demonstrating the use of a pen to smooth and define seams once turned inside out.

Figure 4: Participants show their birds to the group as they successfully complete their soft circuits.

This process of learning - applying new knowledge and techniques and rectifying any mistakes made- instilled a sense of personal fulfilment and provided opportunity for social interaction. Across both workshops participants expressed satisfaction with their creations but e-textile participants expressed particular joy at successfully completing their circuits, showing their lit-LEDs to the group and sharing that they were 'proud' and 'pleased' with their accomplishments (Fig 4) and some planning to further their new skills by undertaking future e-textile projects.

Discussion

This study explored two research questions:

1. Are there any quantitative wellbeing differences between traditional and e-textile crafting?

2. What are the wellbeing experiences of traditional and e-textile crafting?

Both qualitative and quantitative data revealed a significant increase in wellbeing following both traditional and e-textile crafting. The WEMWBS result is perhaps unsurprising as parallels exist in both crafting experiences - both are hands-on activities, grounded in textile construction techniques and act as drivers for social activity and interaction. However, comparison of the qualitative data of the workshops reveals that the experiences of traditional and e-textile crafting can be very different, and therefore could impact differently upon wellbeing: the traditional textile crafting workshop is an exercise in personalisation whereas the e-textile crafting is focused on learning a new skill. Our results reflect Hendry & Kloep's (2002) notion that wellbeing is also dependent on undertaking new challenges and experiences, and that improved perceptions of one's capabilities and self-esteem help towards stabilising or improving wellbeing. Our findings also

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link with the Five Ways to Wellbeing (Aked et al. 2008) model which purports that it is important to 'Keep learning and engage in challenging and rewarding activity' (one of its' five evidence-based actions for improved wellbeing). Participants' descriptions of 'relaxation' and 'flow' are similar to those reported in previous work (Corkhill et al. 2014, Yair 2011) where crafters have achieved experiences akin to meditation and mindfulness, both of which are beneficial to wellbeing.

Like our study, previous works have established commonalities between both traditional and digital crafting (e.g.. Buechley and Perner-Wilson 2012). Consistent with our study, their findings established that both crafts can produce enjoyment, fulfilment and frustration, this was also demonstrated within research undertaken by the Crafts Council (e.g. Yair 2011).

Limitations and Future Work

We acknowledge limitations within this study including gender imbalance and participants' own inherent interest in textile crafting activity. This might produce possible bias in assessing the impact of textile-based crafting upon wellbeing. Additionally, the sampling for this study was self-selected and therefore participants who had previous positive experiences of this type of crafting could be naturally drawn to textile making as a pastime or personal coping strategy for everyday life stresses.

Future work might include: replication with specific sample groups (e.g. by gender); carrying out a series of textile crafting workshops over a longer time span to measure wellbeing longitudinally; and applying the workshop process to different crafts such as pottery, to examine and gain deeper insight into the wellbeing impacts of e-textile and traditional textile crafting.

Conclusion

This paper details the use of the WEMWBS scale to explore the impact of both traditional and e-textile crafting upon wellbeing. Statistical analysis demonstrated a significant increase in wellbeing across both the traditional and e-textile workshops and thematic analysis of conversation revealed experiences consistent with positive wellbeing. However, whilst our findings suggest that both types of textile crafting are beneficial for wellbeing, differing wellbeing effects were observed as a result of the respective workshops. In the traditional textile workshop participant experience was characterised as 'relaxing', whereas in the e-textile workshop, participant experiences were focused on learning and applying a new skill (i.e. soft circuitry).

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A HEALTHY LIFE WITH TYPE 2 DIABETES: PERSONAS OF PATIENTS WITH A LOW SOCIOECONOMIC STATUS

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Abstract

The prevalence of type 2 diabetes (T2D) is relatively high among people with a low socioeconomic status (SES). As lifestyle is crucial in T2D management, patients are advised to live healthily, but incorporating lifestyle changes in daily life is not easy. It may be even more difficult for people with a low SES, as they often struggle with more urgent issues in daily life that supersede healthy lifestyle. How to promote a healthy lifestyle such that the needs of low SES patients are met? A boundary condition is a thorough understanding of the target group, and of the differences between individuals in this group. Too often, people with a low SES receive either general advice, or advice targeted to literacy level or ethnic background, whereas the diversity within the low SES population is much wider than that.

We developed personas to identify archetypes of the target group, each reflecting a distinct pattern in goals, attitudes and behaviours, to help grasp the diversity of the target group. Ten interviews with low SES T2D-patients revealed their perceptions and experiences related to what is important in life, a healthy lifestyle, living with diabetes, and lifestyle advice. Following Goodwin's persona development methodology (2011), three groups were qualitatively extracted from the data. In short, the personas are: 1) the worrisome caregiver: wants to live healthier, but is incapable of incorporating advices into one's life; caring for others is first priority; 2) the conscious self-confident: willing and able to follow up advice in order to reduce medication use; 3) the self-willed survivor: dealing with multiple (health) issues, and dedicated to solve things one's own way. Each persona likely responds differently to health promoting strategies. Additional research is needed to enrich the set of personas, for example by verifying them with the target group's family or health professionals.

Keywords: personas, lifestyle, type 2 diabetes, low socioeconomic status

Introduction

Health differences between social groups are prevalent worldwide. Socio-economic status (SES) – often measured by educational level, income, occupation and/or neighbourhood deprivation – often plays an important role in these health differences. Life expectancy of people with a low-level education is as much as 5 years shorter than life expectancy of people with a high-level education. Focusing on life expectancy in 'perceived good health', the difference between these two groups is 14 years . The differences in health and life expectancy are partly due to differences in lifestyle. People with a low SES usually have unhealthier eating habits, smoke more often, and are less often physically active in their leisure time (Geurts and van Rossum 2015; Kunst 2017; Beenackers et al. 2012). They also have a higher risk of lifestyle-related diseases, such as type 2 diabetes (T2D).

Being diagnosed with T2D can impact a person's daily life significantly. Whereas patients may want to continue to live their lives as usual after the diagnosis, they are urged to change their lifestyles drastically (Johansson, Ekebergh and Dahlberg 2009). They receive information about a healthy lifestyle (nutrition, exercise, smoking) from their General Practitioner or his/her assistant (Rutten et al. 2013). Although this healthy lifestyle could yield large health gains (Witkamp et al. 2017), changing a lifestyle is not easy. Diabetic patients indicate that they find it difficult to consider their lifestyle continuously, and to fit the advice in with their daily lives (Ahlin and Billhult 2012). If health professionals want to aid people to live more healthy lives, they need to incorporate the patients' daily reality into their health advice. To find solutions that truly assist people in maintaining a healthy lifestyle, these solutions need to be developed with and for the target group.

This paper describes a first step towards that final goal. We qualitatively investigated what it means for T2D patients with a low SES to try to live healthily. We aimed to gain insight into their daily lives, their experiences, and beliefs related to living healthy, and differences that may exist between people in this target group. For that purpose, we developed personas: fictitious archetypes that represent a specific part of the target group, each reflecting a distinct pattern in goals, attitudes and behaviours.

Interviews with the target group

Methods

The interview guide was developed with input from eight external professionals, each experienced in working with the low SES target group from different disciplines including healthcare, research, and design. Besides suggesting specific health questions to ask, they advised us to not only talk about health but also about respondents' daily lives in general, to prepare an assignment for respondents prior to the interview, and to recruit a diverse sample (e.g. in terms of cultural background).

Between March and September 2018, we held 10 semi-structured interviews with T2D patients with a low SES. SES was determined either by neighbourhood or by educational level. Respondents were recruited through local key figures (e.g. the general practice nurse), and local activities (e.g. organized group walks).

Respondents were asked to make three photographs prior to the interview of 'something related to health'. The photographs were meant to have respondents think about health already, and as a means to break the ice; respondents were invited to talk about the photos early in the interview. The interview guide (available on request) included the following themes:

- Background (open and general)
- Daily life in general (what/who is important)
- Healthy living (meaning and importance)
- Life with diabetes (practical implications and meaning)
- Lifestyle advice (provided by whom, content, adherence)
- Conclusion (expectations for the future)

Interviews lasted one hour and were mostly held at the respondent's home in the Netherlands. They received a €10 gift token as a sign of appreciation after completion of the interview. Respondents gave written informed consent before the start of the interview. All interviews were audio-recorded and transcribed verbatim.

Results

We interviewed seven women and three men. Respondents were 64 years old on average (age range 50-87). Three respondents were born in the Netherlands, three in Surinam, two in Morocco, one in Turkey, and one in Aruba. Participants were diagnosed with T2D 14 years ago on average; two of them received the diagnosis less than a year ago, five more than ten years ago. Four respondents lived alone, four together with a partner, and two together with partner and children. Five participants were retired, three had paid jobs, one was in search for a job, and one was on social security. Two respondents had completed a high education (bachelor's degree), three a middle education (intermediate vocational), and five a low education (primary or lower secondary). Eight respondents (including those with high and middle educational levels) lived in a neighbourhood with a relatively low status score.

Five respondents described their health status as 'mediocre', three as 'good', one as 'very good', and one as 'very bad'. Some respondents indicated to have trouble understanding letters or brochures. Most respondents indicated to have accepted their disease. Although all respondents had been asked to make photographs prior to the interview, less than half of them (four out of ten) had actually done this. The other respondents had not, for various reasons, e.g. because they were unable to make photos with their phones, or because they had forgotten.

Figure 1: Photograph A taken by respondent prior to interview

Respondent about photograph A (Figure 1): *"On my fridge, I have a couple of lists with all sorts of things. […] These are lists of how many fats, how much salt, how much sugar there is in all these different things. So what you'd best avoid or are allowed to eat."*

Figure 2: Photograph B taken by respondent prior to interview

Interviewer about photograph B (Figure 2): *"What is that at the bottom?"* Respondent: *"Those are bacteria, some sort of probiotics. And it lives on sugars. And that's supposed to be very healthy. I know that from a friend of mine, a fellow believer."*

The interviews provided insights in perceptions, worries, and experiences of people with T2D, and the diversity among them. The transcribed interviews formed the basis for persona development.

Persona development

For the development of personas based on the interview data, we followed the relevant steps described by Goodwin (2011):

1. Identify variables on which respondents differ from each other

2. Map respondents on variables

3. Identify patterns

4. Define goals

5. Clarify distinctions and add detail

6. Develop the narrative

Step 1. In a working session with the project team (consisting of both designers and academic researchers), the variables on which respondents differ from each other were identified. In preparation for this session, three project team members read all interview transcripts. During the session, the team reached consensus on the following variables (anchors between brackets):

- Perceived support from social environment (related to diabetes) (much-little)

- Familiarity with diabetes (e.g. what they can expect) (much-little)

- Importance, priority of diabetes (high-low)

- Focus of attention (self-others)

- Worries about consequences of diabetes (e.g. hypo, co-morbidity) (many-few)

- Self-reflection (high-low)

- Self-control (high-low)

- Confidence in (following) advices of health care providers (much-little)

- Confidence in own ability to control diabetes (much-little)

- In search of solutions themselves (yes-no)

- Disease burden (high-low)

- Worries about other issues than diabetes (many-few)

Step 2. All respondents were mapped on the variables from step 1 (see Figure 3).

Step 3. In a second working session with the project team, we identified patterns in the answers.

Figure 3: Overview of respondents mapped on variables. Each colour represents one respondent.

Figure 3 shows all respondents mapped on the identified variables. Looking for patterns, we noticed, for example, that the pink and the purple paper strips were often positioned in close proximity. Checking the corresponding interview transcripts confirmed their similarity in terms of the variables. The transcripts were essential to verify whether respondents with similar patterns indeed belonged to one group. This necessity was exemplified by two respondents who showed similar patterns for some variables, but only for those variables where their position was not very pronounced (positioned near the middle). The transcripts revealed that the respondents did not fit in one group.

Step 4. After multiple iterations of searching for patterns and checking transcripts, we identified three main groups with distinctive goals. Nine out of ten respondents could be placed in these three groups. One respondent (the dark red paper strip (Figure 3)) showed deviant answers. The transcript showed that this was a respondent who was diagnosed with T2D only recently, who did not physically notice having the disease, and who had not shared the news with anyone. Compared to the other respondents, this person was an exception; and we did not have enough data to add this person as a fourth group. It could be that this person will eventually fit in one of the other groups, e.g. when the disease becomes more manifest.

Step 5. Based on the identified variables, the background information of the respondents, and quotes from the interview transcripts, we further refined the three groups.

Step 6. The narratives for the three personas were developed, but are not reported in this paper, as explained in the discussion section. They are available on request.

Results

The three distinct subgroups or personas we identified and refined are:

1) The 'worrisome caregivers'...

"My hobby is to take care of others. And very little time for yourself."

- … worry much about the consequences of diabetes, and have little confidence in their own ability to control the disease.
- … have difficulties following health advice; they want to but can't manage.
- … are easily tempted to behave unhealthily. They keep on trying to change that though.
- … have confidence in health care providers.
- … try to gather much information, but don't manage to structure and apply it themselves.
- … primarily take care of others, and take little time for themselves.

2) The 'conscious self-confidents'...

"Well, I just accepted it [diabetes]. My greatest goal is to once live without tablets."

- … are aware of the consequences of diabetes but have confidence in their own ability to control the disease.
- … aim to live healthily (and they often succeed) in order to need as little medication as possible.
- … have confidence in health care providers.
- … find their way relatively easily through the information they receive.
- … like to have a check-up once in a while (e.g. of their blood values), for confirmation.
- … want to be a diabetic as discreetly as possible

3) The 'self-willed survivors'...

"And then I know I'm not supposed to, but you also have to enjoy a bit, right?"

- … have relatively little confidence in health care providers. Like to do things their own way; take care of things themselves.
- … are aware that some things are not healthy but want to enjoy life too.
- … worry much about other things, such as their own health.
- … feel that health problems hold them back.
- … perceive considerable support from their social environment. Search for like-minded to exchange experiences.

Discussion

This study provided insights into how T2D patients with a low SES view a healthy life. The diversity within this patient group was captured in three personas. The personas can help others to put themselves in the position of the target group, for example when designing healthcare solutions for this group.

The results of this study, including the personas, were discussed in a peer review session with about 20 experts from various disciplines (e.g. health care, design, research). Overall, the personas were recognizable to participants, although they missed a persona with less motivation to be healthy than the three personas we developed. They felt that the personas make people think, and will likely be helpful for professionals who develop policy or services for the target group, but do not actually work with people in this group. The personas trigger empathy and creativity. Participants especially valued the identified variables (step 1-5); they indicated that these variables clearly reflect underlying needs of the target group. There was less consensus about the narratives; the details made the personas livelier, but made it, for

example, difficult to extrapolate the persona to individuals with other characteristics. Therefore, we decided to focus on the personas' position on the identified variables in this paper.

Some caution is needed in using the personas. First, the personas are based on ten interviews. Additional research among the target group is needed to verify whether the current set of three is sufficient, or whether the set needs to be extended or adjusted. Besides research among the target group, it may be worthwhile to verify the personas among their social environment (e.g. professionals who work with them, friends or family). Second, this study focused explicitly on perceptions and experiences of people in the target group. Therefore, only those people were interviewed. It might well be that their views deviate from the experiences of professionals. Third, although personas help to differentiate among T2D patients with a low SES, it is still necessary to acknowledge that every single person is unique; attention for individual differences remains essential, also within one persona.

In sum, this study showed that the target group of T2D patients with a low SES is indeed heterogeneous. Patients differ from each other in how they cope with their disease and regard a healthy life, and thus likely respond differently to health promoting strategies. The personas give insight in the factors underneath the differences, and as such provide hints how to target efforts to promote a healthy lifestyle. The personas are not end-products, they need further development and validation in follow-up studies, in which researchers, designers, health professionals, and people from the target group join forces to design proper solutions that support a healthy lifestyle.

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HOW ARCHITECTURE CAN IMPROVE THE QUALITY OF LIFE OF INDIVIDUALS SHOWING CHALLENGING BEHAVIOUR: A CASE STUDY AT A DUTCH VERY-INTENSIVE-CARE FACILITY

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Abstract

Challenging behaviour, such as aggression towards oneself, others, or objects, arises in interaction with the environment and may prevent individuals from participating in society and compromise their quality of life (QoL). Literature suggests that architects can contribute to prevention, by influencing challenging behaviour before rather than after its occurrence. By conducting a case study at a very-intensive-care facility, we explore how architecture can contribute to the QoL of intellectually impaired (and autistic) individuals showing challenging behaviour.
The case study is based on interviews with residents and care providers, and direct observations of their daily life. Preliminary findings confirm the relevance of architecture in influencing challenging behaviour. They suggest that the residents are dependent on the (visual and auditory) connection with the care provider. Also, care providers confirm the importance of this connection for the quality of the care they provide. At the same time, residents may experience anxiety triggered by fellow residents and their challenging behaviour.
Residents may also feel stress when faced with unexpected situations and this may lead to an onset of challenging behaviour. Sensory sensitivity, specifically to noise and heat is also relevant for their QoL.
The findings will be further substantiated through multiple triangulation with available data (personal files, incident reports, photographs). Future research, specifically focused on intellectually impaired individuals showing challenging behaviour, is needed to better understand the similarities and differences between their needs and the needs of autistic people.

Keywords: architecture, autism, challenging behaviour, intellectual impairment, quality of life

Introduction

Emerson (1995) defines challenging behaviour as culturally abnormal behaviour of such intensity, frequency, or duration that the person's or others' physical safety is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to the use of ordinary community services. It includes self-injury and various forms of aggression. The main reasons for showing challenging behaviour include a desire to increase social attention, escape undesirable situations, adjust levels of sensory stimulation, or increase access to preferred objects or activities (Emerson, 1995). A high percentage of intellectually impaired people showing challenging behaviour have a diagnosis on the autism spectrum (Carpenter, 2011).

According to Simó-Pinatella et al. (2013, 4582):

> '...challenging behavior is one of the largest barriers to ensuring that people with intellectual disabilities [...] are able to participate in the community. These difficulties have become one of the main causes of social exclusion.'

In recent years we have seen a lively debate on suitable living environments for intellectually impaired individuals showing challenging behaviour. From an architect's point of view this debate raises the question how architecture can contribute to creating environments that positively influence such behaviour. Although architecture cannot cure challenging behaviour, it does have impact on the occurrence of particular activities or psychological states (e.g., stress), which in turn affects such behaviour.

In the Netherlands, two cases illustrate living conditions bare of dignity, a sense of home, and choice. In 1988, images reached the media of a young woman chained naked to a wall, showing the helplessness of care providers in handling challenging behaviour. That this helplessness did not vanish became apparent in 2011: videos were published of a Dutch boy chained to the wall in a barren environment. Both persons' quality of life (QoL) improved greatly with a change of their treatment, but also of their living environment (Van Zijl, 1999; Vriesema, 2012). In an effort to prevent individuals with challenging behaviour from escaping or becoming aggressive, towards themselves, others, or the physical environment, spaces are sometimes made vandal-proof. By that these rooms may be experienced as sterile, stripped of a sense of home, and in some cases even inhuman. Healthcare organizations tend to respond by trying to contain such behaviour through policies and procedures (Farrell, Shafiei, and Salmon, 2010), which may create a chain of risk reduction that compromises the QoL of individuals showing it:

> 'Lack of control over one's [physical, interpersonal and programmatic] environment may lead to a vicious cycle of behavior. Environmental factors lead to an onset of behavior which challenges others, which in turn leads to the person's environment becoming more restrictive (less access to activities, less control etc.). This restrictive environment may in turn lead to an increase in behavior, which may lead to further environmental restrictions (Parris and Watson, 2011, 30).'

Our research is motivated by the hypothesis that, besides appropriate treatment, people's QoL can also be enhanced by architecture. Architecture can contribute to prevention, since it affects the occurrence of particular activities or psychological states, and by doing so, influences challenging behaviour before rather than after its occurrence. With their research on evidence based design, Roger Ulrich et al. (2008) demonstrated the effect on patient outcomes of the physical environment, such as nature views and daylight. Moreover, spatial features like crowdedness, lack of privacy, or too much noise directly lead to stress (Mobach, 2009). Stress can also be triggered by an environment that causes

uncertainty, lacks control, and presents too much novelty (Sternberg, 2009). In this context, the built environment is considered one of the most crucial factors influencing a person's QoL (Health Council of the Netherlands, 2009). The World Report on Disability (WHO, 2011) recommends creating enabling environments, environments – physical, social, and attitudinal – that do not disable, but foster participation and inclusion.

An important relation exists between challenging behaviour and the environment (Carpenter, 2011; Farrell et al. 2010). Farrell et al. (2010, 1649) even state that 'manipulating the environment (physical and cultural) clearly offers one way to reduce CB (challenging behaviour) …' However, knowledge seems to be lacking of how the environment should be manipulated to do so. The central research question of our study is therefore: 'How can architecture contribute to the QoL of people with an intellectual impairment, and possibly autism, showing challenging behaviour?'

Method

In addressing this research question, qualitative research was conducted with case study research at a exemplary Dutch very-intensive-care facility. This facility was specifically designed for individuals with an intellectual impairment showing challenging behaviour. Therefore this studies case is an excellent example of an extreme case, allowing us to understand the limits of existing theories and develop new concepts, variables, and theories (Flyvbjerg, 2011).

The first author is the architect of this facility. She also acted as a researcher (henceforth, 'the researcher') and explicitly sought to learn as a reflective practitioner (Schön, 1983). This approach enriched the data with an insider perspective of architecture and the design proces. The research was conducted with a team of professors, and a healthcare practitioner who is also the mother of a child with an intellectual impairment showing challenging behaviour.

This study was approved by the Social and Societal Ethical Committee of the KU Leuven. All names used are pseudonyms and are not in any way related to or can be traced back to respondents.

Setting

The very-intensive-care facility, in use since 2013, is located in a residential care park. Residents whose former living condition, treatment, and behaviour turned into an undesirable dead-lock, can be transferred to the facility, where they receive intensive treatment in small groups. The most stable group of four individuals with best communication skills, living there since its opening five years ago, was selected.

Data Collection

The observations, resulting in fieldnotes, and interviews took place in April/May 2018. One week, the researcher was part of residents' daily life for observation and to conduct unstructured interviews with two members of the group, seven care providers, and the team manager, all of which was recorded. Five of the interviewed professionals are the group's primary care providers; the others provide care to other groups but function as a stand-in, if necessary. The latter provided insight into differences and similarities with other groups.

The members of the group are:

• Lilith is a 33-year-old lady. She has a diagnosis on the autism spectrum and anxiety disorder. She shows an emotional age of 3 and verbal age of 6-11 years.

• Daniel is a 26-year-old man. He has a diagnosis on the autism spectrum and post-traumatic attachment disorder. He shows an emotional age of 0 - 18 month and a verbal age between 1,5 and 3,5 years.

- Hilde is a 40-year-old lady. She has a diagnosis on the autism spectrum and shows an emotional age of 3 and a verbal age of 7 years.

- Stefan is a young man of 18 years. He has a diagnosis on the autism spectrum. Since we didn't receive the approval of his parents to analyse his personal files we don't know more about his emotional or verbal age.

Since the members of the group have difficulties expressing themselves or their spatial experiences, only two of the residents were interviewed. During the interviews, a translating care provider was present, who adjusted questions to the individuals' capacities.

All participants were informed about the study, and the fact that the researcher is also the architect of the facility, in written form and orally by the manager. All of them, or their legal guardians, gave their consent to be observed and interviewed.

Data Analysis

The transcribed interviews and fieldnotes were analysed roughly following the QUAGOL (Dierckx de Casterlé et al. 2011). The preliminary findings of the case study were also compared with related work.

The interviews and fieldnotes are in Dutch. Relevant quotes have been translated to English by the authors. The case study is still in progress; preliminary findings need to be confirmed by multiple triangulation with other data.

Findings

An initial analysis of the interviews and fieldnotes resulted in three major topics: the (visual and auditory) connection resident – care provider and resident – co-resident; the importance of predictability; and the sensory sensitivity, specifically to noise and heat.

Residents who participated in the case study seem to be dependent on the connection with the care provider. The nearness, visual or auditory, to their care providers provides them a sense of safety.

…Daniel has a very low emotional age, therefore, if you leave the room Daniel doesn't realize that you're in the hall. Just like a child when the mother walks away. (Care provider 1)

The participating care providers also report a need for connection to the resident in visual and auditory sense, since it allows recognizing the state (s)he is in. When the resident shows the first signs of stress, they can immediately make a connection and influence a possible onset of challenging behaviour.

…as soon as you hear the door handle move you want to look into the hallway to see who's leaving his room. Because this has effect on the other residents in the living room. In order to be ahead of situations we need the overview. (Care provider 2)

Most residents seem to experience stress from the (challenging) behaviour of fellow residents. Their unpredictable, loud, and sometimes aggressive behaviour is frightful and also challenging given the residents' (sensory) sensitivity.

Lilith can experience the living room as unsafe and is quite afraid of her fellow residents. She does everything to prevent certain co-residents to get too close. (Observation)

Daniel is often a target of hard objects that are thrown at him. (Care provider 1)

Individuals showing challenging behaviour may experience stress when faced with unpredictable situations, e.g. somebody entering unexpectedly, not knowing who is behind a door or around a corner. Residents seem to be supported by predictability and overview, since they see others

approaching. Overview promotes also the visual connection with the care providers and enhances the residents' sense of safety.

> If you put Lilith on this couch in the middle of the living room and something happens behind her she'll start to look behind her in sheer panic. She really wants to know what's happening and misses the overview in that moment. (Care provider 3)

Not only unexpected situations, also unexplainable noise, e.g. the gurgling sound of a nearby bath being emptied, may cause fear and lead to an onset of challenging behaviour.

> ...if the bath gets emptied then the gutter goes really gghhhpt. It really scared me....I was scared shitless. (Stefan)

During the night, noises like screaming and smashing doors may lead to stress and a possible outbreak of challenging behaviour. Also the lack of control over temperature, noise, light, and smell can cause stress.

> What I don't like about this house is that we have such small windows (to open) and that my room gets so hot. (Lilith)

The unexpected shattering of dishes and screaming of a co-resident frightened Stefan in his room. He ran towards the noise, started cursing at the co-resident, and threatened to hit her. (Observation)

Several care providers stated that the transfer of sound between the apartments was often a reason for the onset of challenging behaviour at night.

> It's really about door open, door close. This noise carries through all the walls. (Care provider night watch)

During the design process it was decided that only the small and highly placed windows could be opened, because the organization was worried that residents might escape, others might enter, and that unwanted items might be exchanged.

Preliminary findings suggest that this is in line with the residents' feeling of safety, since they tend to be afraid of somebody entering their room through the windows.

Unfortunately this choice for safety ignores the wish for influence on temperature and prevents proper cross-ventilation.

Discussion and Conclusion

These preliminary findings from the ongoing case study provide initial insights to start answering our research question: 'How can architecture contribute to the QoL of people with an intellectual impairment, and possibly autism, showing challenging behaviour?'

Connection, in relation to overview, is one of the most frequently mentioned topics in the interviews and observed in all four residents, but seems to receive little attention in related work. Important to the group members seems to be the self-regulation of interpersonal distance; nearness to the care provider and distance from potentially frightful encounters with fellow residents,. The other topics; importance of predictability and the attention to the sensory sensitivity, are supported by previous research, specifically in sources about autism (Mostafa, 2014). This suggests that architecture which promotes sensory adjustment, e.g. possibilities to cross-ventilate and excellent acoustic measures, may improve the QoL of these residents.

Even though none of the group members are alike, our preliminary findings suggest that, regardless of their noticeable differences, they seem to share similar preferences and needs.

Limitations

Given the significant body of literature on sensory environments (Snoezelen), these might have been interesting to investigate, but these were absent in studied facility.

Possible limitations of our study are that the interviews with the residents needed a 'translating' care provider who might influence the answers. The fact that the researcher is the architect of the building might be seen as an advantage but also as a possible limitation, since it might involve 'bias' and restrain participants from being completely honest. This study uses the combination of the different perspectives (outsider/insider; practitioner/researcher; architectural design/facility management/ healthcare) as a strategy to enrich the analysis, ensure its trustworthiness, and avoid bias.

One might argue that findings from a single and extreme case cannot be generalized. However, a carefully selected single case study can not only generalize findings (Flyvbjerg 2011), but also support exemplification and transferability.

Future work

To gain deeper insight into the group's daily life, findings will be further substantiated through multiple triangulation with more available data. These include personal files, incident reports, lists of reparations, and pictures of three different walks through the building. The mix of resident-centred data sources, various methods, and investigators with different backgrounds will provide a rich and credible representation of residents' life in the built environment.

Future research, specifically focused on intellectually impaired individuals showing challenging behaviour, is needed to better understand and confirm the relevance of our current findings. Moreover, empirical research on the similarities and differences between the needs of individuals showing challenging behaviour and those of autistic people is recommended.

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CREATIVE WELLBEING FUTURES: FRIENDLY HACKING, LO-FI LIVING LABS AND IMPROVISED CO-CREATION

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Abstract

Evidence about the benefits of using the arts for health and wellbeing promotion has prompted the World Health Organisation to recommend the incorporation of art programs as part of future health policies. However, implementing art programs as part of care services is not easy, and designers, artists and health workers find several operative and technical barriers as part of the process. Literature reporting on successful art programs makes emphasis on outcomes and impact, but do not tell much about the 'behind scenes' process that made the programs possible. This paper aims to fill this gap and contribute to the discussion about the arts in health by sharing experiences of a participatory design project where designers, allied health professionals and psychiatric inpatients collaborated to co-create the Creative Wellbeing Program. The design process that led to this program built on 'friendly hacking' principles to constitute a 'lo-fi

living-lab' focused on conducting non-intrusive design interventions based on the delivery of art activities. These interventions made possible to 'live-prototype' the activities the program would have and informed the design of toolkits and guidelines for its implementation. The Creative Wellbeing Program encourages participants to use visual arts as a mechanism for positive self-reflection and personal expression through the production of symbolic meaning. The paper discusses how this project gives an idea of how the future of mental healthcare could look like and concludes by encouraging health organizations to facilitate collaborative work between designers, artists, staff and users to incorporate creative practices as part of their care services.

Keywords: arts in health, participatory design, hacking, lo-fi living labs

Introduction

A recent report of the World Health Organisation reviewing hundreds of studies documenting benefits of the arts for health and wellbeing suggests that creative practices should play a significant role in the future of health services and policies (Fancourt and Finn 2019). The use of creative activities as part of healthcare services has a long history. This practice is usually classified in two different categories: art therapy, run by art therapists to achieve clinical goals, and arts in health, run by artists, designers and healthcare professionals to promote general wellbeing (Sapouna and Pamer 2016). The benefits of both approaches, and their different variations, have been demonstrated in an extensive body of literature preceding the WHO's report. Nevertheless, the report is important because its influence in future policies will open opportunities for the design of creative practice programs in the healthcare sector.

Despite the benefits of the arts for health and wellbeing, the design and implementation of creative programs in health facilities can be challenging. In the specific context of mental health, which is the case discussed in this paper, bureaucracy and an unimaginative system are some of the limitations that workers find when they attempt to implement creativity (Gillam 2013). In addition, there are time constraints and lack of frameworks, guidelines and tools for running art-based activities in meaningful ways and beyond recreation and leisure. Anecdotal evidence shows that sometimes art activities are seen as a mechanism of distraction for keeping patients 'busy' while psychiatric medicines take effect.

Many health organizations and art centres have been able to overcome these difficulties and develop creative programs. Most reports of these initiatives discuss their outcomes, evaluation and impact, but not the collaborative processes that creative practitioners and healthcare workers deploy as part of their conception, design and implementation. In other words, there are very few accounts of the 'fuzzy-front end' (Sanders and Stappers 2008) of the design of these projects, which is a discussion that can inspire and provide insights for future programs and inform policies.

This paper contributes to fill this gap in the context of the arts in health by presenting the design process that led to the Creative Wellbeing Program (CWP), an ongoing initiative to incorporate art activities in the care services of Bendigo Hospital's Psychiatric Services. This initiative is part of an ongoing partnership between RMIT University and Bendigo Hospital, and builds on previous research where Sumartojo (2020) looked at practices of 'care on the move' in this psychiatric unit. The design process of the CWP was informed by hacking mindset and improvisational techniques that made possible to introduce meaningful creative practices in mental healthcare using a participatory bottom-up approach, without requiring expensive interventions or bureaucratic processes.

Although the project started before the WHO's publication, we consider their report important as it will open up future opportunities for collaborations between creative and health disciplines. In this context, the CWP can work as an example of how designers and healthcare professionals can collaborate to shape together a future health system where creative practices play an important role in preventing illness, promoting health, and managing treatment.

The following sections present the design process behind the CWP and its outcomes. Following calls from the field Participatory Design to engage with politics of self-representation (Light 2018), the discussion is written in first person and plural. The first person (I) is used to introduce and recognize my own position and agency as designer working in a healthcare setting, and the

plural (we) to acknowledge the role of participants as active agents in the project. I have chosen this style as an attempt to capture elusive aspects of the design process usually overlooked when reporting research and to acknowledge that as author, I am presenting a personal perspective of collective and collaborative experiences.

Friendly hacking and the lo-fi living Lab

The CWP is part of a research project that built on the concept of friendly hacking to constitute a lo-fi living lab within a psychiatric unit. Friendly hacking is a framework based on Participatory Action Research, where multidisciplinary teams are embedded in organizations to challenge the robustness of public policy and instruments, identify weakness and implement improvements (Jégou et al. 2013). Inspired by this framework, I embedded myself in this psychiatric unit and initiated an unstructured collaboration with members of the allied health team to explore opportunities for conducting design interventions. My initial aim, following previous participatory design projects where friendly hacking has been used, was to set a living lab (Nilsson, Topgaard and Ehn 2014). However, as I adjusted myself to this context and realised that staff were everyday designing (Duque 2018) and using visual and material slang (Ventura, Keinan-Guy and Adani 2018) to improvise their own solutions, I reframed my intentions and configured what I call a 'lo-fi living lab' (LFLB): a space for unsophisticated and improvised co-creation of using tacit knowledge, low-tech and DIY processes.

Building on previous research about the role of food and cleaning trolleys in the delivery of care services in this psychiatric unit (Sumartojo et al. 2020), one of the design interventions planned as part of the LFLB was to create trolleys for assisting the delivery of occupational therapies. As the project evolved, I found that one

staff member was running improvised art sessions as part of these therapies. Instead of using a room allocated for allied health activities, which implied to take inpatients out of their everyday environment, she decided to bring the sessions into the wards and embed them into their everyday life. For doing this, she adapted a clinical trolley (Figure 1) to transport art tools and materials that were put on a table around which patients gathered around. Based on this experience and her expertise, we both proposed a project for designing a trolley for enhancing the art sessions and transforming them into a cohesive art program.
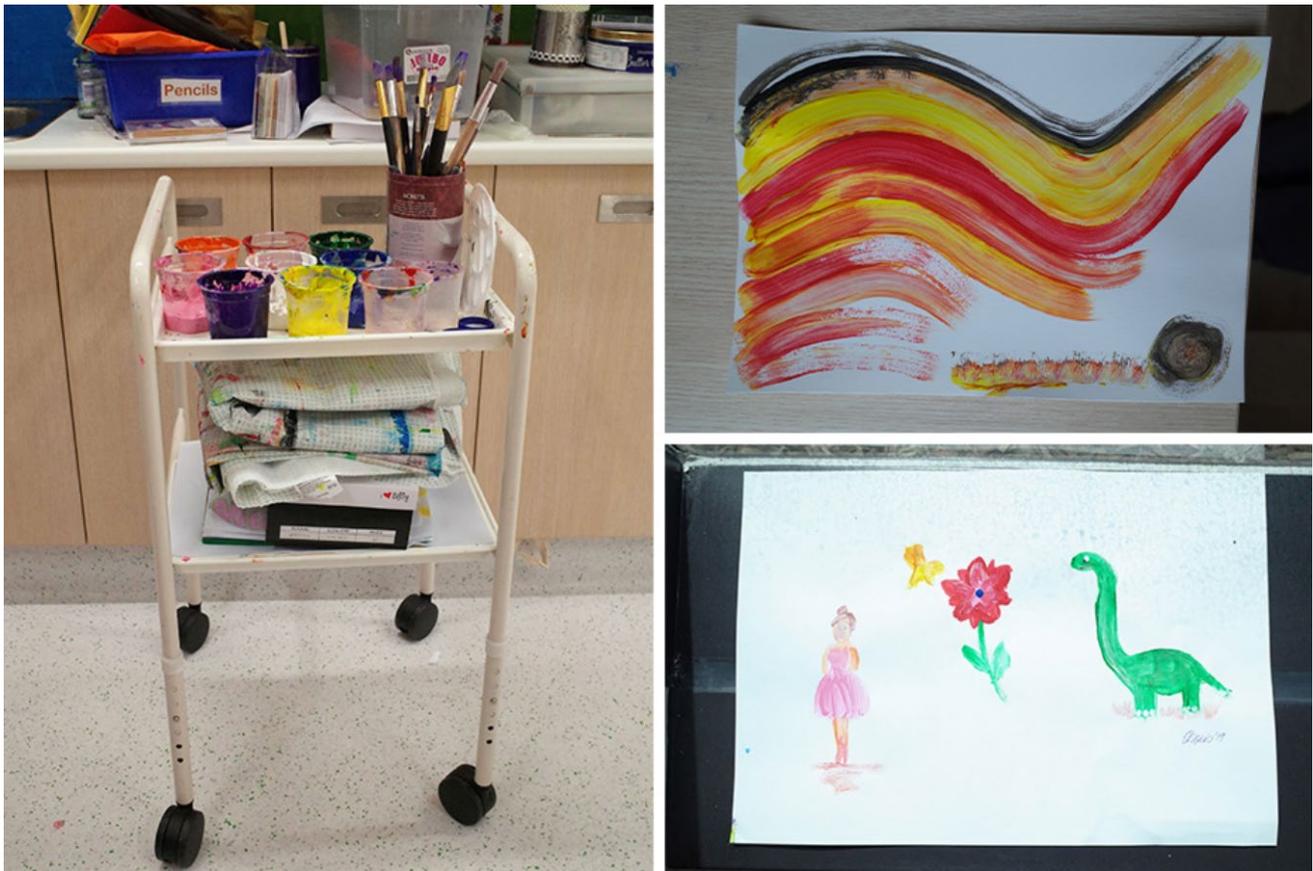
Figure 1: Clinical trolley utilised in the improvised art activities and patients' work

Inspired by hacking and lo-fi techniques, I decided that instead of organizing codesign workshops with staff and patients, the best way of imagining how the trolley would work and look like was live prototyping with them the activities that would be part of the program (Figure 2). Building on creativity and arts in health frameworks (Gillam 2018) I prepared non-disruptive design interventions (Calderón Salazar, Zuljevic and Huybrechts 2018) based on art sessions that would help me to discuss the future trolley with future users of the arts program. I transformed a second-hand hospitality trolley into a vehicle for storing and bringing tools and materials into the wards, and for displaying visual guidelines with examples of things that could be made with them. Using second-hand picture frames, I organized pop-up exhibitions to showcase the works made during the sessions in the wards and invited patients to comment on their works.

The non-disruptive interventions allowed us, not just to discuss, but to co-create different aspects of the future art program (e.g. trolley, art sessions, exhibitions) with a variety of stakeholders (e.g. participants, other patients, clinicians, allied health staff, managers, cleaners, security guards). Through this process we found that the trolley should incorporate an external storage system to keep tools and materials that staff could put in the trolley depending of the activities they wanted to run, and that the design should be open for appropriation in use (Bjögvinsson, Ehn and Hillgren 2012) to integrate new techniques and functions as they emerge.
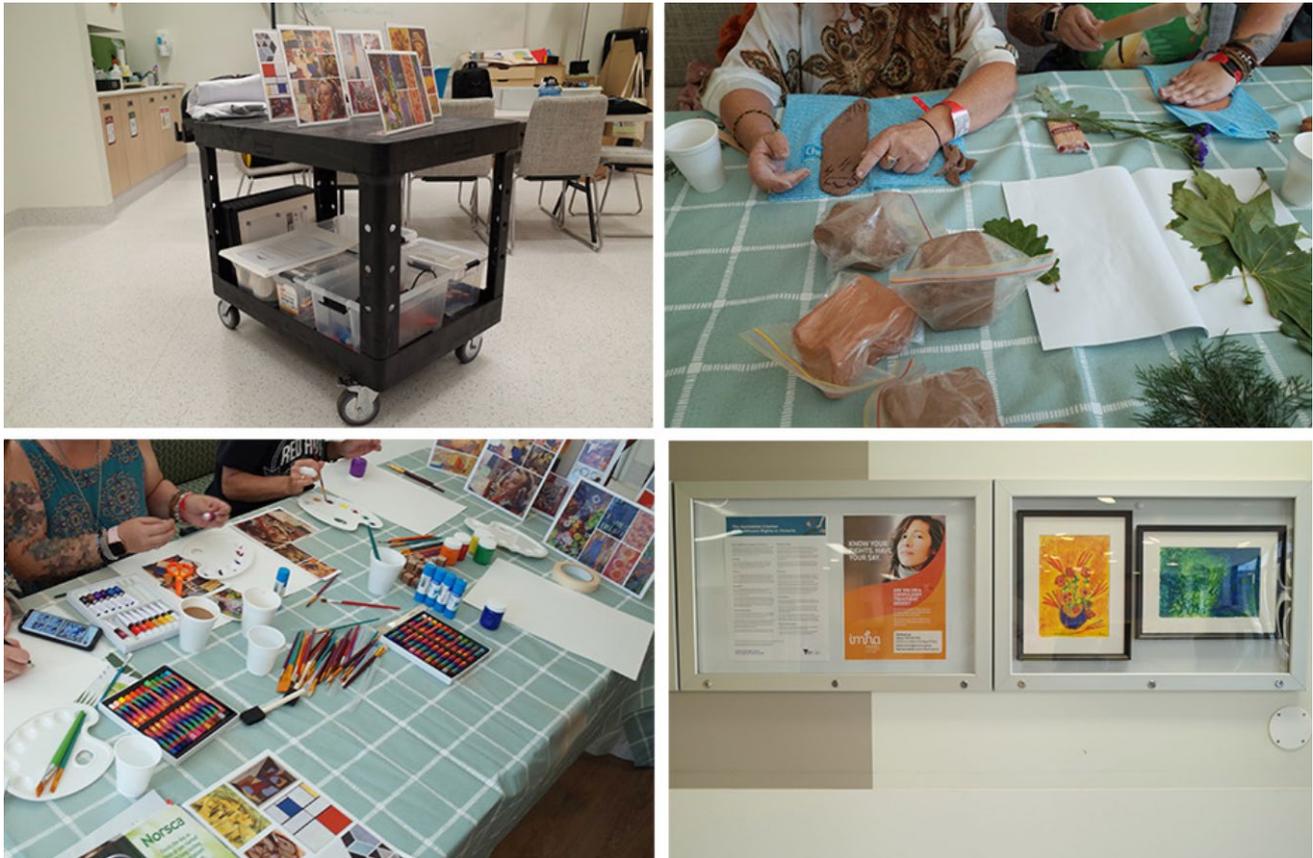
Figure 2: Live prototyping sessions

Although the live-prototyping sessions revolved around creative skills, we decided to focus the program not just on technical aspects of art, but on creative expression. More than learning a technique or reproducing a style, the art sessions would allow participants to explore their own feelings, reflect on their emotions and express themselves producing symbolic representations. We also found that running art exhibitions was a rewarding experience for participants and allowed other patients to engage with art contents.

Subsequently, based on insights from these interventions, the first functional prototype of the toolkit system was manufactured, and using this prototype we initiated a pilot implementation. The final design was inspired by IKEA hacking (https://www.ikeahackers.net/ 2019), and included the arts and crafts trolley, a storage system, and exhibition displays. In the live prototyping sessions, we utilized several IKEA products that were easily adapted to

different functions, and for the final design we decided to incorporate these products. The use of IKEA hacking makes possible the future appropriation and reproduction of the trolley by other health facilities and enables staff to adapt the system to new functions once the project has concluded and there are no designers around.

Discussion of results

Insights and experiences from the collaborative design process shaped the CWP. Although this initiative is based on the delivery of visual art activities, it goes beyond the use of arts and crafts as recreation or distraction and aims to engage inpatients of the psychiatric unit in creative practices that contribute to their wellbeing. The activities, including art sessions and art exhibitions, provide a safe space for self-reflection, personal expression and production of symbolic meaning. The program includes two elements: the toolkit system for delivering visual art activities,

and guidelines explaining how to facilitate those activities in ways that contribute to the wellbeing of participants.

The creative wellbeing toolkit system responds to requirements identified in the design process and characteristics of this context (Figure 3). It includes a trolley that operates as a movable storage and display system, and whose contents can be easily changed depending on the that will be delivered. Rather than having predefined art activities based on techniques or styles, staff can configure the trolley for mixed visual arts by choosing from a series of IKEA's Trofast boxes containing specific tools and materials and sliding them into the trolley. By changing the contents and accessories, the trolley can be used for delivering activities based on specific techniques (e.g. pottery, painting, photography) or topics (e.g. vision-boards, zine making), depending on the physical and cognitive abilities of different patients and the purpose of the sessions. The toolkit also includes movable displays for exhibiting the works made by participants.

Figure 3: Final toolkit for implementing the Creative Wellbeing Program

The use of a trolley and movable displays makes it possible to run program activities across different places and for diverse publics. When the project started, one of the issues raised by staff in charge of occupational therapies was that having to take patients out of the wards and taken to a different room out of their living environment could be intimidating and coercive and put limits to the number of participants. Our moveable approach overcomes this problem and presents the arts as part of the everyday life of a psychiatric ward, rather than something exclusive to art spaces or art studios. The exhibitions allow other patients to engage in creative activities as 'art audiences'.

The creative wellbeing guidelines explain how to use the toolkit system for wellbeing promotion. The guidelines used in the first live-prototyping sessions introduced participants to art styles and techniques and explained how to use specific tools and materials to reproduce them. Most of the time, however, participants did not follow these guidelines and decided to mix-up styles and techniques to represented personal themes in their works. This 'bottom-up co-creation' process made me aware that for contributing to people's wellbeing, the CWP should go beyond technical skills or reproduction of art styles and use visual arts as mechanisms for creative expression. Following this insight,

the final guidelines invite participants to self-reflect in positive ways about their lives, better understand their feelings and emotions and express themselves by producing symbolic meanings. Although these elements (self-reflection, emotions, expression and symbolic meaning) are at the centre of art therapy, the CWP is different because it is not run by art therapists but allied health staff and does not link creative

expression to clinical outcomes. We do not see this as a limitation, but as a specific approach to the use of the arts in health for creating de-clinicalized art spaces within a clinic. The CWP pilot implementation demonstrates that this perspective can contribute to the wellbeing of participants through self-esteem, sense of achievement, and emotional expression.

Figure 5: Creative Wellbeing Program pilot implementation

Conclusion

This short paper presented the design process that led to the CWP. It attempts to fill a gap in the field of arts in health, where current discussions make emphasis on outcomes and evaluation of art initiatives, but overlook the tactical procedures involved in their conception and development. The design process discussed here has a collaborative nature, but a different approach to traditional participatory design processes. Instead of disrupting into a context to run co-design

workshops to collect information and going back to the design studio to complete the project, I built on friendly hacking to embed myself in the hospital through the installation of a lo-fi living lab, from where I conducted non-disruptive design interventions to live-prototype an arts in health program with staff and patients.

This approach enabled improvised co-creation processes, where several stakeholders had a direct input shaping the project process and its outcomes. The resulting program responds to specific

characteristics of this psychiatric unit (e.g. architecture, patient distribution, social and cultural conditions), and it might not fit or work well if it is taken as it is to other facilities. For this reason, the paper makes more emphasis on the process and less on the outcomes, and the invitation to health organizations is to establish meaningful partnerships with creative disciplines to make possible long-term collaborations between artists, designers and healthcare workers. These partnerships are crucial for creating art programs able to build on existing capabilities and respond to requirements of specific contexts.

Creative practice programs at the intersection of design and health, where the arts are used, not just as distraction or recreation, but as means for creative expression, can contribute to shape a future where the idea of 'the patient' understood as someone who is just 'waiting' to get healthy while receiving treatment, can be transformed into a new one, where users of health systems are creative agents that participate in the management of their health and wellbeing.

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RADICALLY SELF-ORGANIZED CARE: WHAT CAN DESIGNERS LEARN FROM THE EVOLUTIONARY DYNAMICS OF COOPERATION

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Abstract

For many years, top-down performance management systems have strongly influenced organizing structures in the health sector (De Blok, 2010). Recently, new organizational forms based on self-governance have begun to emerge where authority is more widely distributed amongst healthcare staff and work is conducted by decentralized, self-managing teams or networks. In this paper we aim to develop a better understanding of the distinctive design properties of these highly collaborative organizational structures and to reflect on the designer's role in this context. We are interested, firstly, in exploring how service and system designers can best support health organizations to advance in such a changing environment, and, secondly, how design practice might help to address the inevitable tension between (a) formal bureaucratic controls and mechanisms for accountability and (b) continual adjustments and distributed authority. Elinor Ostrom's Core Design Principles, founded on her Nobel-prize winning work in the management of Common Pool Resources, have advanced to describe the evolutionary dynamics of cooperation more generally. We propose that combined with insights into humanization these principles may provide a sustainable approach for the future design and delivery of care provision. Investigating a healthcare case study characterized by self-organization, we aim to facilitate a collective reflection and inspire further experimentation in the field.

Keywords: service design, evolutionary science, cooperation, self-organization, humanization

Introduction

Over recent decades, there has been a growing interest globally in the development of programmes to support healthcare professionals and managers in improving the quality of healthcare services and associated health outcomes. Although today many advocate the early involvement of patients, carers, healthcare professionals and members of the public in the healthcare design process, for many years top-down performance management approaches from the industrial sector have been used as key management strategies in healthcare systems, underpinning the vertical design of many healthcare organizations (De Blok, 2010). Such approaches have resulted in some efficiency gains, arguably a key measurable benefit for any healthcare system. However, what has come to be viewed as a reductionist industrial manufacturing perspective is increasingly judged as insufficient (Kings Fund, 2020). Transactional healthcare models have lost sight of the whole person and the interconnectedness of medical needs and conditions (for example, we see 'the diabetic' as opposed to a 'person who also happens to have diabetes') despite healthcare, at its core, being deeply human and relational, delivered by and for people (Haque, 2015). As the healthcare system struggles with the context of rising demands and limited resources, the need for creativity has also come into focus alongside a recognition by long standing leaders of the Quality Improvement (QI) movement of the limitations of the industrial management practices which have largely shaped mainstream healthcare improvement work (Batalden, 2018). In response, this paper explores what designers can learn from evolutionary dynamics of group collaboration and (re) humanising care practices.

Dehumanization in healthcare

Michel Foucault used the term 'clinical gaze' to describe not only the way doctors have come to view patients today but as representing an entire worldview that defines roles and relationships in the healthcare system, which type of knowledge is taken seriously, how power is being exercised and how care is organised (Foucault,1973). From this has arisen the notion of the 'production-line healthcare worker' who aims to manage care through care pathways akin to mechanical production lines - by reducing inefficiencies and accumulating marginal gains of time - but to the detriment of the relational and human aspects of health (Hannah, 2014). Although a production-line metaphor can acknowledge the dynamic nature of healthcare by allowing space for energy, creativity and improvement it also indicates a lack of meaning, evolution, purpose, connection and soul (Laloux, 2013). Treatment of people as mechanical systems often results in a particular form of dehumanization — objectification — in which others are viewed as being incapable of emotional responsiveness or interpersonal warmth (Haslam, 2006). Through the prism of Haslam's framework, the positivist turn in organizational studies appears like a form of mechanistic dehumanization which results in leaving little humanity at the core of a modern organization (Petriglieri, 2020). For healthcare, this is deeply problematic given that positive health is based on the fundamental principles of common humanity, interconnection and our relationships, not merely the absence of disease (WHO, 1948).

Haque and Waytz define dehumanization as the denial or removal of distinctively human qualities of a mind, independent thought or feeling for other people (Haque, Waytz, 2012). They identify six key causes of dehumanization in our healthcare systems and propose a series of strategies for (re)humanising care through incorporating improved clinical practices and organizational measures (see Figure 1).

1 Individuation	Reverse the medical practices that anonymise patients and healthcare professionals and incorporate ways that individuate and personalise people instead	
2 Agency	Reorientate attention toward people's capacity to plan & choose and treating patients as active partners in clinical decision making, despite possible physical limitations caused by disease or illness	
3 Similarity	Discourage labeling patients as their diseases and instead emphasise the humanity in us all	
4 Personification	Think of a 'patient' as a whole person as opposed to reducing them to a mechanical system made of physiological parts and subsystems and humanise medical events through narratives and storytelling	
5 Empathetic Balance	Combining part empathic and part cognitive problem solving when deciding on diagnosis, prognosis and treatment and selecting individuals capable of devoting cognitive skills and social skills to their profession	
6 Moral Engagement	Decrease the psychological distance between doctors and patients and reduce doctors' having to temporarily suspend themself from the role of committing harm and inflicting pain	

Figure 1 Six strategies for (re)humanization (adapted from Haque and Waytz, 2012)

Evolutionary Science For Self-organised, Cooperative Behaviour

As causes of dehumanization began to be explored, a growing recognition has emerged that evolutionary processes can be harnessed as a way to humanise organizations and create new environments that support cooperation and balance individual self-interest with group purpose (Atkins et al, 2019). Evolutionary science offers a novel perspective for design practice. One key insight relates to small group formations that shape the basis of the social environment of most of our evolutionary history (Atkins et al. 2019). Similar to the cells of a multicellular organism, Atkins and Wilson (2019) argue that small groups need to remain the key building blocks of modern large-scale organizational structures and that we can learn from evolution when seeking to understand the way they are established. Evolutionary science not only tells us where we come from but also provides ideas about what we need to do, in order to consciously shape our behaviour to be more cooperative and human with each other.

Multi-level selection theory (MLST) as defined by David Sloan Wilson, could provide a suitable lens for designers to better understand some of the evolutionary drivers underlying healthcare including the behaviours of a healthcare organization and its workers. It examines two concurrent and often conflicting forces, such as the purpose of an organization as a whole and the interest of individuals within it. Understanding the interaction between the levels is critical because knowledge of how humans tend to behave individually and within groups, shaped by, for example, status seeking, leadership preferences, a sense of fairness and gender differences, allows us to generate novel predictions for when we should expect to see more individual (self-interested) or more collective (altruist) behaviours. Such understanding may in turn allow us to design more mindfully for an appropriate balance between the two.

Although organizational leadership has historically adopted a top down hierarchical approach to management, recent research suggests a new paradigm is surfacing, one that demonstrates striking similarities with insights offered by MLST. This new organizational paradigm advocates rehumanization and is characterised by three key pillars of 'self-management, evolutionary purpose and wholeness' (Laloux, 2015). The latter suggests the arrival of a new *homo economicus*[1] who relies on their entire authentic and human self in the workplace, as opposed to a narrowly confined professional persona. This radical departure from our existing view on human nature[2] not only changes what we do individually but it determines the forms of governance we design and implement and enabled fundamental breakthroughs in organizational human collaboration (Laloux 2014).

Laloux identifies a set of organizational paradigms that are operating concurrently today and that move along an evolutionary spectrum of organizational consciousness. Today, we see some real-world examples of pioneering, humanised organizations which operate with novel structures and management practices based on high levels of cooperation and a strong sense of individual autonomy. They tend to be self-managed and purposeful, produce significant cost savings in corporate functions, are able to re-engage staff through autonomy and improve the quality of the services provided. At their core, these new practices demonstrate how we may be able to deal with the complexity of our times in completely new ways and how work can become a place of personal fulfilment and growth.

The Buurtzorg model of care

One inspiring example rapidly spreading across the sector is the Buurtzorg model of care. Originating in the Netherlands in 2006, Buurtzorg is a model of community nursing. Each neighbourhood is looked after by a team of nurses who take time to connect and get to know the residents. It is widely cited as an evidence-based approach to improving the delivery of integrated nursing and social care in community settings. Buurtzorg's organizational structure is simple and flat with no middle management layers, no departmentalization and minimal back-office functions. Home care employees are organised in independent and self-managing teams with no team leaders, avoiding line-managerial direction. The model is characterised by high levels of patient and staff satisfaction, professional autonomy exercised through self-organised nursing teams, client empowerment and holistic, patient-centred care. Buurtzorg is remarkable in that it is built on a shared mission of helping residents to manage their own lives as much as possible and giving its care team an extraordinary amount of freedom and agency to do just that. It provides an excellent example of the cultural evolution that can take place when groups are provided with local autonomy and an ability to self-organise by adopting a complex form of polycentric governance combined with semi-autonomous decision-making capabilities.

Buurtzorg is just one examples of organizations being set up with the intention of placing humanity at its core and using self-organization to achieve that. We propose that there is value for designers working in healthcare to better understand

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[1] Classically, the homo economicus is solely focused on satisfying their own self-interest at the lowest possible cost irrespective.

[2] See 'Tragedy of the Commons' by Hardin, 1968. It provides a vivid parable of a social dilemma: In an imaginary village, farmers are free to graze their cows in a commonly owned pasture. The pasture can only support so many cows but each farmer can gain by adding more of their cows to the herd, resulting in the tragedy of overuse.

the evolutionary dynamics of cooperation in order to improve health services. Our interest is to understand the ways that a healthcare organization that exists within largely traditional management and hierarchical structures can reinvent itself and how designers can effectively support self-organization using the principles of evolutionary science for healthcare. If succeeding at group level is a key driver for evolutionary transitioning, and thereby limiting the opportunities for individuals to benefit at the expense of others, we suggest that one way of framing the conversation is by investigating the relevance of Ostrom's Core Design Principles in designing better healthcare solutions. Ostrom's work around polycentric systems is said to have particular relevance in healthcare and has recently been explored in the context of health and social care provision for formerly incarcerated prisoners in the United States (Robert et al. 2020).

Theory & Methods

We conducted a review of literature relating to Buurtzorg implementations. Based on Yin's definition of a case study[3], we also aimed to understand the context in which Buurtzorg was implemented and its impact on creating more humanised and humane service interactions. We have analysed and reviewed reports on Buurtzorg by means of desk research (including published articles on Buurtzorg, internal documentations, in-depth evaluation reports, news articles, internet sources, filmed staff meetings) to map and identify to which extent Buurtzorg follows the evolutionary dynamics of cooperation inherent in all species, and thus foundational evolutionary principles. We looked at Buurtzorg through the perspective of evolutionary transitions studies (Wilson 2008; Smith & Szathmary, 1995, Van Vugt, 2006) and specifically Ostrom's

conceptualization of the conditions of self-organization and cooperation which provides a framework to understand the evolution of group level adaptations.

Ostrom observed that self-organization happens in structured environments, under specific conditions and within specific domains in collective action processes. She found that while individual actors have self-organizational capabilities, there are also conditions that determine whether or not they will organise themselves. She codified the conditions of self-organization in collective action processes using a set of Core Design Principles (CSPs), which resulted from her investigation into groups who manage publicly accessible and finite resources and avoid top-down regulation in favour of balancing individual and collective interests. In order to practically adopt the principles to improve group collaborations, Wilson (who co-authored the original CDP paper together with Ostrom) amongst others recently created an iteration of the CDPs entitled 'Prosocial or 2.0 Version' (see Figure 2) which we adopt in this paper (Atkins et al. 2019). As a generalised version of Ostrom's original principles, 'Prosocial' uses the essence of Ostrom's work but broadens it in scope with the aim to develop a more practical and therefore improved way for applying the principles to all kinds of groups and at various organizational levels. Good action-led principles, according to Atkins et al., should have scope, precision and depth, in that they should be general enough to be applicable to a variety of circumstances and contexts but specific enough to provide practical and useful guidance.

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[3] As "an empirical inquiry that investigates a contemporary phenomenon within its real-life context" (Yin, 2003)

Prosocial version of Ostrom's Core Design Principles

Shared identity & purpose
Defines group. Without shared identity and purpose, there is no possibility of being a cooperative group

Equitable distribution of contributions & benefits
Principle 2-6 exist to ensure effectiveness. Balancing individual and collective behaviour and seeking to suppress selfishness while encouraging creativity, individual engagement, and cooperation.

Collaborative relations with other groups (using principles 1-7)
Scale to entire systems. This points to the fact that the first seven principles are replicable at higher levels of organization and facilitates not only internal but also external cooperation.

Fair & inclusive decision making
See principle 2

Monitoring agreed behaviours
See principle 2

Authority to self-govern (according to principles 1-6)
Ensures effectiveness while supporting engagement. It is essential to preserve a group's self-determination and the capacity to manage itself to ensure people engage across all principles.

Graduated responding to helpful and unhelpful behaviour
See principle 2

**Fast and fair conflict resolution**
See principle 2

Figure 2 Prosocial Core Design Principles building on Ostrom's original CDPs (adapted from Atkins, Sloan Wilson & Hayes, 2019)

By mapping the Buurtzorg case against the prosocial version of Ostrom's Core Design Principles, we analysed to which extent it utilises the core design principles and is therefore inherently, perhaps unintentionally, built on aspects of multi-level evolutionary science. Cross-referencing this with Haque & Waytz' work in humanization in medicine, we then aimed to better understand if this may offer a set of guiding heuristics and a way to design for self-organization and evolutionary purpose in autonomous groups.

Using Evolutionary Dynamics of Cooperation to Design for Radically Self-organized Care

We found striking resemblances between the way Buurtzorg constituted itself based on an initial experiment and the scientific research found in evolutionary science, notably MLST and the concept of major evolutionary transitions as exemplified in Atkin et al.'s updated prosocial set of design principles. Buurtzorg appears to organise itself according to many of the reformulated principles by Atkins et al. By doing so, it achieved the highest client ('patient') satisfaction in the country, 40% low¬er costs than their peers, used far less medicine, won 'best employer' prize 5 years in a row, employed 850 self-managed teams freed from bureaucratic tasks, and proved to be very profitable (Olesen, 2016). We also found that applying Atkin et al.'s design principles may positively complement Haque & Waytz's prospective strategies for rehumanising medicine.

PROSOCIAL VERSION CORE DESIGN PRINCIPLES (OSTROM & ATKINS ET AL.)	BUURTZORG NEIGHBOURHOOD CARE CASE STUDY (BUURTZORG NL)		HUMANISATION STRATEGIES (HAQUE & WAYTZ)
1. Shared identity & purpose	/ A key element of Buurtzorg is having a clear purpose and a shared mission that ties the whole organisation together: helping patients lead better lives	/ Each team signs up to the mission of taking the best possible care of their 'clients' but figures out autonomously how this is best done for each individual person	/ **Agency.** Helping patients lead better lives translates into supporting 'clients' to recover their ability to take care of themselves & reorientate agency towards co-production of health / **Individuation.** By focusing on empowering 'clients' to lead better lives as opposed to fixing an ailment, 'clients' experience a strong level of trust and connection
2. Equitable distribution of contributions & benefits	/ Under a union agreement nurses are paid according to their educational level with a standard annual increase and bonuses spent on years working for Buurtzorg	/ Nurses earn the highest salaries of any home care nurses in the Netherlands. Nurses are paid more than other organisations but are not paid extra for specialisation	
3. Fair & inclusive decision making	/ Decision-making is collective, based on an 'advice process' which means shared consensus must not be reached as long as there is no objection to a proposed idea. There are no line managers, or team leaders or people of positional authority to make decisions on behalf of the teams.	/ Team members can request changes which are evaluated by 'Ecare' in terms of a set of agreed criteria: a) does the proposed change serve the client and/or the professional?, b) does it create additional complexity?, c) in what ways is this change beneficial to clients or professionals?	/ **Similarity.** Balancing individual and collective interest (including sense of compensation fairness) encourages the nurses to 'go the extra mile', emphasising aspects of common humanity and fairly distributed systems / **Agency.** Decision-making based on a set of shared principles, encourages nurses' overall engagement in providing care and collaboration between client and nurse in order to find the most suitable treatment option for the client
4. Monitoring agreed behaviours	/ Individual team members mutually agree to be available 24/7 and to meet a productivity target of 60%	/ Teams use Buurtzorg's quality system which involves monitoring patient satisfaction & recording outcomes. The adoption of this system was discussed and tested extensively in practice by the teams themselves.	/ **Empathetic balance.** In reorienting agency towards the client, it allows nurses to combine part empathic and part cognitive skills when deciding on diagnosis, prognosis, treatment and care logistics in collaboration with their clients / **Moral engagement.** Mutually agreeing on a shared set of working principles refrains individuals from behaving in ways that violate set standards to the detriment of client care
5. Graduated responding to helpful & unhelpful behaviour	/ Team members appraise each other on the basis of a competence appraisal system agreed by the team.	/ The organisational structure has evolved and continues to evolve on the basis of the teams experimenting, retaining their best practices and transmitting their best practices to other teams for their consideration	/ **Personification.** Referring to their patients as 'clients' creates a sense of seeing the whole person instead of reducing a person a mechanical system made of separate parts
6. Fast & fair conflict resolution	/ New teams have access to training on decision-making, conducting meetings, active listening, non-violent communication, conflict-resolution and problem solving	/ Independent regional coaches assist with problem-solving. They help with coping with difficulties, crises and emergencies, allocating roles & responsibilities, meeting productivity targets & raising a flag to the team	
7. Authority to self-govern	/ Teams do not operate under the supervision, instruction or direction of the directors, the regional coaches or anybody else. They are operationally autonomous and self-governing.		/ **Individuation.** With nurses deciding how many and which 'clients' to serve, they are able to forge less anonymous and more caring relationships with their clients
8. Collaborative relations with other groups	/ By embarking on a multi-level approach to care delivery, Buurtzorg enables more integrated, community-based care	/ Coaches support the notion of establishing a learning culture, by interconnecting different teams. They have no job description, no performance targets, no responsibility for team performance and have no decision-making or other authority.	/ **Personification.** By liaising with the client's family and friends and other involved health and social care professionals as part of routine procedures, nurses are able to offer more integrated, personalised care

Figure 3 Applying Ostrom inspired Prosocial Core Design principles to the Buurtzorg model of care to understand how they can contribute to humanization in healthcare (authors' own)

However, despite Buurtzorg building on principles of cooperation, we noticed an absence of practices that explore early citizen involvement in relation to creating changes to the prevailing care system and conclude that there is an opportunity to further the active participation of citizens as co-producers of health. Reflecting on our retrospective case study (Figure 3), we propose that the generality of the Ostrom inspired core design principles - guiding what to do functionally to ensure

cooperation within groups - could be combined with Haque & Waytz' insights into (re)humanization - guiding how to do it relationally in the most human-centred and humane way. This could enable healthcare designers to apply them as a set of emerging premises in organizational healthcare contexts - from improving internal functioning of a healthcare team to improving or innovating the ways that healthcare organizations deliver care.

Reflections on the designer's role

We view design practice and its methods as one means of enabling self-organised cooperative ways of working which actively contribute to humanising healthcare. By building on Ostrom's original design principles and merging these with deeper insights on how to rehumanise aspects of medicine, we hope to inspire designers and healthcare practitioners in finding ways to self-organise and humanise health services. As a combined set of premises, they could help us understand what constitutes the distinctive design properties of deeply human and highly collaborative organizational structures, and most importantly, design for them.

The emerging premises we explore in this paper remain untested in practical design terms. As a next step, we recommend using them in the context of improving relationships between healthcare organizations and between individuals in the healthcare ecosystem. Our hope is that through continued evaluation of the premises, design practice can help to establish the conditions that nurture new conversations amongst groups, create a shared identity with a clear purpose, addressing equity, inclusiveness in decision making and above all, humanity, in a different, prosocial way.

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THE ART OF HANDING OVER: IMPROVING THE PATIENT HANDOVERS AT THE INTENSIVE CARE UNIT BY A HUMAN-CENTRED DESIGN APPROACH

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Abstract

This study aimed to enhance the patient handovers within the Intensive Care Unit (ICU) by design, based on experienced qualities and pain points by the ICU team, existing of doctors and nurses. At the ICU, care is delivered by multidisciplinary healthcare teams who strongly rely on teamwork and communication. Patient handovers are scheduled moments of communication where information between different healthcare professionals is exchanged. However, patient handovers involve failures as well, which can be the result of educational, psychological, and organizational factors. To discover how design can overcome these failures in information sharing, first observations and interviews within the ICU were done. The aim of the observations was to reveal everyday practices of the ICU team. The purpose of the interviews was to get a deeper understanding of their personal experience with the different patient handover moments. The observations provided insights in the interactions between doctors, nurses, and both groups. The interviews revealed the experiences ICU doctors and nurses have with patient handovers. The obtained insights were captured in two work models showing the handover activities, touchpoints, and experienced qualities and pain points over time. Based on that, a design was iteratively created in co-creation with the ICU team and evaluated within an ICU. All in all, it was discovered that a design should facilitate more structure, overview, and reflection. The human-centred design approach in combination with Research through Design (RtD) turned out to be key during the study.

Keywords: intensive care, patient handovers, human-centred design, research through design

Introduction

The Intensive Care Unit

An Intensive Care Unit (ICU) is a complex adoptive system for the provision of care for critically ill patients. At the ICU, they can be provided with intensive and specialized medical and nursing care, an enhanced capacity for monitoring, and multiple modalities of physiologic organ support to sustain life during a period of life-threatening organ system insufficiency. Admitted patients need 24 hours a day specialized medical care and the admission time can vary from hours to weeks, or even to months (Marshall et al. 2017). The ICU team exists of highly trained doctors (intensivists, fellow intensivists, and residents) and nurses who are specialized in caring for critically ill patients. Other healthcare professionals, such as cardiologists and surgeons, are often closely involved in patient care as well.

Patient Handovers

A patient handover is a process that involves the passing of responsibility for some or all aspects of care for a patient or group of patients, and the sharing of relevant patient information. Information shared includes clinical information, functional status, changes in clinical status, and plan of care as well as psychological and social issues (Wilson et al. 2009). To enhance communication about patient data, both the ICU doctors and nurses document their findings in the Patient Data Management System (PDMS). This is a software package supporting the data documentation of patients specifically designed for critical care departments.

As patient care responsibility is transferred or shared among different healthcare professionals continuously, the communication between them is fundamental for the quality and continuity of patient care (Cohen et al. 2012). However, patient handovers

at the ICU currently involve failures in information sharing. These failures can be a consequence of educational, psychological, and organizational factors (Weller et al. 2014) (Figure 1).
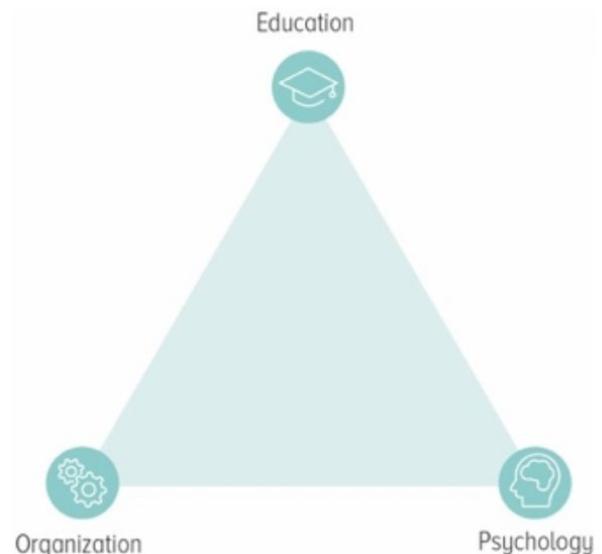
Figure 1: Failures in information sharing can arise from education, psychology and organization.

Aim and scope of the project

This project was initiated by doctors working at an ICU within an academic hospital who identified a need for enhanced patient handovers at their department. Besides qualities of the handovers, such as the good relationship between the team of doctors and team of nurses, they discovered that the handovers are often ineffective and inefficient. Furthermore, the handovers did not always facilitate a shared understanding of the patients, although this is crucial. Therefore, the main question to be answered during this project was: How can design support that the patient handovers within the ICU are experienced as more effective and efficient, and simultaneously realize a better shared understanding of patients' needs among the ICU team?

Methods

This study was executed in a period of five months by one Industrial Design student as a graduation project. Since it aimed for a design solution as outcome, design-related methods were applied. The study started by diving into the context through fieldwork existing of observations and interviews. To translate the obtained insights into design, a research through Design (RtD) approach was leading. RtD covers a range of approaches in which design and research activities inform each other with the aims of generating new insight and new solutions (Stappers and Giaccardi 2017). Since the project was done in collaboration with an ICU, doctors and nurses as participants for interviews, co-creation sessions, and evaluations could be recruited via the unit's team leaders.
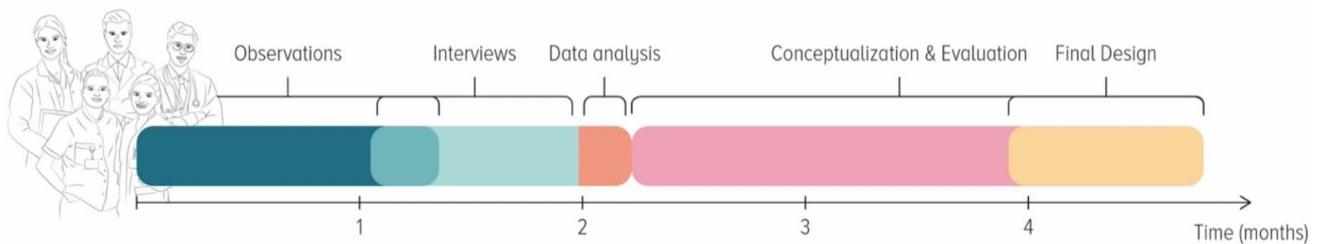

Figure 2: Study process

Observations

The aim of the observations was to understand and interpret the behaviour of ICU doctors and nurses throughout their day. Mainly semi-structured observations were done: The behaviours of interest were not defined prior to the study. Simply field notes were made. This allowed for being open to every kind of behaviour, suiting the explorative nature of this study.

The observations took place several times a week over a period of four weeks. Three different observational roles were taken on. The observer-participant role was taken on when observing the different handover moments, the participant-observer role was taken on when shadowing doctors and nurses, and the complete-observer role was taken on when observing the hallways and rooms by walking around at the unit (Mulhall 2003) (Figure 3).
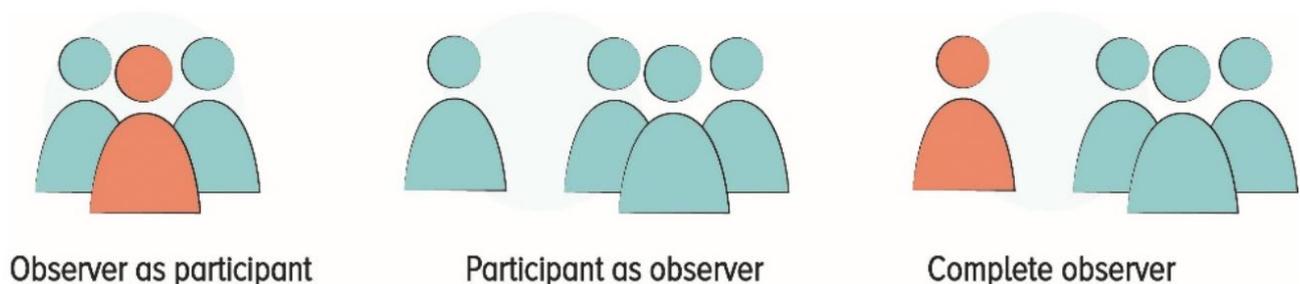

Figure 3: Observational roles

185

Interviews

Interviews followed to obtain a deeper understanding of the ICU team's experience with and needs regarding the different handover moments. In total, twelve interviews were executed.

Participants

To get a proper view on the experiences and needs of the ICU team, it was decided to involve doctors as well as nurses into the interviews. Eventually, six doctors and six nurses were recruited. The participants varied in age (29-64 years old) and gender (half male/half female).

Sensitizing

Collecting the desired insights required that the participants be had been involved in the research topic for some time, which required some preparation. Therefore, the interviews were based on sensitizing materials (Sleeswijk Visser et al. 2005) (Figure 4).


Figure 4: Sensitizing booklet

Procedure

One week prior to the interviews, the participants received a sensitizing booklet, which they had to complete and bring to the interview, where these booklets were discussed. The interviews were semi-structured, as this offered to have a clear focus, but simultaneously ensured some flexibility. Every interview lasted 30-55 minutes and was recorded and transcribed afterwards.

Data analysis

The field notes, interview transcripts and sensitizing booklets were analysed. Thereby, Grounded Theory was leading (Corbin and Strauss 1990). This means that the data was leading, resulting into emerging, non-pre-defined themes rather than being hypothesized beforehand. First, the observation notes, transcripts, and sensitizing booklets were re-read and relevant passages in were highlighted. Then, interesting passages were stated on post-its, whereupon these were clustered into categories. Eventually, two work models were created (Beyer and Holtzblatt 1998).

Conceptualization and Evaluation

Based on the fieldwork analysis it was possible to brainstorm about different concepts. The concepts responding to the identified needs during fieldwork were quickly sketched and discussed with the ICU team. Furthermore, a co-creation session was organized which invited the ICU team to think collaboratively about how products, systems, or services could enhance handovers (Boeijen et al. 2017).

Data and Design Development

Insights from the observations and interviews

The observations provided insights in the interactions between doctors, nurses, and both groups. The interviews revealed experiences and ICU team regarding patient handovers. The created work models included the handover activities, touchpoints, and experienced qualities and pain points over time (Figure 5).

Figure 5: The created work models presented in a handover room.

It was discovered that there is a lack of common purpose: Every handover moment has a specific goal, but everyone attending has a (slightly) different interest or expectation of being there.

> 'You have intensivists who are going to give very comprehensive education. That can be fun, but often you lack time for that. It is just the wrong moment' – Nurse

Moreover, discussing many complex patients in a short amount of time makes it difficult to keep the overview and understand the core message. The PDMS should support this but turned out to result in an information overload during handovers.

> 'We have screens in the handover rooms, but you have to flip through pages a lot. Lots of information is presented simultaneously, which makes it difficult to have an overview.' - Doctor

Furthermore, though teamwork is one of the most important elements within an ICU, there exists still poor collaboration and communication. This directly hinders handovers as well.

> 'Sometimes it is more an internal discussion of the doctors. Then I am just sitting there without being involved.' – Nurse

Insights from Conceptualization and Evaluation

Figure 6: Co-creation session and concept proposals

By discussing potential concepts and a co-creation session with ICU team (Figure 6), it was discovered that a common handover structure is necessary, but yet difficult to realize because of different priorities.

> 'It is important that a common perspective of the handovers is formed among the ICU team' – Doctor

Also, many different ideas for improvement of the PDMS arose, which included a presentation mode, an overview screen, and more integration of the doctors' and nurses' interface.

> "I think it is very useful to make a presentation mode for the PDMS, especially when the patients have to be divided over the nurses.' – Nurse

Furthermore, a need for reflection became clear, which was especially recognized by the team leaders and the department head.

> 'Making sure the nurses feel heard is actually a task we have to fulfil as doctors, but this is not always observed by us' – Doctor

Creating and evaluating the final design

Eventually, the obtained insights were translated into a final design: ICoon, partly paper based and partly digital, consisting of three components: overdragen, overzien,

and over hebben (Figure 7). Overdragen is a guideline for the handovers. It aims to align the expectations of the ICU team regarding each handover moment by providing structure. Overzien is a dashboard implemented in the PDMS especially designed for the handovers. It provides a clear overview of the patient population and only shows relevant information. Over hebben is a tool to facilitating critical reflection within the ICU team on scheduled moments. The tool includes different reflective questions presented stepwise.

ICoon is an example of a design for enhanced patient handovers, based on the insights obtained in this study. It was not intended for further development or implementation, but the aim was to obtain additional insights through evaluation of the design. Therefore, ICoon was evaluated through semi-structured interviews with the ICU team, in which prototypes of the different components were presented (Figure 7). Moreover, ICoon was tested during two actual handover moments of the doctors and one handover moment of the nurses (Figure 8).

Figure 7: From left to right, 'overdragen', 'overzien', and 'over hebben'

The doctors and nurses agreed that overdragen summarized their common perspectives regarding the handovers and provided them with a clear structure.

'It makes the patient handovers more effective in the sense that people are now better able to distinguish main issues from side issues.' - Nurse

The dashboard overzien improved the patient overview and assisted in focusing on the most important aspects of patient care.

'You use the human senses effectively to facilitate absorption of the necessary patient information' - Doctor

Over hebben, the tool for reflection, was valued a lot among all the doctors and nurses as they expected it might improve their teamwork, but the future use and implementation was questioned.

'This lowers the threshold to start a discussion and change things, which is very important' -Doctor

Figure 8: Evaluation

Results

Based on the findings, it can be concluded that a design aiming to enhance patient handovers within an ICU should facilitate more structure, overview, and reflection.

Structure

Structure turned out to be an important element within handovers, however the highly varied patient population within the ICU makes it difficult to come up with a detailed and consistent communication structure. Nonetheless, structure can be created in a sense that agreements about important elements for each handover moment have to be made explicit so that the team will comply with them. Aiming for a common structure will result in more efficient handovers. Moreover, it will ensure that expectations are aligned, thereby making the handovers feel effective for everyone.

Overview

Overview mainly relates to seeing the overall picture, the ability to distinguish details from main issues and communicating that well. The PDMS can have a central role in this, as this system includes all patient data, which currently can cause an overload of data during handovers. It would be recommended that this system assists in forming an overview, by showing a patient overview, distinguishing patients based on criticality, and only showing the relevant information for each specific handover moment.

Reflection

Intensive teamwork requires reflection, which is often lacking at critical care departments because it does not seem to be priority. However, there exists a need for reflection within the ICU to improve teamwork. Reflection will allow the ICU team to speak out and ensures that the handover procedure will keep on corresponding to the necessities of doctors and nurses continuously. Moreover, reflection can reduce the gap that is still present between doctors and nurses.

Discussion

Strengths and limitations

This study investigated how the patient handovers within the ICU could be enhanced by design. Convincingly, the adopted human-centred design approach in combination with RtD greatly supported the development of the design and the obtained insights. ICoon is only one example of how these principles can be applied to a design. It will be interesting to evaluate how these principles will apply to other ICUs as well. However, more research is needed to investigate that.

Therefore, a limitation of this study is the local impact, as only one academic ICU was included. In the future it would be interesting include a more heterogeneous population, with as a first step involving medical professionals of ICUs from different hospitals including peripheral hospitals as well.

The power of RtD

The RtD approach in combination with an open and enthusiastic attitude as a designer opened up the possibility to extensively collaborate with the ICU team. Continuously aiming for their involvement in the process allowed for multiple iterations in which the input from the ICU team was leading. This involvement resulted in a fruitful design: It seamlessly suited they current workflow and did not require extra protocols or work, which is often the case with innovations.

Aiming for ongoing change

Elaborating on that, the adopted human-centred approach turned out to be a key element in this study, because this leads to ongoing change (Mezirow 1997). Thorough involvement of the ICU team was entailed by investing in the relationship with them by being physically present, talking to them in the corridors, and leaving artefacts made physically behind. This study showed that this approach, including relatively small investments in a relatively short amount of time, supports the implementation and continuation of new tools and services within an ICU.

Conclusion

The research question to be answered was: How can design support that the patient handovers within the ICU are experienced as more effective and efficient, and simultaneously realize a better shared understanding of patients' needs among the ICU team? Through fieldwork and conceptualization activities ICoon was designed and evaluated with the ICU team. Combining all the insights, it can be concluded that to enhance the patient handovers at the ICU, more structure, overview, and reflection should be provided. A common structure will make the handovers more efficient and entails that expectations are aligned, making the handovers feel effective for everyone. Overview will assist the ICU team in forming a shared understanding of each patient's needs. Reflection will ensure that the handover process keeps on corresponding to the necessities of the ICU team continuously. Adopting a human-centred design approach in combination with RtD turned out to be key during the study and would be interesting to repeat in other hospitals as well.

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THE ARCHITECTS INFLUENCE ON DESIGNING AGE-FRIENDLY HOUSING: PILOT STUDY INSIGHTS

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Abstract

Housing design is influential in enabling older people to maintain independence, enhance social inclusion and alleviate loneliness.

Existing literature has carved ways forward in understanding the interrelationship between health and housing. In identifying barriers impacting on older people's wellbeing, a variation of diverse housing options is required.

The growth of age-segregated housing, coupled with existing literature offers designers a broad understanding of age-friendly housing exemplars, however these are predominately apartments located in the South of England. In the North East, knowledge in relation to the provision and design process of housing for older people remains 'very patchy'.

This research focuses on addressing the under-researched area of age-friendly mainstream housing in the North East and, in turn, the influence of the Architect's agency and design process. To ensure the future-proofing of UK housing and support older people's health and wellbeing through actively ageing-in-place, this research explores the knowledge base of architects.

This paper reports on qualitative methods adopted (semi-structured interviews and sketching research method) and findings elicited from two pilot studies undertaken with two architectural practitioners based in the North East.

The preliminary findings highlight the initial notion of how attaining subject-specific knowledge (such as age-friendly design, healthy ageing and wellbeing) influences the agency and design process of an Architect. However, the understanding of the term knowledge within an architectural context is confused, resulting in Architects retreating back to their respective 'silo' of only adhering to building regulations.

This paper seeks to interest key stakeholders (such as policymakers, architects and developers), in the potential of age-friendly housing for future-proofing the UK housing stock. Specific findings provide insight into the moves being taken forward by North East Architects in terms of age-friendly design, healthy ageing and wellbeing.

Keywords: Future-proofing; Age-friendly Design; Housing; Agency; Design Process; Older People; Wellbeing.

TIME MOVING: A PARTICIPATORY EXHIBIT TO EXPLORE TEMPORAL PERCEPTIONS AROUND DEATH AND DYING

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Abstract

Time Moving engaged in public making of timelines through storytelling utilizing participatory materials with the intention of creating an environment for the public to express and explore temporal awareness. This public experience engaged in questions of disorientation/orientation to time horizons – an integral aspect to decision making and communication at the end of life. Designers may make use of participatory experiences, like Time Moving, to build temporary assemblies (Lindstrom & Stahl, 2014) that facilitate group storytelling conversations, and generate new capacity for expression on topics like death and dying. How time is experienced during moments of death and dying can change as temporal awareness shifts, priorities change, and capacity/physical constraints arise. To engage the public to explore this concept of time and temporal perception at end of life, Time Moving invited response to three prompts: (1) When you think of time, what does it look like? (2) What did time feel like during your end of life experiences? (3) How is dying time different than living time? Share a story or memory of death in shapes, yarn, etc. More specifically, these questions were asked to gain initial insights into experiences around disorientation/orientation to time horizons and perceptions of end of life. This interaction was designed with the intent of creating a public space for people to share and express their own personal end of life experiences and temporal perceptions, alongside others. Beyond these three prompts, Time Moving also offered supporting end of life materials and resources, facilitating access to local health services outside of the exhibit context. This paper will examine the use of participatory exhibit based approaches, like Time Moving, in generating new knowledge around topics like death and dying, as well as how results from exhibit based research may further contribute to understandings of quality whole person care.

Keywords: exhibit, end of life, participatory research, person centred care

Introduction

Death and dying is a universal experience, but it is also unfamiliar and ambiguous. Despite the understanding that we will all have experiences with death and dying, public discourse on these subjects remains taboo (Wildfeuer, Schnell, & Schulz-Quach, 2015). These social restraints on death can have broader health implications like lack of preparedness for end of life, emotional strain in bereavement for family and friends, unexpected legal responsibility to close contacts, (Banner, et al., 2019).

The number of older adults is anticipated to increase exponentially over the next 30 years (Bohnert, Chagnon, Dion, 2015). This spike in the population age, foreshadows increased demand for end of life care. The person centred care framework (McCormack, 2003; McCormack & McCance, 2006) provides opportunities for collaboration with designers on these issues. The framework denotes person centred care as subsisting of four distinct constructs: (a) prerequisites of the carer, i.e.: personal knowledge of self and interpersonal skills, (b) the care environment, i.e.: supportive organizational systems, sharing of power and potential for innovation and risk taking, (c) person-centred process, i.e.: shared decision making and engagement, and finally, (d) expected outcomes of persons involved in care in a therapeutic environment of shared decision-making. Participatory design techniques and a constructivist epistemology are congruent with this theoretical approach to health care.

In the case of Time Moving, we consider this work to be an arts-based participatory design exhibit. Arts-based research is defined as inquiry which is committed and immersed in the craft of artistic practice (Eaves, 2014). Arts-informed research, alternatively, is research which uses art as a source of inspiration in source or re-presentation of new knowledge (Eaves, 2014). Either approach offers an opportunity for a constructivist paradigm to flourish (Rossiter et al., 2008).

To investigate death and dying we developed Time Moving, a participatory design exhibit, that sought to examine expectations at end of life and temporal perceptions in circumstances of death and dying. In this paper we will examine Time Moving, how exhibits can be used to produce and translate knowledge on death and dying, and the design implications exhibition based research can have on future methodological approaches in health design research and broader health oriented research.

Design of Time Moving

Time Moving is a participatory installation series that intends to explore temporal perception in end of life experiences. Time Moving was open to the greater Toronto public for one week in January, during the DesignTO festival. DesignTO is a city-wide event series in which designers and artists celebrate and feature their work in a variety of spaces housed around Toronto. Members of the public are invited to view/participate in numerous design works.

Figure 1: Curvilinear space created by the exhibit structure

Time Moving was assembled using pieces of pre-built furniture to create a temporary engagement space inside an open area at OCAD University in downtown Toronto. The human-scale structures were positioned in a curved floor plan to create a dynamic flow through the exhibit to encourage participants to move through and engage with the materials presented (Figure 1 above). Information panels about the exhibit's themes of time and temporal perception were mounted to one side of the exhibit space, while the prompts and activities were set up on the other side. Lighting was selectively placed to highlight prompts and the associated materials to be used for responding to the prompt, increasing the visual and tactile interest of the exhibit.

Graphic design decisions were made to complement the subject matter and activities in the exhibit. The information panels used sketches from another version of Time Moving as a background to create visual references, with the intent of prompting participants to respond in a similar fashion. The minimalist aesthetic complemented the structural exhibit

pieces in two ways: to create a backdrop for engagement and not draw attention away from the activities; and to create an informal and welcoming space for abstract expressions.

The three prompts of Time Moving were:

1. People have different ways they think about time. Choose or draw a shape that looks the most like time to you

2. There are many ways we experience time in end of life, what did time feel like in your experience?

3. How is dying time different from living time? What does time look like? Share a story in yarn, shapes, etc.

Each prompt was associated with different materials. In the first activity exploring what time looks like, tactile materials included pins, rubber bands, markers, chalk (Figure 2 below) and tulle-like ribbons. Small visual images that conveyed time, such as calendars, hourglasses and clocks were presented as reference. The variety of materials provided options for participants to express themselves, ensuring they had the opportunity to be as representative or abstract as they wished.

Figure 2: Examples of materials available

In the second activity, participants were encouraged to respond to the prompt through writing and/or drawing. The materials used were clothing pegs, cards, markers and pens. Once participants have created their response, the cards are hung on clotheslines within the exhibit structure. We found this activity to be more clear-cut and straightforward than the other two activities in the exhibit.

Finally, the third activity compared dying time and living time, with the prompt encouraging abstract expressions. Similar to the first activity, the materials provided were pins, rubber bands, yarn, markers and chalk. Participants also repurposed materials from the other two activities to express their ideas on the tapestry.

Results

Time Moving gathered a large amount of engagement with over 100 participants contributing their own lens on temporal disruption in end of life. This allowed for specific inquiries into variances of temporality without losing focus of the broader topic area of end of life. Each prompt within Time Moving progressed into heavier interactions, and created engagements in which participants had to reflect in increasingly complex ways. Staggering the interaction in this way, allowed for a thoughtful buildup on reflection on end of life experiences, and served as a forward for thinking openly about death, dying, and temporality.

In the first phase of the interaction, participants were given a selection of choices to interpret how they viewed time by selecting shapes that were most representative of time. Moving forward, the interactions became more fluid in how participants used the materials. The second prompt asked participants to share an experience of time in end of life, writing on a small postcard (Figure 3 below).
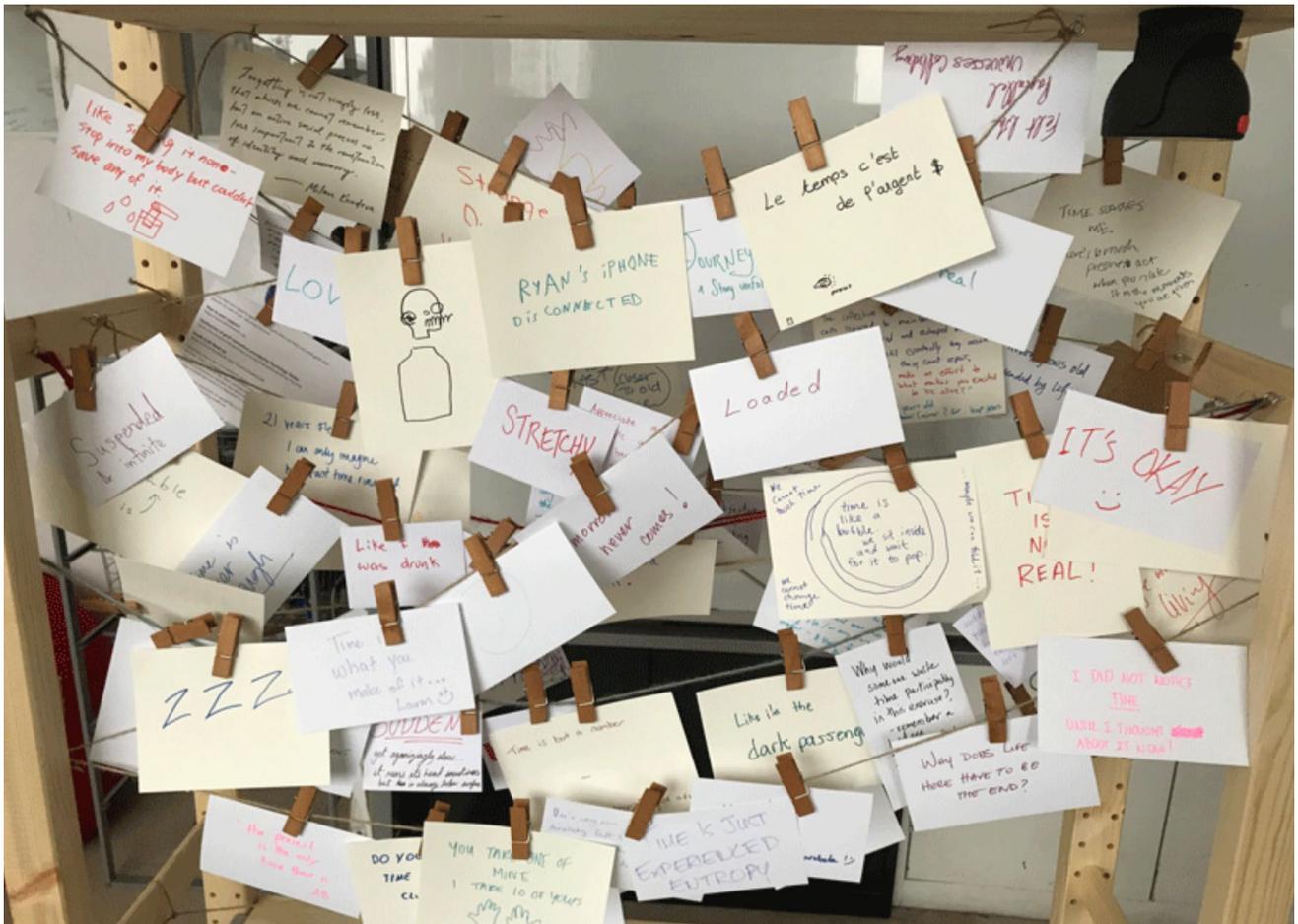
Figure 3: Responses to the second prompt on experiences of end of life

There were no restrictions on how they used the material, or on what types of interactions they chose to talk about. In the analysis we saw the range of responses from this activity where some participants wrote song lyrics, abstractions from TV and movies, others wrote long theoretical explanations, and some offered small drawings. The final prompt encouraged collective making, building a tapestry weaving together various responses (Figure 4 below). In this section, participants were welcome to express their memories as literal or abstracted as they wanted. Some used chalk to draw timelines, marking specific points with narrated explanations, others tacked yarn and rubber bands in amalgam shapes.

Overall, the objective of the exhibit design was to create visual curiosity and interest throughout the exhibit, which invited participants to gather and engage with the exhibit. The outcome was a collaborative tapestry showing the nuances of temporal perception in moments of end of life. Timelines, memories, considerations, critiques, and images collectively united to create a blended image of the temporal horizons in end of life

Time Moving unveiled various examples of disorientation in moments of dying. Participants created standard timelines showing disruption and confusion in moments of dying, drawing tangled lines and loops representative of these moments. Others created abstract images in the form of drawings and shapes, forming the yarn and elastic bands into various open-ended patterns. Some used words, phrases, song lyrics, and other pop culture references as a representation of how time felt. The result of this work was a larger complex narrative that revealed the multiple co-existing interpretations on death, dying, and time.
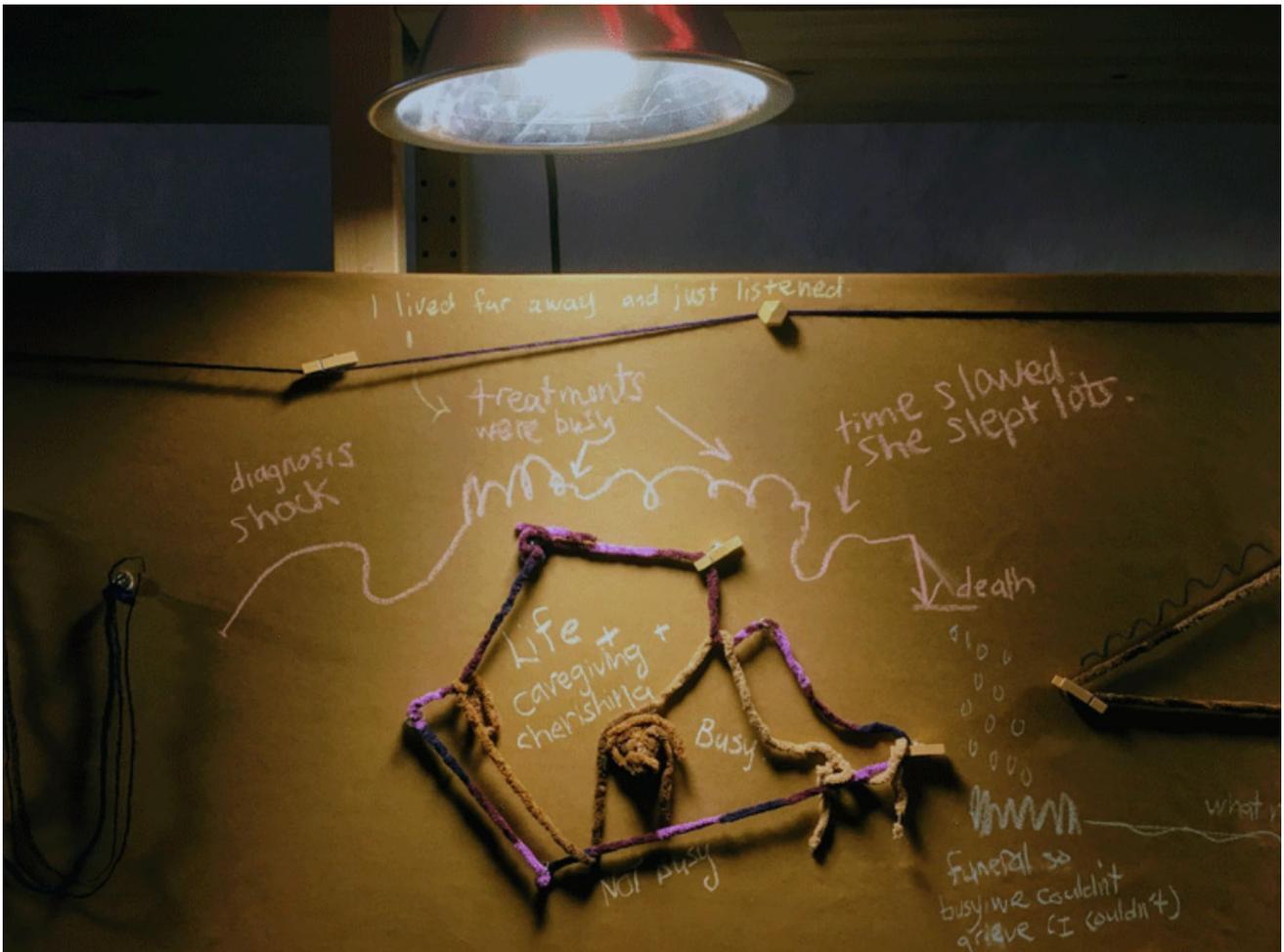
Figure 4: Tapestry

Discussion

Within Time Moving we saw that the public interacted with the work and redefined traditional experiences of dying to share the temporal ways in which dying influenced their lives. As a result, hundreds of participants explored the fluidity of temporal perception using chalk, yarn, and shapes as an aid in retelling their narrative. The knowledge produced within this work suggests the possible uses for design in end of life, and how exhibition and design can influence decision making in end of life.

Arts-informed and arts-based approaches are increasingly being used in health research (Lapum et al., 2016). This is one way to provide the public with alternative platforms to express difficult or hard to put into word topics, like death and dying. Art-based research can add depth and insight to qualitative inquiries, and can produce

new knowledge that may not have been discovered using a traditional research approach, as well as serve as a vehicle for knowledge translation (Fraser & Sayah, 2011).

In the exhibit "the 7,024th Patient", health researchers use photography and poetry to re-present interview data collected from people on their experiences of open heart surgery. The exhibit re-presents their contemplations of their mortality, agency and identity. The exhibit was installed at a major cardiac hospital in Canada, and open to all. Follow up interviews with health care providers who attended reported this exhibit enhanced their empathy in practice, supported them to include holistic care approaches, and improved their relational care (Lapum et al., 2016). Yet these participants also reported the context of their care matters: they required

institutional and leadership support to fully integrate these new perspectives in practice (Lapum et al., 2016).

As context of person centred care influences engagement, so too context matters for participatory exhibitions. Time Moving was installed indoors at OCAD University. This meant the participants were mostly members of the university community. Compare this engagement with an iteration of Candy Chang's Before I Die (2012) installation, the exterior location affords greater public participation and engagement with this installation may reflect different viewpoints on death and dying, from increasingly diverse backgrounds.

Time Moving, positioned itself as an exhibit that sought to uncover if temporal perception changes in experiences in the end of life. Informing this work was various health sector perspectives, including work from Glaser and Strauss (1968) who explored temporal trajectories in dying. This work continues to influence the post-modern healthcare structure, and deepens the discourse on death and dying in general. Glaser and Strauss (1986) suggest that time has shape and that dying trajectories exist. These trajectories are narrative archetypes of typical dying experiences that occur within acute care. This research has influenced how practitioners engage with their patients about dying. The concept and prompts in the exhibit built off of previous health and design research, and showed the potential of the exhibit not only as a producer of knowledge, but also as a way to translate well established research and interdisciplinary knowledge that otherwise may have been unattainable to the general public.

In the context of health care, people are meant to be active decision makers in their health, yet patients experience a hierarchy of knowledge in a paternalistic health care structure (Rothmann et al., 2016). These structures foster superficial or tokenistic engagement (Rothmann et al., 2016), at the loss of achieving the processes or outcomes of person centred care (McCormack & McCance, 2006). Participatory design exhibits offer a unique opportunity for people to meaningfully engage and share decision-making about death.

By virtue of this meaningful engagement, participants are able to reflect on their core values and beliefs regarding death. This process allows participants to orient their end of life decisions against these values and beliefs, and to share guiding principles with family and friends who may go on to serve as their substitute decision makers. Time Moving empowers persons and their supports to advocate for the death they want, thus achieving the expected outcomes of person centred care (McCormack & McCance, 2006).

Conclusion

We have explored how participatory design exhibits can be used to engage with the public in new ways, and may contribute new knowledge and understanding. In hosting our own exhibit, Time Moving, we examined end of life experiences, and how these moments may alter temporal perception. By developing Time Moving, we were able to create a temporary assembly that brought together various social groups to participate in the anonymous creation of temporal timelines and horizons. This work allowed for knowledge creation and mobilization to occur in real time. Many social scientists, artists, and designers (Glaser & Strauss 1968, Copp 1998, Candy Chang) have explored death and dying within their work(s), however, social restraint on these topics remains present. There is a lack of environments, outside of specific healthcare contexts, that host open, fluid, and continuous conversations on end of life (Copp,1998). Participatory exhibits have a role to play in both uncovering and mobilizing knowledge on end of life..

Acknowledgements

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DYING. USING A PUBLIC EVENT SERIES AS A RESEARCH TOOL TO OPEN COMMUNICATION ON DEATH AND DYING

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Abstract

This paper will explore the use of public engagement as a strategy for encouraging and enhancing conversations about end of life through the variety of events that were part of the Dying., a public event series that ran in the 2019 DesignTO festival. Dying. invited practitioners, researchers, artists, and designers to collaborate with the wider community to explore the topic of death and dying. The Dying. series attracted over 4,000 attendees in 2019, 14 speakers, and 12 exhibiting artists. These events included public engagement through interactive exhibit, a public art/design show, public lectures, participatory art installations, participatory design workshops, and evidence-based game playing. Dying. encouraged dialogue among community members and practitioners, initiating non-medical portrayals and expression of experiences associated with dying and death. Part, research tool for knowledge mobilisation, the interactive exhibits served to engage the public in sharing experiences of end of life in light weight and playful interactions, as well as more heavy weight interactions. Data gathering for research on health topics using participatory public exhibit was part of the research intention behind the design of the exhibits. Dying. opened an interdisciplinary dialogue between designers, medical practitioners, and the public, addressing a need among practitioners for more opportunities to share their work and learn from colleagues, and a need among the public for opportunities to hear and experience a more varied discourse about death (knowledge mobilization). Dying. creatively offered the public multiple ways to engage with the topic of end of life also supplying supporting resources on advanced care planning and other aspects of end of life decision making.

Keywords: interaction design, end of life, participatory research, design approaches

Introduction

Death, and the process of dying, has been seen in more recent history as a medically orientated event. As death more often occurs in medical settings, the circle of those who have experienced death first hand grows fewer (Holyoke et al., 2016). Since death is unfamiliar, many people experience fear and avoidance with the subject of death. It is recognised that one consequence of this is that only a small number of people have considered or written an advanced care plan or considered their preferences for care or end of life wishes (Holyoke et al., 2016). As a large portion of the global population approaches older adulthood, communities have the opportunity to reimagine death and dying, change conversation about death, and encourage advanced care planning. Responding to this opportunity, an interdisciplinary movement towards a more holistic approach to death has emerged through public events, including medical practitioners such as BJ Miller and Atul Gawande, and design studios such as Falmouth University's MOTH (UK), Open IDEO's End of Life project in collaboration with The Helix Centre and Sutter Health (UK). Interdisciplinary interest in this topic is mirrored in the public realm with grassroots events such as death cafés offering the opportunity for dialogue about death in familiar environments. Art and design initiatives have offered reflective and speculative installations such as Hereafter (Barcia-Colombo, 2018) which offers participants services in digital legacy, using 3D body scans and digital reconstruction to curate virtual memorials after death.

Participatory public events, such as festivals, offer an opportunity for a diversity of people to engage in discourse at their own comfort level. A characteristic of participatory events is the use of storytelling and creative self expression to encourage engagement. Festivals are an environment in which engagement is heightened, allowing for

dialogue, and new social positions, in which various social groups, normally separated, come together to build new social realities (Picard & Robinson, 2006). Festivals on death and dying are beginning to occur on a more regular basis around the world. By the nature of the engagement that festivals enable, participatory arts based events are a platform for knowledge mobilization, where ideas and information flows between participants (Kontos, and Naglie, 2007; Rossiter et al, 2008; Cowdell, Booth & Appleby, 2017). Participatory events have the capacity to mobilize knowledge shifting public opinion, even with difficult topics such as end of life.

Dying., was a public participatory event series launched in 2019 in Toronto, Canada. Dying. invited practitioners, researchers, designers, artists, and the wider community, to collaborate on and explore the topic of death and dying through the lens of art and design. Through the Dying. series, interdisciplinary dialogues emerged as medical and allied health practitioners, artists, designers, and the general public shared and constructed a varied discourse on death and dying. In this paper we will explore how Dying. provides a research tool to enable knowledge mobilization, and how, through the variety of interactions that can occur with public engagement at festival events, Dying. contributes to opening communication on contemporary issues on death and dying.

Festival as Knowledge Mobilization

Increasingly, health researchers are expected to meaningfully bring knowledge into practice (Graham, Tetroe & KT Theories Research Group, 2007). As such, implementation science and over thirty frameworks have been developed to support the iterative process from results to mobilization (Graham, Tetroe & KT Theories Research Group, 2007). These frameworks support knowledge exchange along a spectrum of interactions and engagement. Increasingly, knowledge

translation is identified by its focus on the decontextualized, unidirectional flow of information from research to practice (Abma et al., 2017).

A trust-based alternative to knowledge translation is knowledge mobilization. Knowledge mobilization is described as the flow of knowledge between individuals in a highly contextualized, reciprocal relationship (Abma et al., 2017; Cowdell, Booth & Appleby, 2017). Based in part on Friere's work on participatory co-learning (as described in Minkler and Wallerstein, 2011), knowledge mobilization focuses on social interactions to co-create and make sense of knowledge (Abma et al., 2017). The approach recognizes tacit knowledge as essential and the nature of knowledge as emergent inquiry (Van de Ven & Johnson, 2006). It is philosophically congruent with a constructivist paradigm, arts-informed approaches and participatory design (Abma et al., 2017).

Examining Death through Festivals

Festivals offer a unique vehicle for designers, artists, academics and health researchers to engage in knowledge mobilization with members of the public. Festivals produce and mobilize new knowledge relevant to various disciplines, while revealing the complexity of the issues under exploration (Van de Ven & Johnson, 2006). One such example being "Death: the Human Experience" an award-winning public engagement exhibition run through Bristol Museum in the United Kingdom (UK), the festival invited the public to consider ethical and cultural perspectives on death, and their trends over history.

Dying. Festival Theme

Dying. was situated within DesignTO, an annual design festival in Toronto, Canada. The Dying. event series (or festival theme) is an ongoing collaboration between Taboo Health, Ontario College of Art and Design University's (OCAD U) Health Design Studio, and festival organisers DesignTO.

The goals of Dying. are to (a) facilitate dialogue across boundaries in conjunction with moments of expression (b) broaden conversations and scholarship in relation to issues of death, dying and design; (c) make and strengthen connections across disciplinary spheres and practitioners (d) develop embedded and change orientated resources for educators, designers, health professionals and researchers.

To widen the scope of disciplines engaging with Dying., we embraced an arts-informed knowledge mobilization approach, in acknowledging how it may support new perspectives, interpretations and knowledge (Eaves, 2014).We organize the events to support a range of interaction opportunities that align with concepts from knowledge mobilization including: community engagement, creative self expression, storytelling, play, learning and relationship development (see figure 2 below).

In the first installment of Dying., these events comprised 4 main streams of engagements including (1) a public art/design show, Dying.exhibits, (2) public lectures, Dying.discussions, (3) public engagement through interactive exhibits, Before I Die, and (4) end of life decision making serious game playing, Hello. These are described below:

Before I Die.

"Before I Die" chalkboard wall from Candy Chang's open sourced public art project model (2012), facilitating engagement on end of life for the general public who did not directly attend the Dying. series. The wall was mounted on the exterior of the OCAD U in downtown Toronto. Throughout the week, the wall was populated with hundreds of responses. The "Before I Die" wall served as a lightweight interaction supporting community engagement and creative expression.

Dying.exhibits

Dying.exhibits featured 12 artists and invited participants to think about their

relationship with life and death as a process without polarity. Rather than thinking about death as a period at the end of a sentence, the work exhibited considered death and dying as an ellipsis; an invitation to continue the conversation after what might seem like a natural end. The work within the exhibit portion of Dying. probed into conceptual thinking on life as it continues after the event of death; extended through objects, memory, narrative and ritual.

Participatory Installations

DIYing Free

An interactive installation, DIYing Free is a Do-it-Yourself Coffin that the public were invited to lie in and take selfies. The coffin is constructed from an openly available cardboard template and made from discarded packing cardboard.

Ellen Snowball's Room 237

An immersive installation, Room 237 captures the emotions of loss and grief experienced in a recreation of a long term care room, retelling the story of losing a mother to dementia.

Time Moving

Time Moving is a participatory installation which invites the public to reflect on their perception of time during end of life (Paper 1, 2020). The impact of the installation emerges as a tapestry of representations, conversations and perspectives collected together. The installation series continues to investigate temporality during death, and has been extended to explore digital communication and death (Paper from CHI, 2020). Time Moving served as a lightweight to heavyweight interaction supporting community engagement, creative expression and storytelling.

Constellations

Constellations is a participatory installation which invites visual storytelling about death and end of life (Oikonen & Hale-Wilkes, 2019). Participants express their experience of death by circling colourful strings around various pegs. Each peg represents a junction in their story of experience: support systems, perception of preparedness, and their experience of grief unfolding.

Hello - End of Life Game Play

"Hello" is a conversational card game about death, dying and end-of-life. Developed by Common Practice LLC, Hello engages participants in discussions about end-of-life and advance care planning (ACP) through structured participation in small groups (Van Scoy, et al., 2016). "Hello" served as a heavyweight interaction supporting community engagement, storytelling, play, and relationship building.

Dying.discussions

A keynote speaker and mini-symposium were central parts of the Dying. series. In 2019, Dying., hosted 14 speakers at the mini-symposium. The event aimed to offer attendees broad perspectives, and opportunities to participate in open conversations about death, dying and design, covering contemporary topics such as medically assisted dying, body disposal and sustainable death practices, death awareness and HIV communication, reflective practice for palliative care, and design of palliative services for those who are housing insecure and who may be street involved. Dying.discussions served as a heavyweight interaction supporting community engagement, storytelling, learning, and relationship building. The topics of discussion illustrate the opportunity that such events play to make more visible contemporary social issues.

Results

In this paper we have focused on the structure of Dying. 2019, and the framework that describes the structuring of knowledge mobilization through the festival event series as a tool for design researchers in health. If we consider attendance and interaction as a metric of success, Dying. 2019 saw over 4000 people interacting in a tangible way with the festival events.

Figure 1: Opening night

The success of Dying. 2019 allowed for Dying. to be held again in 2020 with over 3000 people interacting in tangible ways. In continuing to offer death, dying, and design theme to the DesignTO festival, this work has broader community implications, however. Festivals and large event series can stimulate interdisciplinary alliances between a variety of community stakeholders. Dying. Exhibits saw submissions from over 50 artists and designers. In its second iteration Dying. discussions became Dying.dialogues with over 30 submissions from a range of thinkers, designers, and practitioners, on death and climate change, medically assisted dying, equity and access to end of life care, legacy, and public access to end of life decision support through public spaces were some of the topics discussed.

Discussion

The culmination of the components of Dying. created an intentional engagement opportunity in which participants could experience a dialogue on death and dying that is different from the dominant medical discourse. In this way the festival nudges social change on issues of death and dying. Picard (2016), suggests that festivals or large social gatherings, can assist in the individual navigating through social changes and transitions. Further Picard (2016), argues that the format of the festival serves as a good vehicle for positioning lived experience within narratives of death and dying. The impact of the festival can disrupt our social beliefs and alter our symbiotic framework when thinking about life stages and transient periods (Picard, 2016).

The variety of events within Dying. allowed for various types of interactions. Playful exhibits and participatory artworks invited the public to explore, and immerse themselves within the work and alternative ideas on end of life. In creating these lightweight and invitational interactions we may have attracted interest from different groups to safely explore ideas of death and dying and stimulate new social narratives

that may have otherwise not arisen. The success of these playful interactions may have permitted extended participation in other components of the Dying. series which had denser more heavyweight interactions involved within them. Thinking about the structuring of the experience of the Dying. Festival theme, we designed a pattern of engagement opportunities that serve as a framework for knowledge mobilization initiatives expressed here in the form of a matrix:

Figure 2: A framework for knowledge mobilisation activities through participatory engagement

The variance in structuring this event series with diverse levels of lightweight and heavyweight participation created spaces in which interdisciplinary conversations could occur to unearth and mobilize new and tacit knowledge and narratives on death and dying (Anoize, et al., 2014, ; Picard, 2003). The impact of these festivals, as with other knowledge mobilization efforts, cannot be measured by researchers alone (Abma et al., 2017). The outcomes of these collaborations can increase self-reflection and knowledge mobilization within the local community, and stimulate multi-sensory experiences for publics to explore their own ideas and concepts of death and dying.

Conclusion

The Dying. series investigated how multifaceted public engagement(s) like, festivals and event series can be used to house and cultivate public discourse on death and dying. These events can enrich and encourage new citizen engagement on end of life topics, and situate these dialogues within the public's routine lives. Dying. nurtured this engagement through a series of open participatory events including public lectures and art shows, evidence-based game play, and outdoor interactive installations. Dying. continues to work on supplementing the discourse on the potential of art and design in end of life, in 2020 the series ran again, and plans for the 2021 season are in place. As this series continues to develop we will continue to open opportunities for public community conversation and interactive experiences on topics surrounding end of life.

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SUPPORTING PEOPLE'S INDEPENDENCE THROUGH VOICE USER INTERFACE (VUI) DEVICES

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Abstract

The use of well-designed assistive devices may improve the quality of life of individuals living with severe and permanent impairments and reduce the burden on their caregivers.

Interactive Smart Agents (ISA)s use the latest smart home technology to control devices around the house through voice interfaces. This study aims to investigate whether ISAs may be effective to support individuals who are affected by multiple sclerosis, stroke and spinal cord injury (SCI). The study's approach is user-centred to ensure inclusion. The study has achieved NHS Research Ethics Committee (REC) and Health Regulatory Authority (HRA) approval (Project ID: 255096) and includes two main parts: 1. the initial development of an adoption model informed by secondary research and exploratory primary data, 2. a second in-depth investigation of the initially identified constructs and relationships through a multi-points qualitative study including prototype evaluation.

The research is in collaboration with the North Thames Regional Environmental Control Services (NTRECES), an NHS organisation that provides Environmental Control (EC) devices to manage the patients' electrical and computing appliances. Clinical staff have indicated an increasing patients' demand of ISAs instead of traditional EC devices and have suggested that their clients are keen to experiment with more intuitive interfaces.

This paper presents the findings from the first part of the study and it is structured as follows: in the first and second sections literatures on ISA and technology adoption are reviewed respectively. In the third section findings from the preliminary study are presented. In the fourth section a proposed model of adoption of ISAs among severely disabled patients is discussed.

Keywords: voice user interface, sustainable health and well-being, interactive smart agents, technology adoption.

Interactive Smart Agents (ISA) and Sustainable Healthcare

The use of emerging technology in healthcare is one of the fundamental markers of a sustainable healthcare system. A sustainable healthcare system should be economical, adaptable and acceptable (Fineberg 2012). In order to move towards a sustainable system, the healthcare services may have to invest more significantly in the latest technological equipment and inventions to be utilised at home (Pencheon 2014). This also aligns with the NHS's goal (Smith 2019).

ISA devices like Amazon's Alexa, can support the care of older adults with multiple and chronic conditions (Halim 2019). ISA devices, or smart speakers, operate through VUI. Through ISAs users can control other smart devices around the house, including lights, door locks, TV and thermostats. ISA devices can also be used for streaming music, accessing online information and setting reminders. Investment in technology to deliver patient-centred care has been the focus of much debate (Klecun 2016). Albeit not designed specifically to support healthcare services, ISA devices can aid the care of older adults with chronic conditions. Voice might be a preferred mode of interaction amongst older adults, given its natural attributes not requiring demanding and technical learning. Although ISAs adoption among this segment of the population is still ambiguous (Spinelli, Micocci, Martin, and Wang 2019), their benefits in primary care settings have already been discussed (Halim, 2019).

Technology Adoption

According to previous research, on average one third of all assistive technology devices get abandoned (Goodman, Tiene, and Luft 2002). Factors responsible for this are: lack of motivation, changes in medical condition, difficulty in device configuration, appearance, performance, lack of training for the users (Goodman, Tiene and Luft

2002; Carmien 2010). Low appeal and basic functionalities contribute to increase the stigma associated with assistive technology (Ringland, Wolf, Boyd, Baldwin, and Hayes 2016).

The Matching Person and Technology (MPT) model (Goodman, Tiene, and Luft 2002), suggests that designers should focus on three factors: i) psychosocial environment ii) personal traits iii) technology. Factors like age, gender, social status, financial situation, have been recognised as having significant impact on access to information, digital literacy and availability of resources (Greenhalgh, et al. 2013).

The Technology Acceptance Model (TAM) (Davis, 1989), Unified Theory of Acceptance and Use of Technology (UTAUT) (Venkatesh, Morris, Davis, and Davis 2003) are well-known theoretical contributions in this field. Along with these theories the Theory of Reasoned Action (TRA) and the Theory of Planned Behaviour (TPB) (Ajzen 1991) have been used to understand the adoption of technology, and through some adaptations, scholars have been able to cater for specific emerging technologies (Kowalczuk 2018; Yang, Lee and Zo 2017).

Given the ability of TPB to be used across different settings (Matheison 1991; Heath and Gifford 2002) TPB is the blueprint for the adoption model presented later on. TPB states that an individual's behaviour is determined by the individual's intention to perform that behaviour. This behavioural intention is in turn affected by an individual's attitude, subjective norms and Perceived Behavioural Controls (PBCs) (Ajzen 1991; Heath and Gifford 2002).

Technology adoption literature has little contribution to make towards the understanding of technology adoption behaviour by users with disabilities (Djamasbi, et al. 2006) and the application of any adoption theoretical framework without modifications may not be specific enough to capture the factors playing a role in the adoption of ISA devices by

the specific user group considered in this research. This is the intellectual gap underpinning this research.

Findings from Primary Data: Patient's Observations

NTRECES is an NHS based organisation in north-west London. To gather an initial understanding of the patients' abilities and requirements some preliminary observations were carried out. Ethnographic-inspired observations occurred by shadowing NTRECES staff during patients' home visits and hospital outpatients' rehabilitation sessions. All the patients were either existing patients or new referrals. The observations were followed by interviews with clinical staff, patients, EC designers and providers. These initial explorations were carried out from August 2017 to October 2018.

Initial inquiries from the NTRECES clinical staff revealed that the target user group for this research has the following characteristics:

- They have minimal exposure to technologies available on the market due to their mobility impairments. Most of their exposure to market and innovations is through, friends, family, caregivers and the media.

- Their adoption or acceptance decision about a technology differs from the norm as their assistive technology devices are funded by the NHS.

NTRECES's patients are issued with EC equipment to control the electrical and computing devices around their homes. Most of the EC equipment is controlled by a switch, a single click button, which scans through a menu of options, until the required one is highlighted (Wellings and Unsworth 2011). As more devices are added to the EC system, the selection and control of each individual device becomes a lengthier and slower task

(Verdonck, Steggles, Nolan, and Chard 2014). Moreover, for patients with severe or deteriorating mobility impairments, clicking the switch can be cumbersome (Craig, Tran, McIsaac, and Boord 2004).

Patients demonstrated great interest in ISA devices and often enquired whether NTRECES would issue ISA devices. For patients who are paralysed from the neck down, the use of their voice to control facilities around the house would provide them with meaningful degree of independence. As humans communicate through verbal dialogue, ISA may prove to be the most intuitive device for them (Cohen and Oviatt 2015).

A comparison between technology has highlighted that ISA devices can support all the functionalities that are enabled by EC devices, bar a few (Shamim, Spinelli, Woodcock, and Nair 2019) (see figure 1). Hence, a network of EC devices controlled by a central ISA is possible and would enable patients with mobility impairments to have a better quality of life. ISA devices are however designed as mainstream consumer technology and not as an assistive technology.
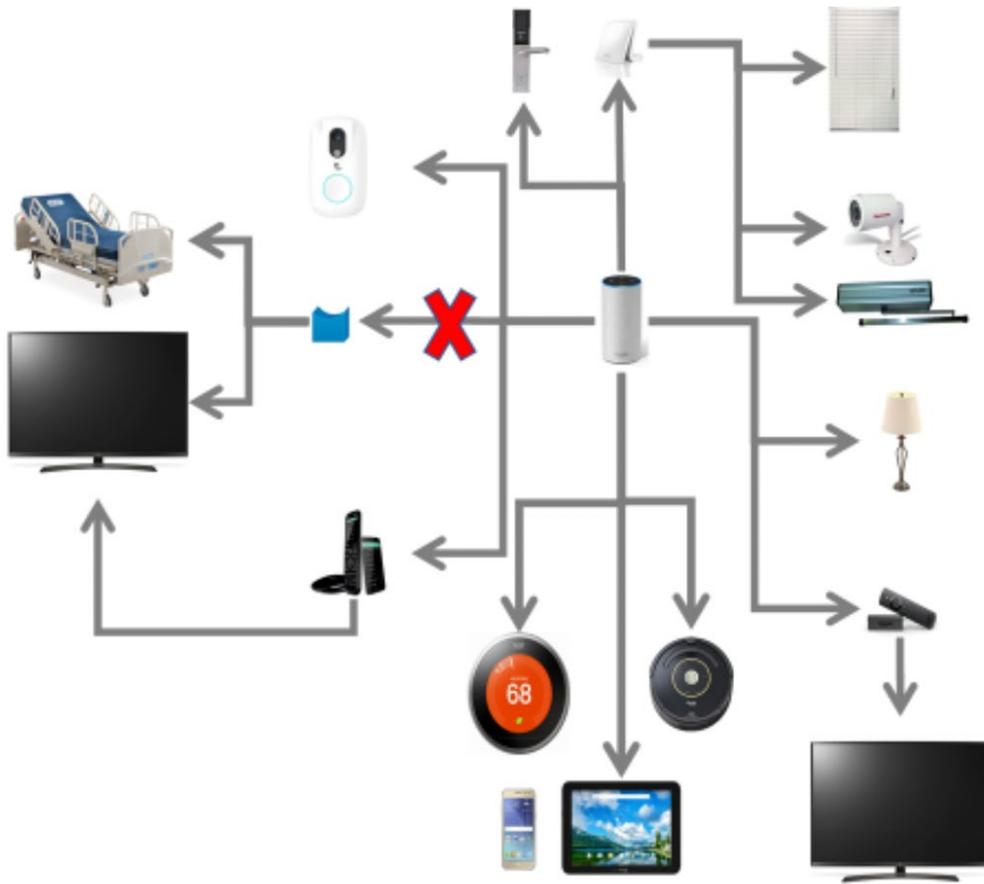
Figure 1: Map of the functionalities that ISA devices can and cannot provide

Due to the innovative nature of the technology and the unique interface modality, users may attribute to ISAs certain characteristics of anthropomorphism, that may lead to emotional attachment and recognition and/or assignment of agency (Lopatovska and Williams 2018).

In the next section a model of adoption bringing together secondary research and exploratory primary research is presented. It represents an attempt to modify existing technology adoption and consumer behaviour frameworks to consider the specifics details of the users in question and the technology considered.

A Proposed Model of Adoption of ISAs Among Severely Disabled Patients

The underlining assumption of this research is that understanding the factors that influence users' behaviour may directly impact the design of the technologies in both their functional and non-functional requirements and may suggest improvements in the service provided by NTRECES.

Model's Components

The model proposed here (see fig. 2) includes:

- A set of factors, here named User Characteristics, that are determinants of Attitude and of PBCs.

- An extended and modified list of items that constitute PBCs.

- An extended and modified set of items defining Subjective Norms.

- An additional set of items linked to the quality of the interaction with ISAs, here called Voice Interaction Experience

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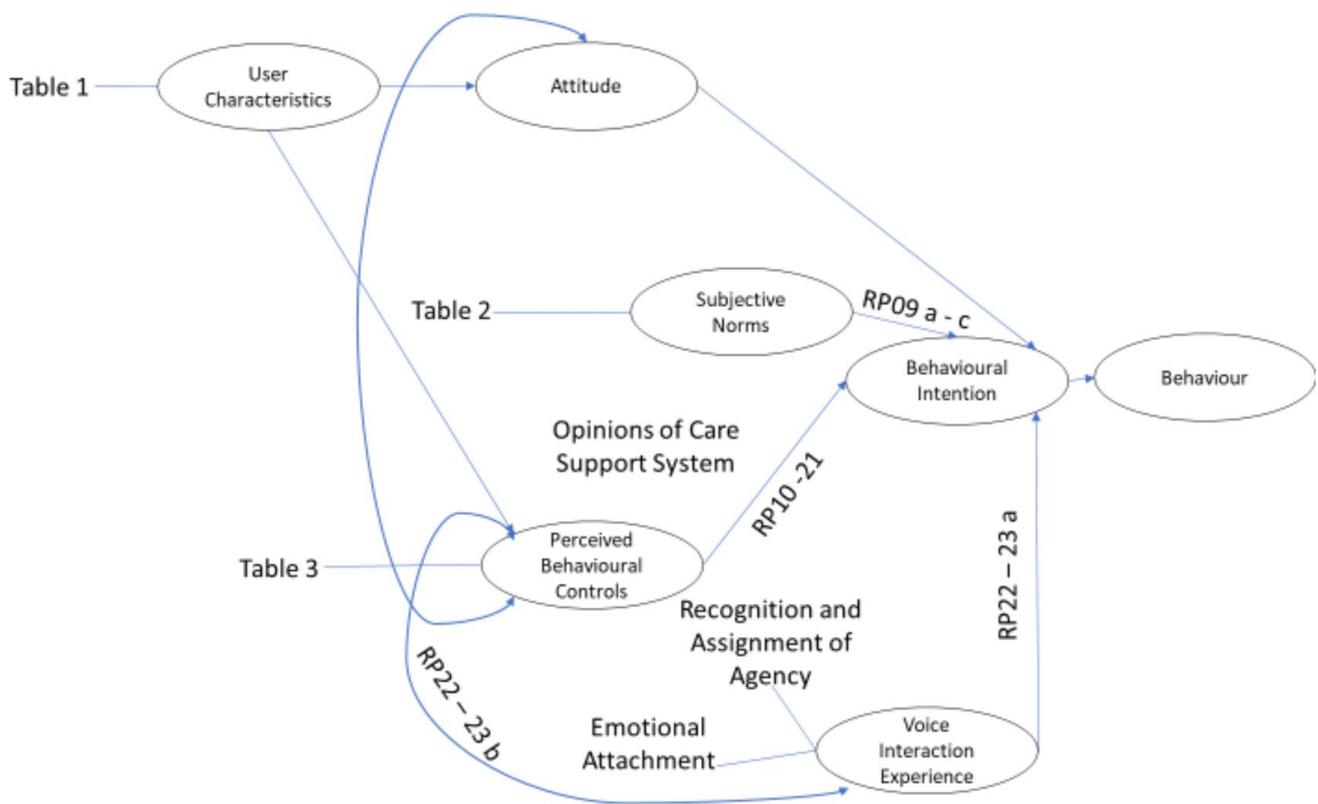
Figure 2: Proposed model of acceptance of ISA devices among NTRECES patients

Attitude

If a user has a positive attitude towards adoption of a technology, then the user develops a positive intention towards said behaviour (Ajzen 1991; Davis 1989). Scholars demonstrated that a positive user attitude leads to the adoption of smart speakers (Chu, Galetzka, and Van Deursen 2019). Hence:

(RP) 01: Positive attitude towards ISA devices is associated with the intention to adopt them.

User Characteristics

Users' personal characteristics play a significant part in the uptake or abandonment of technology (Goodman, Tiene and Luft 2002; Samaradiwakara 2014). The relevant user characteristics are presented in table 1. In the proposed model the user characteristics affect both Attitude and PBCs (see fig. 2)

User characteristics	Literature in support	Research propositions
Age	(Conci, Pianesi, & Zancanaro, 2009)	RP02a: Old age has a negative effect on PBCs. RP02b: Old age has a negative effect on the attitude towards intention to adopt ISA device.
Gender	(Li, Glass, & Records, 2008)	RP03a: Females have a negative attitude towards intention to adopt ISA device. RP03b: Females have a negative effect on PBCs.
Desire for Independence	(Kintsch & Depaula, 2002)	RP04a: Desire for independence can positively influence attitude towards intention to adopt ISA device. RP04b: Desire for independence can have a positive effect on PBCs.
Voluntariness	(Agarwal & Prasad, 1997)	RP05a: Voluntariness to try a new technology have a positive attitude intention to adopt ISA device. RP05b: Voluntariness to try a new technology have a positive effect on PBCs.
Openness to Innovation	(Laukkanen & Pasanen, 2008)	RP06a: Openness to innovation leads to a positive attitude towards intention to adopt ISA device. RP06b: Openness to innovation has a positive effect on PBCs.
External Engagement	Primary research	RP07a: Users with higher external engagement have positive attitude towards intention to adopt ISA device. RP07b: a higher level of external engagement has positive effect on PBCs.
Income	(Feder, Just, & Zilberman, 1985)	RP08a: Users with higher income have a positive attitude towards intention to adopt ISA device. RP08b A higher income has a positive effect on PBCs.

Table 1: User Characteristics affecting Attitude and PBCs

Subjective Norms

According to the TPB, the opinion of the people who are important to the user, is vital in forming one's intention. Yang, Lee and Zo (2017) established in their study that if the people who are important to the users think they should use smart home services then it will result in the intention to use smart home services. This model suggests that:

RP09: There is a positive relationship between Subjective Norms and the Intention to adopt ISA devices.

There are three items included in Subjective Norms, as per table 2.

Subjective Norms	Literature in support	Research proposition
Peer Pressure	(Ajzen, 1991), Primary research	RP09a: Social peer pressure positively affects the intention to adopt ISA device.
Trust in NTRECES Advice	(Ajzen, 1991), Primary research	RP09b: Trust in NTRECES advice is positively associated with intention to adopt ISA device.
Care Support System	(Ajzen, 1991), Primary research	RP09c: There is a positive relationship between the opinions of those who provide care and support and the intention to adopt ISA devices, specifically if caregivers are enthusiastic towards ISA devices, the users will form a positive intention to adopt.

Table 2: Subjective Norms affecting behavioural intention

Perceived Behavioural Controls

PBCs are the users' perception of how difficult or easy it is to perform a certain behaviour, in this case to use ISA devices. This perception is based on previous experience and anticipated obstacles (Ajzen, 1991). PBCs have been demonstrated to have a positive effect on behavioural intention (Yang, Lee, and Zo 2017). The model here proposes that:

RP10: PBC is positively associated with the intention to adopt ISA devices.

Extending and applying the definition of PBCs by Ajzen (1991) to the context of this study, several factors that constitute PBS has been identified and listed in table 3.

PBC	Literature in support	Research proposition
Familiarity with technology	Primary research	RP11: There is a positive relationship between familiarity with technology and intention to adopt ISA device.
Technical support system	(Goodman, Tiene, & Luft, 2002)	RP12: Users with a good technical support network have a positive intention to adopt ISA device.
Residence type	Primary research	RP13: Users' residence owned by a housing association negatively effects the attitude towards the intention to adopt ISA devices.
Trust in NTRECES advice	Primary research	RP14: Trust in NTRECES advice leads to a positive attitude towards the intention to adopt ISA devices
Lack of access to open market	Primary research	RP15: The lack of access to the open market has a negative effect on the intention to adopt ISA devices.
Perceived ease of interaction	(Davis, 1989)	RP16: PEoI leads to positive attitude towards intention to adopt ISA device.
Perceived reliability	(Goodman, Tiene, & Luft, 2002)	RP17: Higher perceived reliability leads to positive intention to adopt ISA device.
Perceived confidentiality	(Yang, Lee, & Zo, 2017)	RP18: Higher perceived confidentiality results in a positive intention to adopt ISA device.
Perceived security	(Jutai & Day, 2002), (Kowalczuk, 2018)	RP19: Higher perceived security has a positive impact on intention to adopt.
Perceived usefulness	(Davis, 1989), (Kintsch & Depaula, 2002)	RP20: Higher perceived usefulness leads to a positive intention towards adoption of ISA device.
Perceived trust in service provider	(Chung, Iorga, Voas, & Lee, 2017)	RP21: Perceived trust in service provider leads to a positive intention towards adoption of ISA device.

Table 3: Items included in PBCs

Voice Interaction Experience

This study proposes a construct, Voice Interaction Experience, that acknowledges the unique characteristics that VUI enables (Lopatovska and Williams 2018). These are described in table 4.

Voice Interaction Experience	Literature in support	Research proposition
Identification and Assignment of Agency	(Klein, 2016), (Wagner, Nimmermann, & Schramm-Klein, 2019)	RP22a: Identification and assignment of agency to ISA devices will positively affect the intention to adopt the ISA device. RP22b: Identification and assignment of agency to ISA devices has a positive effect on PBCs.
Emotional Attachment	(Knijnenburg, Willemsen, Gantner, Soncu, & Newell, 2012)	RP23a: The Greater the emotional attachment to the ISA devices, the stronger the intention to adopt the ISA device. RP23b: Emotional attachment has a positive effect on PBCs.

Table 4 Items included in Voice Interaction Experience

The model proposed is an initial elaboration of secondary and primary research. Future work, consisting of primary qualitative data collection and analysis will clarify and qualify the postulated research propositions and the existence of new ones.

To investigate the proposed research propositions, data will be collected from a sample of 15 patients. The protocol will include three visits to each participant at their place of residence. The repeated visits over a course of 5 months have been designed to enable the collection of deep insights in the characteristics, socio-technical environment and user requirements. Data generated from visit 1 will lead to a prototype of an ISA based EC hub able to demonstrate the control of few functions around the home. Visit 2 will be centred on the prototype and capture details on PBCs and Voice Interaction Experience. Visit 3 will focus on user-prototype interaction and service provision that may enable adoption. The final outcomes of this study will consist of a refined model for the adoption of ISA devices among patients with severe mobility impairments and a set of design and service improvements that would enable the adoption of ISA technologies as assistive devices.

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DEVELOPMENT OF SENSOR TIGHTS WITH INTEGRATED INERTIAL MEASUREMENT UNITS FOR INJURY PREVENTION IN FOOTBALL

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Abstract

In elite European football, 6 to 7 hamstring muscle injuries occur per team per season, which results in an absence of 14 to 180 days (Ekstrand et al. 2017). These injuries occur typically in the last part of a training or match. This implies that the accumulation of demanding actions is an important factor for hamstring injury risk. In current practice, physical player load is measured at the field by deriving the global location of the player with GPS and RFID systems. However, these systems are not able to monitor leg movement and to distinguish demanding actions like kicking, cutting and jumping. In order to monitor these actions in the field, a novel design is being developed. The design consists of five sensor nodes with IMUs (Inertial measurement units), integrated in sports tights.

IMUs can measure linear accelerations, angular velocities and magnetic fields in three directions. From these measurements, 3D kinematics of the lower limbs can be derived. An iterative design approach is used to develop the tights. Four prototypes will be developed. Each prototype is tested in a football specific setting, to identify areas of improvement from a technical point of view as well as from a user's perspective. The final aim of this research is to develop sensor tights that can be worn unobtrusively by football players in the field. Real-time data are retrieved by the coach. This allows the coach to intervene when there is a high injury risk.

Keywords: wearable sensors; injury prevention; smart clothing

Introduction

Football is played by more than 260 million people worldwide (Fédération Internationale de Football Association 2007). During an elite football game, players run about 10 km at 80 to 90 percent of their maximal heart rate. Numerous explosive actions take place, including high intensity sprints (which are quick accelerations followed by deceleration), turning, tackles, jumping, kicking and sustaining forceful contractions to maintain balance of the body and to control the ball (Stølen et al. 2005).

Hamstring injuries in football

As explained above, physical player load is very high, which results in a high rate of injuries. Overuse injuries are in most cases located in the hamstrings, groin, knee and lower leg. Hamstring injuries are the most common injuries in football. Each season, 6 to 7 hamstring injuries occur in each professional team (Ekstrand et al. 2017). The hamstring muscle group is situated at the back of the thigh and helps to extend the hip and to flex the knee. A hamstring injury is a strain or tear to the tendons or the muscles of this muscle group.

Measuring player load

The International Football Association Board (IFAB) decided in 2015 to allow wearable technology on the field. However, safety concerns have been raised and some sports organizations even banned existing electronic systems (Daniel et al. 2017). Therefore, it is of great importance to create products that are safe to use.

Several products exist that can measure physical player load or performance at the moment, e.g. camera systems (e.g. Prozone Sports Ltd ®, UK), GPS systems (e.g. Catapult Sports Ltd, Australia and Zephyr Performance Systems, US) or RFID Systems (Inmotio Object Tracking, NED). Data for these systems can be used to derive the athlete's velocity or to classify activities, as shown in a study regarding classification of activities of elite female football players (Datson et al. 2017). Other systems like the LPM (local position measurement) system of Inmotio are equipped with an accelerometer and can measure average acceleration and deceleration quite accurately (Stevens et al. 2014).

However, in order to be able to obtain information about the actual player load, we need to have detailed information of the local upper and lower limb accelerations and forces and not just the speed and global position of the athlete.

Therefore, this research proposes the design of a new product with integrated sensors that can measure linear accelerations, angular velocities and the earth magnetic field at the lower and upper legs. The sensor data can be used to obtain the orientation of each leg segment in real-time. In this way the exact movement of the leg can be detected, which provides better insight in the load at the hamstring muscles to prevent injuries in the future.

The Designer's role

The research project about the development of the new sensor tights involves several disciplines. Two human movement scientists are working fulltime on translating the sensor data to valuable information or parameters to predict injury risk. A sports doctor and an embedded scientist are involved to monitor the applicability in a real sports setting. An electrical engineer, software engineer and a smart textile researcher are working on the hardware and software of the tights.

The specialists in the team are responsible for certain parts of the design. The role of the designer is to lead the design process by stimulating ownership by the specialists of the subsystems, while keeping challenging them to consider the perspectives of the other stakeholders. Integration of the subsystems is done by the designer with the application in mind.

The two main research questions that need to be answered are:

1. How can we reliably measure leg segment movement during football with IMUs?

2. How can we create an easy-to-use and comfortable wearable that has a high acceptance rate among football players?

Method

A participatory design approach (Dell'Era and Landoni 2014) was followed. The users in this stage are human movement scientists, embedded scientists and sports doctors and in this project, they are a 'partner' in the development process. The movement scientists are involved in every main decision in the design process. Professional football players, who will wear the product, are also observed and consulted from the start of the development process.

Analysis phase: List of criteria

To create a complete list of requirements several stakeholders are interviewed, including movement scientists, sports doctors, physiotherapists and professional football players (figure 1). Furthermore, a series of football trainings is observed, and actions are counted, to get an idea of the type and quantity of actions that are involved when the product is worn. The total observation time is 90 minutes.
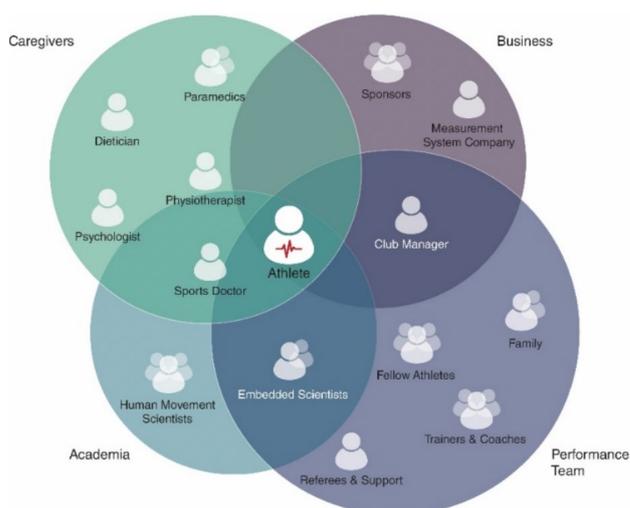

Figure 1. Stakeholder Map

Design phase

During the design phase, an iterative design approach is used. The project timespan is four years and every year a new, improved prototype is planned to be created. These are the main milestones. Quick prototype to test subsystems are made in between as well. Figure 2 shows the project plan and the current status of the project.
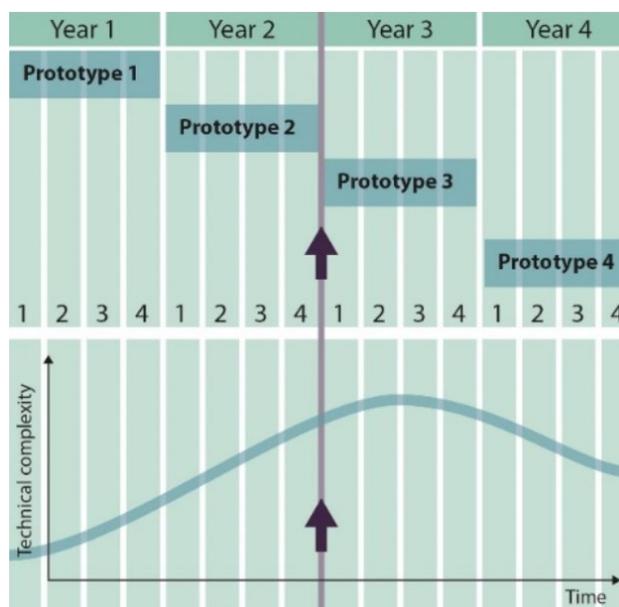

Figure 2. Project plan: the purple arrow shows the current status

In this paper we describe the design and development of prototype 1 and 2.

The first three prototypes are research prototypes for the human movement scientists. These prototypes are used as a measurement tool to identify hamstring injury risk factors. Since these prototypes are used for scientific research, the technological demands (e.g. sample frequencies and measurement ranges) are high. Once hamstring injury risk factors are identified and the required specifications of the sensor tights are known, the final product will benefit from this knowledge and can possibly be simplified. This will decrease the threshold to production and sales and increase acceptance by amateur football teams. The final product will be used by sports coaches, trainers and athletes.

Evaluation

To answer the two research questions, the evaluation of each prototype consists of two parts: the technical validation and user experience tests. Insights of these tests are used in the improved design of the next prototype.

Technical validation

For testing the status of the reliability of the system, each prototype is validated according to the following protocol at the KNVB Campus (Zeist, The Netherlands) (Bastiaansen et al. 2019; Wilmes, Ruiter et al. 2019).

Different football specific movements are executed, such as a jump, kick, acceleration run and deceleration run, at different intensities (low, medium, high). The movements are recorded by a VICON system (assumed to be the golden standard in movement tracking) and by the sensor tights. The sensor data are translated to orientation data with a biomechanical model developed by the movement scientists. Joint angles (Figure 3) of both systems are compared and root means square errors (RMSEs) are calculated.
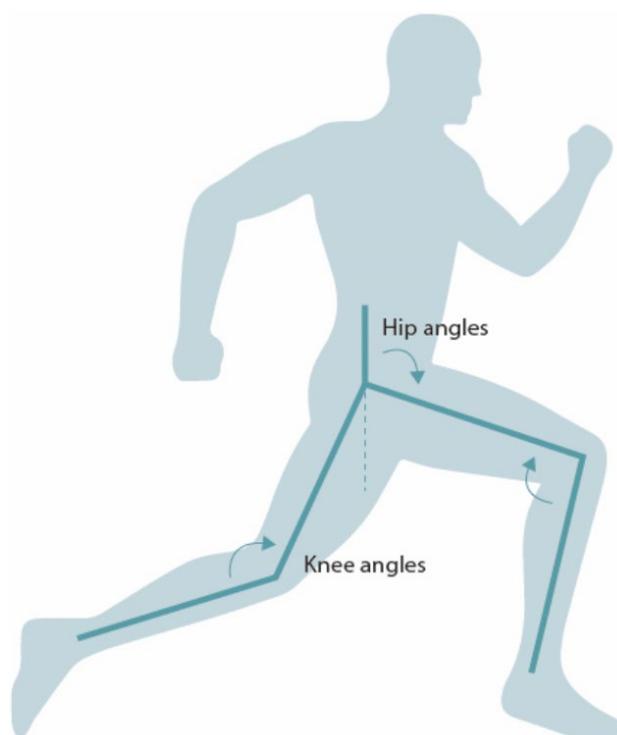

Figure 3. Visualisation of joint angles of interest

User Experience tests

To test the degree of comfort and ease-of-use, the tights will be worn in trainings too. Wearers are asked about their experience and if they feel restricted by the tights through a short questionnaire. The human movement scientists, who are identified as the users at this stage, are also asked about their experience in using the product. Questions about ease of use are asked.

Results

Analysis phase: List of criteria

Below, the most important criteria for the development of the sensor tights are highlighted:

1. Five IMUs are integrated in the pants, one at the trunk, one at each upper leg and one at each lower leg. They gather accelerometer data, gyroscope data and magnetometer data in x,y,z directions.

2. Raw data are saved and can be read out at a computer.

3. The electronics will not harm the wearer and fellow players during a match.

4. The product is comfortable to wear and does not restrict the athlete's movements.

5. The IMUs do not move with respect to the skin.

Design phase

To identify the best sensor locations, a trade-off was made between minimizing the risk of soft tissue artefacts (STAs), which increases technical reliability, and using a safe and comfortable location in a football context.

Based on the observations of the trainings, it was found that the following types of physical contact occur the most: duel face-to-face (A), duel face-to-back (B) and duel side-to-side (C). This type of contact is often limited to the feet and arms. In training exercises that involve physical contact, this was 0.064 (A), 0.046 (B) and 0.084 (C) times per player per minute. Sliding, which can potentially move or break the sensors, occurred 0.008 times per player per minute. From a soft tissue artefact study, it was concluded that sensors at the side of the thigh and shank, show the lowest soft tissue artefact.

To find the best sensor locations, several consultation sessions where held with the movement scientists. Figure 4. shows some visual material that was used in the sessions.

Figure 4. Material used in the consultation sessions

Although physical contact may occur at the side of the thigh during trainings, this location was chosen for the upper leg sensors to keep STAs low. The lower leg sensors are placed at the inner sides of the shanks, near the knee. The central processing unit, containing the battery, microcontroller and SD card was placed above the sacrum.

Prototype 1

Prototype 1 (Figure 5) uses an Arduino Due (Arduino, USA) and the 9 DOF IMU sensor MPU9250 (Invensense, USA). These components are chosen to enhance quick prototyping. The MPU5250 sensor is widely used in movement tracking, but measurement ranges are limited (16g, 2000°/s). Wires are sewn to commercial tights in a serpentine pattern to allow stretchability and the sensors are encapsulated in silicone rubber to minimize injuries during player to player or player to ground contact.

Figure 5. Prototype 1. Sensors are the black square units connected to the wiring; the white spheres are reflectors of the VICON system

Prototype 2

Prototype 2 (Figure 6) uses an STM32 microcontroller (STMicroelectronics, Switzerland), the ICM20649 IMU (Invensense, USA) and the AK8963 magnetometer (AKM Semiconductor, USA). Printed circuit boards (PCBs) are custom-made. Strips of fabric are patterned on commercial tights (Figure 7). Teflon coated stranded copper wires are laced in the strips in a serpentine pattern. The wiring is connected to the PCBs with wire-to-board connectors. Little sleeves are placed at the tights to hold the sensors and a larger pocket was created for the central processing unit.

Figure 6. Second prototype of the sensor tights

Washing tests with the connectors and wiring were executed. Prototype 2 is washable for at least ten times, when the sensor nodes and central unit are disconnected. The measurement ranges of the sensors are larger (32g, 4000°/s). The electronics are integrated better and higher sample frequencies can be reached (>250Hz) compared with prototype 1 (150Hz).
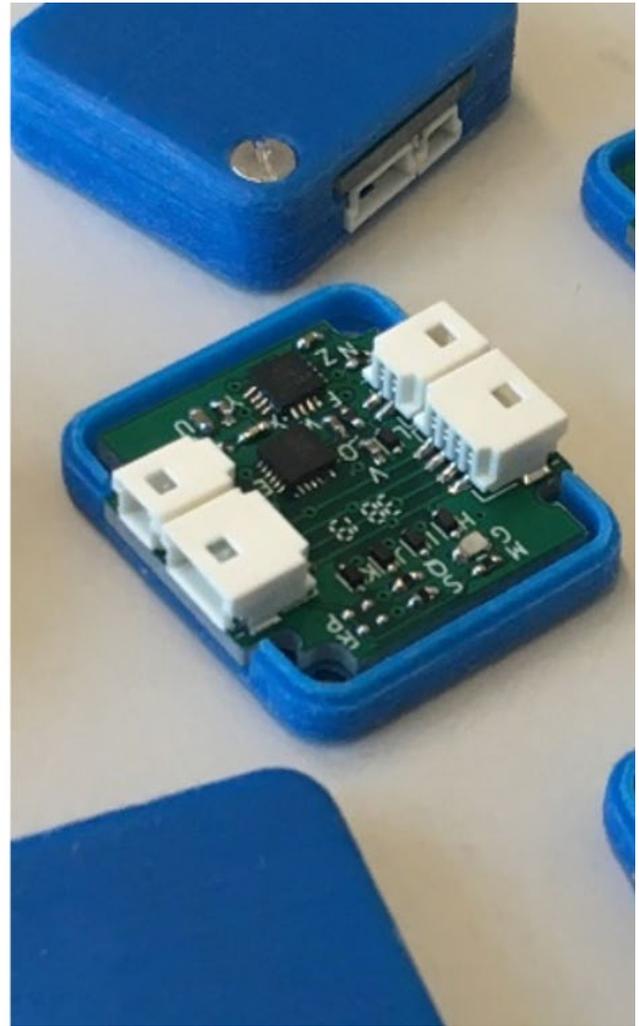
Figure 7. Left: wiring laced in strips of textile, right: the sensor node (21*24*8 mm, and 3.6 gramms)

Evaluation

At this moment, prototype 1 is validated and the prototype 2 is ready for validation.

Technical validation prototype 1

From the technical validation of prototype 1, it was found that RMSEs of the hip and knee flexion/extension angles are around 5 degrees (Vinasithamby 2019). Thus, concurrent validity with the VICON system is good. However, RMSE increases with exercise intensity. Besides, the maximal sample frequency is ± 150 Hz. This is relatively low, compared to commercial IMU systems, which can have a sample frequency of ± 250 Hz.

User experience prototype 1

Wearers of the tights (n=3, male, amateur football players, 20-40 yrs. old) mentioned that they did not feel the sensors and they did not feel restricted in their movements by the tights. However, there was a risk to get entangled with the wiring. Moreover, the pocket that contained the Arduino and battery, shook during exercises which was experienced as mildly uncomfortable. These comments are taken into consideration for the next prototype.

Discussion

The observations of football trainings gave insight in where the sensors could be placed to ensure safety and comfort. However, STAs need to be considered as well. To identify the best locations of the sensors for these first prototypes, a trade-off was made. The sensors at the thigh, can potentially be a problem in duels and with sliding. Therefore, it would be interesting to investigate slightly different locations, for example closer to the knee.

Insights from the development and evaluation of prototype 1 are used in the development of prototype 2. The central unit for prototype 2 is much smaller, more robust and more compact. Furthermore, the wiring is covered by a layer of textile to prevent entanglement.

For prototype 2, a user interface with some buttons and LEDs was added. With the interface, the user can start and stop measurements, highlight certain activities and show the status of the device. The current interface will be tested and improved based on user tests. For prototype 3 it is considered to change the buttons and LEDs based on the feedback from the user tests.

At this moment, the product provides the user, now still a scientist, with the raw data through an SD card. Once we know more about the hamstring injury risk factors based on the research of the movement scientists, a design project can be initiated about how we can communicate these data to the coaches and trainers. It needs to be considered to show the information to the football players too.

A concern that needs to be mentioned is that, during the interviews with professional football players, they reported unanimously that they were not going to wear tights during a public game. It appears that playing with bare legs is customary in current football culture. To increase acceptance among football players, the appearance of the product must change. Shorts are a better option, but the lower leg sensors are still required for research purposes. For the next prototypes it will be discussed whether shorts will be the final product and if separate wireless sensors, for example in the shin guards, are required.

In short, a second fully working prototype of the sensor tights is developed and will be evaluated in a technical validation study and user experience tests. Future prototypes will focus on even better integration of electronics and washability. In a later phase, a user interface to show hamstring injury risk will be developed in collaboration with the human movement scientists.

Acknowledgements

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