"WHAT REMAINS?"

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USE CO-DESIGN TOOLS AS SERVICES THAT REMAINS

What remains? is a design research project that is part of a larger investigation into how game elements can be used as motivational triggers to stimulate Alzheimer patients physically and socially. *What remains* uses co-design tools and turns these during the engagement with participants in the project into a service that remains and persists after the designers leave.

CO-DESIGN & EMPATHIC DESIGN

Mattelmaki and Sleeswijk Visser (2011) state that "co-design activities typically aim at searching new potential directions and producing design ideas and solutions." Since co-design is generally a collaboration between designers and a small representation of the people who will use the designed product or service in the future, it is fundamental to use an empathic approach. "Empathic design starts with a need to understand user experiences in the early phases of the design process" (Koskinen et al, 2003). However, establishing a group to a co-design with is an activity that takes a long time and requires good preparation, because it is extremely important to find the correct way to enter into people's lives without upsetting them or causing disruptions.

ENGAGING THE HOMELESS - THE ETHICAL PROBLEM OF CO-DESIGN

Starting and ending a co-design project is a delicate matter that involves ethical issues, especially when working with people who are vulnerable such as homeless people, or older people with Alzheimer. In an effort to address and overcome these ethical issues, I have started to work with participants in such research in a particular way.
Fictitious Address is a co-design project and a service system for homeless people. The system helps homeless people to get back crucial documents they have lost, such as an ID card, to get a physical address and to get registered for social services. In order to understand the problems and priorities of homelessness it was important first to design the right conditions for the creation of a group of homeless people to work with on the project. Only after that, it became possible to enter the group as a designer. This step always requires much attention, respect and gentleness. Once the group existed, we shaped our co-design experience together through different sharing activities. Empathy was one of the most important elements that we tried to stimulate with these activities. Over time, the co-design group became a small community that eventually took over the whole *Fictitious Address* service. At this moment I, the designer, could step out of the group again.
The method that was applied focused on respecting the human relations that developed during the joint activities. More precisely, it strengthened the confidence of the group and made them see that they eventually did not need the assistance of a designer anymore to continue to meet, and to keep using the product service system they helped to co-design. By then, they had experienced and were confident they could generate solutions to their

problems themselves. The creation of a small independent community is crucial in achieving this stage.

A similar approach facilitated my detachment from the group of homeless people. During the separation phase, it was very important to find a way to maintain communication with the people that I had been involved with. This resulted in a continuing connection through mainly letters, emails and direct visits every few months. This allowed me also to observe the continuing success of the project, without my direct involvement.

ENGAGING ALZHEIMER PATIENTS - READDRESSING CO-DESIGN ETHICS

At the moment, I am involved in a second project with Alzheimer patients, to further explore and extend the approach I took in *Fictitious Address*. Alzheimer disease is the most common form of dementia. There is no cure for it, it worsens as it progresses, and eventually leads to death. In this project I work with Careyn, a social enterprise dedicated to the health and welfare of older people. Through long observation sessions including conversations with a psychologist working at Careyn, it became clear how older people with Alzheimer spend their days at the centre. The Careyn environment is designed to be very stimulating and staff routines are friendly and comfortable. This is a fundamental quality in successful care for Alzheimer patients. According to Kyttä (2003), "Environmental psychology suggests how a pleasurable living environment is composed of physical, social and emotional environmental offerings or affordances divided into community feeling, aesthetics, safety, recreation, activities and needs of different resident groups".

However, during my visits to Careyn, I also noticed some similarities with observations in care centres by Kälviäinen, (2012): "[On the one hand] care homes filled with devices, messy information boards, differing styles of furniture and stimulation material are fussy and associated with disrespect. Assistive devices stimulate experiences of disability stigma, cleaning items communicate about constant cleaning and an unclean environment, and children's materials imply childish residents. On the other hand too bare environments with cold colours and lighting, public space items and settings present a displeasing, boring and even scary atmosphere redolent of healthcare institutions."

A LACK OF INTERACTIONS

Most striking during all my observations was however that the patients did not have any interaction together. Even though they share some spaces on a daily basis, they are completely confined to their own world, detached from the environment in which they live and from the world outside the care home. In order to understand and explore opportunities to create social stimulation between older people with Alzheimer I used co-design as a research method. Through co-design "designers (or design researchers) can facilitate the initiation of collaborative processes as well as participating to the process as contributors" Mattelmaki, (2011). Older people with Alzheimer and caretakers at Careyn are involved as the experts that will guide me to understand what Alzheimer disease is. They are the experts of their own life experiences, because every day, sometimes during many years, they have had to deal with their problems and think about possible solutions. I knew from the previous co-design projects *Fictitious Address* that it is necessary to engage participants with and through empathy if I wanted to create a collaborative group with them.

According to a psychologist and caretakers at Careyn, "elderly with Alzheimer are a very delicate group because of their disease. For them it is easy to become restless, aggressive or passive and lost." In order to

become familiar with them I started to spend long periods inside care homes, especially during lunchtime. Lunchtime in the care homes is the moment where the patients gather together to share the same table and food, but during the observations it was clear that they did not have any interaction, communication or conversation together. Yet, eating and speaking together, about the weather, their families, and many other simple topics presented me an intense and good starting point for feeling accepted by patients and caretakers, allowing me to start our collaboration in a positive manner.

FUTURE CO-DESIGN EXPERIMENTS

In order to overcome communication problems between elderly with Alzheimer I designed two group experiments, to be proposed during lunch and dinner at the care home. The aim of these experiments is to stimulate social interaction within a safe and well-known environment by using food and the concept of sharing. Two playful co-design interventions aim to use lunch as a moment to trigger dialogues and more generally communication between people sitting at the same table. In this part of the project, as a designer, it is very important to be accepted as part of the whole group because the co-design experiments are only possible via my direct participation to these activities.

The first experiment comprises feeding each other using long wooden sticks. Each stick is too long for a person to use it her or himself. The experiment proposes to use it for feeding another person through an engaging interaction.

In the second and subsequent experiment each participant has two plates in front of her or himself, one empty and one containing just one of the ingredients of the entire lunch. Each person is asked to place a portion of food on the empty plate and then pass the plate to the person at her or his right. This is then repeated until, step by step, all of the plates have all the ingredients and arrive again at the initial owner of the plate, full of food.

Both experiments will last for a few weeks with the same people, with the main aim to consolidate the group.

CONCLUSIONS

The objective of this approach to co-design is to find ways to slowly enter a sensitive environment with vulnerable people, through creating friendships with the participants and proposing an involvement into activities that stimulate the creation of a collaborative group. This initial part is necessary especially to stimulate mutual trust and complicity between designers and participants.

The end of the co-design experience can be a traumatic event for a co-design group because of the intense relations built during the collaboration. In particular if a co-design group is created with vulnerable people, a lot of new emotions and feelings are involved. Co-design events such as the ones described here typically generate a weekly routine that may create a feeling of safety between the participants. If this safe environment suddenly disappears, this may create problems for some of the participants.

The co-design experience that is created in the projects described here are designed to persist. This principle is the starting point for designing services in the *What Remains* project. Using game elements, these services aim to provide life benefits to older people with Alzheimer. The co-design process still has to go through a number of iterations to find out what interactions and game elements will work best to create a service that can remain after the designer leaves.

ACKNOWLEDGEMENTS

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