‘Ageing Playfully’ Case Study: a story of forgetting and remembering

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Abstract

An increasing interest in exploring how digital innovation could support dementia care has been leading research responding to e-health movements, from caregiving and medical perspectives. Not much investigation has included standpoints of the people with dementia; even fewer are concerned with the emotional side of the research experience per se. The Ageing Playfully project, offered a creative space during a series of playful workshops, where participants by co-designing, had an opportunity to catalyse imagination and social interaction, and reclaim agency in the context of their own lives. The aim of this case study paper, is to open a space for a discussion of transformative implications that this process has on design researchers engaging in the area of dementia. Grounded in these two overlapping creative spaces, a methodology emerged that focused on adding design value to outcomes and to all stakeholders involved along the process. Participating in Ageing Playfully, were twelve co-designers with dementia, two practitioners healthcarers and four researchers from Lancaster University in the areas of design, computer science and health studies. This paper recounts the experience of the design researchers as part of the team and constructs a narrative in which emerging methods together with personal experience are protagonists; a story that offers memories within the forgetful corners of the investigation.

Keywords

Ageing; Dementia; Co-Design; Participatory Design, Method Story; Knowledge Exchange; Researcher Experience

Introduction

'Ageing Playfully' was a cross-discipline, cross-sector collaboration project funded by the Arts and Humanities Research Council, through the Creative Exchange program, one of its four Knowledge Exchange Hubs for the Creative Economies. The main aim of the Creative Exchange was to catalyse collaborations of academics and private and public sector. 'Ageing Playfully' brought a team of researchers and healthcare practitioners from Age UK Lancashire to work with a community of people in the early stages of dementia and their caregivers. The idea of the project was to use co-design processes to explore the potential of digital-physical artifacts to boost wellbeing for people with dementia. Through co-design methods, the project endeavoured to contest the “ill”, “un-able” or “patient” identities that are continuously constructed and reinforced in medical context (Mol and Law, 2004, p.02). ‘Ageing Playfully’ envisioned that creative and participatory activities empower participants and offer space to recover “active” identities and to reclaim agency by becoming designers themselves (Luján Escalante et all. 2017).

Method Story (Hendriks et al, 2015), is a novel approach for sharing experiences and questions about co-design methods and techniques for involving people with mental impairments. Method Story has been employed in this paper, on one hand to make sense of the experience by remembering it and articulating it in a story format; and on the other hand to go beyond the publication of the positive results of design research. In this sense, it is not the aim of this paper, for example, to contribute to the understanding of how dementia might impact upon the person, not even, to understand how digital-physical technologies may be use to boost wellbeing of people with dementia. Using the Method Story, this paper opens a critical space for making sense, and questioning, the role of the design researcher when working together with people with early signs of dementia and their caregivers.

The contribution to the design perspective, is to explicitly share the making of the methodological approach, including the considerations, decisions, adaptations that influenced the empathic design of our research. As researchers and authors of this paper, we take the opportunity offered here, to reflect on how the research transformed our own story as researchers, and the unexpected outcomes that resulted from the quest of co-designing with people with dementia and their caregivers.

After presenting the related work, the paper focuses on discussing and sharing the research team's experience in the Ageing Playfully project using the Method Story. To test the Method Story, the structure of the discussion follows section by section the one proposed by Hendricks et al. (2015). This is then followed by concluding remarks.

Related Work

There has been an increase of the design for health community in participating and leading research projects in the are of dementia. This has emanated from an urgent societal need for improving the quality of life of people with dementia and their caregivers following the steep increase of dementia in the UK (Prince et al, 2014) and worldwide (Prince, 2015) as well as its rising cost for healthcare services (Prince et al, 2014).

Following a growing research literature reporting on the social needs in dementia (Vogt et al 2012; Kitwood and Bredin 1992), much previous work has focused on designing interventions aimed at people at the early stages of dementia and their caregivers. This ranges from facilitating reminiscing and enhancing personhood (Wallace et al 2013; Siriaraya and Ang 2014; Kuwahara et al 2006); to addressing the safety and autonomy of people with dementia (Mountain, 2006; Lindsay et al 2012; Robinson et al 2009); to support activities of daily living (e.g. cooking, improve sleeping) (Ikeda et al 2011; Ehleringer and Kim Si 2013; Hoey et al 2011).

Within this context participatory design has been widely employed as a research method with the aim of engaging people with dementia and their caregivers and designing *with* rather than *for* service users (Hanson et al., 2007; Robinson et al., 2009; Mayer & Zach, 2013; Lindsay et al., 2012; Treadaway et al., 2015). However the exact notion and nature of participatory design within the context of working with people with dementia and limited capacity raises several ethical challenges and concerns (Berghmans and Ter Meulen, 1995; Baldwin, 2005; Dewing, 2007).

There has much written on ethical issues and transformative implications of conducting research in the space of dementia from various disciplinary points of view (e.g. Woods and Pratt, 2005; Strech et al, 2013) and caregivers (Hughes et al, 2002). However, little has been written from the point of view of the increasing number of design researchers engaging in the area of dementia. Participatory processes do not just empower and offer agency to participants but also transform the design researcher's practice, ideas and perspectives and these important implications are rarely addressed among scholars. Findings and outcomes of design research in publications and conferences as usually limited to either participants or to design products, services and processes. This omission presents the design researcher as discrete, neutral or permeable to the transformative process of participatory design. This paper uses the Method Story to unveil the transformative implication of participatory design process to the researcher 's practice.

Discussion

Positioning Dementia

Twelve participants with dementia provided consent to take part in Ageing Playfully, with two support healthcare practitioners also attending the sessions. Although just one member of the research team had experience in the context of dementia, specifically using art therapy, this was the first time that everyone had designed together with people with dementia. This was a great challenge for all members of the research team. We quickly learned that the word 'dementia' carried a negative connotation and stigma, not just for researchers, like us, but also for the people with dementia, their caregivers, family and even healthcare professionals. The first thing we learned about dementia was not to call it dementia. The best way of confronting it was to totally ignore it. To say the word, was definitely uncomfortable for all. Beyond its petjorative meaning, the word was not useful to describe illbeing; participants do not "feel dementia", they feel confused, anxious or sometimes in pain. The first clear strategy was to concentrate on wellbeing instead.

Age UK professionals from Lancaster facilitated a day workshop on the types of dementia for the research team. From this it was learned that there are several types of dementia of which Alzheimer's is just one. The workshop provided invaluable knowledge about how dementia can manifest, things that can be difficult, behaviours to avoid, and dispositions of mood or intention the research team should use to approach the group of people it was going to work with.

Age UK Lancashire had been working for approximately a year with a 'circle of support' that the project was going to join and engage as a focus group. The contrasting languages of dementia as chronic illness and the narratives from the 'circle of support' as a social group that engage in theatre and dancing was starting to show the research team the liminal spaces in which the workshop was going to emerge; in between medical and creative, with the participation of subjects/objects.

The first stage of the project was getting to know all the people attending the 'circle of support.' Importantly, this meant those attending the circle got to know the research team, too. Their sessions tended to alternate activities of singing along and dancing with reminiscent conversations. The research team attended these sessions for a period of approximately two months prior to initiating the workshops. This period of all the participants getting to know each other was essential. We had the opportunity to share social contexts and we participated with the group's activities, becoming familiar with the ways different participants expressed their experience of dementia and the way carers show attention and care for them.

The 'Circle of Support' met every week at an elderly home with a dementia care and rehabilitation unit, in the suburbs of Lancaster. The unexperience team, was certainly nervous; cinematic images of a madhouse and asylums were obscuring the golden autumn day and preventing some of the researchers to advance each step.

The home very quickly dissolved researchers's fears and erroneous preconceptions. In the first visit the research team sat in the back of the room and observed (see Figure 1). We had little participation in the session. The session was led by two healthcare practitioners of Age UK. One, who we will call P, impressed us with his enthusiasm and how all participants seemed to like this. The research team doubted it ever would have such energy to facilitate a session like him. The other one, who we will call S, was loving and caring, calm and patient. We noticed she talked to each individual with love and touch. Again, a question arised in the back of the research team's mind; where or how were we going to find the caring attention to offer in the participatory design sessions.

Figure 1. The research team's first day with Age UK Lancashire Circle of Support at the older people's home in Lancaster.

We continued to attend the elderly's home weekly, finding ourselves more at ease in the way and even participating in the sessions. By the end of this two months we discovered that we were actually looking forward to our weekly afternoons with the support circle and happy to be sharing time and songs with them.

This period helped to dispel our preconceived ideas about how people with dementia behave. Indeed, it was realized that it is not always obvious that someone has dementia, particularly when they are in the early stages of the disease. Based on the notes of this preliminary experience, we started to meet as part of the research team, and we began to give shape to the methodology, aware that we must include the participants in the design process.

Aiming for equivalence

The broad idea was that together as a team of researchers we would facilitate a series of playful workshops. Co-design processes meant that researchers had to allow an equality of control over the process between the team as facilitators and participants as co-designers. What were these workshops about? What were the main themes? What would we co-design? What were the expected outcomes? We did not know at that time. The idea was to answer this essential research question during the process with the participants. In this sense the co-design process does not just encourage a degree of equity in the research hierarchies; whether participant and researcher, but also flexibility in the methodology. The only thing clear to the research team at that point was that it had to include somehow its very own version of P’s enthusiasm and S’ caring attention for these workshops to be successful.

The research team was interdisiciplianry. Amanda is a health researcher, based in the faculty of Health and Medicine, her main contribution to the project was her vast experience using art therapy in research process. Emmanuel brought expertise in co-design methods to explore the intersections of digital technologies and wellbeing and Malé, who was doing her PhD in Digital Cultures, brought experience in design ethnography but had never worked in the health context. Together, inspired by P and S, and cleansed of the bad connotations the the word dementia carries, we initiated the workshops.

Balancing of viewpoints

Part of the task of designing the methodology was to deal with the expectations of all the partners. This involved negotiating the tensions between the delicacy of memory processes and the gleam of technological innovation; the fragility of the process of collaborative ideation with participants -who most of the time had forgotten what was discussed in the last engagement- against the sharpness of institutional interests in impact outcomes. For instance: “what are you designing?” Such occurrences illuminated the particular and sensitive place that dementia has in the public imagination and specifically in the healthcare context.

The first phase of project focused on four workshops; each of these would inform the next one. By the end of the first workshop we expected to learn the main themes of interest from participants, which we would be exploring in the remaining workshops (see figure 2). We aimed to end with one or more prototypes or ideas that would be developed in the design lab in a second phase of the project.

Dealing with ethical challenges

Figure 2 Workshop One: "Our favourite things": show how themes started to emerge.

Following ethics review and approval by the Lancaster University Research Ethics Committee (UREC) and additional permission obtained from the Age UK Lancashire (Lancaster), the research team introduced the project in one of the weekly sessions of the 'circle of support,' involving carers and support workers in the discussion.

Information packs including consent forms were distributed and those wanting to take part were invited to join the first Ageing Playfully workshop.

Written consent was obtained at the start of the first workshop with the assistance, where needed, of carers and support workers. We knew through participants' family and relatives and through Age UK caregivers that people from 'circle of support' were keen to participate. We were confident that all the research team were committed to facilitate the best experiences for the participants. However, that did not stop us asking ourselves in what measure those permissions would be ethically valid when during the course of the research project some of the participants may not remember what they had signed up for. We could not help but feel that we had some co-designers that were there with a potentially declining agency to own and repond to the design process. Working with people with dementia raises ethical questions during the whole process and made design researchers critically evaluate their role, responsibility and rights as researcher, as well as their rights to research.

During the workshops, participants as co-designers expressed enjoyment and enthusiasm when given this opportunity to engage playfully with each other in imagining and building models (see Figure 3). Their carers and support workers noted how the workshop activities seemed to encourage interaction, with even the reticent, less confident members of the group joining in with the model building.

The series of workshop finalized with impressive outcomes: a co-design tool kit and a musical board.

The second phase of the project in the design lab would not involve the co-designers. However during the eight weeks of this first co-design phase, participants appeared to create social connections and some emotional links. There was a sense of friendship between some members of the group and some great moments when they shared personal stories that certainly enriched the project. As a team we were very aware of how the potential for this level of friendly, social interaction was abruptly disrupted by the termination of the project.

Figure 3 Workshop Two "Our very own garden": co-designers modelling their ideal garden and garden activities and features.

Once again, we asked ourselves if we have the right to offer participants a chance to build such a potentially important and most needed space and then at the end of the project suddenly cut them out from it. The project benefited us as researchers from a series of data collection, ideas and prototypes. We have no doubt that all researchers were always thoughtful about offering a meaningful experience in return. The project was always scoped for a limited period of time and the awareness of termination was present. But it felt, that the experience was too meaningful and the termination meant a sense of loss for the participants who were already losing a lot of. Perhaps is the norm for this sort of pilot projects, especially in charitable context. However for several of us, as this was our first project in this area, was harder than we could anticipate.

The project scope included a session of feedback. We were supposed to show all the models and prototypes, show the videos we made together, and provide closure to the experience. Lamentably this last session could not happen, as in the process a change in policy in government and within Age UK – a government funded charity – translated into resources cuts and the 'circle of support' had to close. The research team tried to contact participants but the authorities of Age UK were changed and the professionals we worked with had other responsibilities.

Care Matters: After "Ageing Playfully'

Beyond the impact and outcomes of the project, beyond the methodology and methods, and beyond the project report, Ageing Playfully opened a door for the team in new research interests. By the last session of the workshops, we had learned each of the names and personalities of the participants, we sustained weekly correspondence with them during and after the sessions, and got to know them and their life stories a little bit. For the research team, the end of the project was painful. On the other hand we developed our own –less refined and maybe less efficient- version of P's enthusiasm and S's care. Fundamentally, we found a research interest in continuing to work with older adults and people with dementia.

Ageing Playfully opened a door for us to develop research interests in care and how care matters in the context of involving digital technologies to mediate experience of chronic illness. Currently digital technologies are interfaces for body data collected and interpreted from the medical perspective and for medical use. The questions we asked ourselves during the project directed new research into a theoretical and methodological search, that integrates the emotional textures and qualities of care into the binary objectivity of the digital.

All these connections, exploratory conversations, theoretical research and work after Ageing Playfully are reshaping not just our research profiles, but have also transformed our personal life and the vision of our future practice. We ask ourselves again is this not also an outcome of Ageing Playfully project? We have a sense that we owe our current research direction to Ageing Playfully's 'afterlife,' but there is rarely space in a research paper or report to express the implications one small pilot project may have in the life of the researchers and the experience of research. We took the opportunity of this method story not just to recount how methods emerged, essentially out of enthusiasm and care but to tell a much bigger tale of remembering why we get to care and how.

Conclusions

The project outcomes, which included a design brief for a music- related intervention for social interaction and a set of practical recommendations for researchers, informal and professional carers in running workshops using playful activities that mediate active social interaction and stimulate engagement and contribution to knowledge were shared and published within academic and non-academic contexts. However, the experience of developing co-design research methods, alongside the practise of co-designing and what the research means to the researchers never found a space for sharing or getting feedback.

The story of the method (Hendriks et al, 2015) seems not just to be useful medium for this, but also, a healthy strategy for researchers that may find themselves engaged in the research from rather emotional processes. This is a way to deal with the anti-climax of the process, as well to share learning and experiences that do not usually have a place in outcome-based reports. This storied experience centred on the methods has enormous potential for experimenting with format. Method Story is a tool that can enrich future practices and offer space to share emerging knowledge that would enrich both practices and practitioners.

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Mr Adrian Gradinar: is a Creative Exchange PhD student conducting research in the Internet of Things and how digital information can be integrated with familiar objects.