

Alzheimer – What remains?

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Abstract

'What remains?' is a design research project contributing to a larger investigation about the role of game elements for stimulating positive behavioural changes in Dementia patients.

As soon as the severe health conditions caused by Alzheimer's disease wears away the ability to communicate and provide for self-care, the difficulties in communication and understanding between patients, care givers and elderly relatives provoke a deep state of anxiety and fear in the elderly's everyday life.

To face this issue, a collaboration with a social enterprise - specialized in the field of dementia care – was instigated and generated support capable to stimulate a more in-depth cooperation between designers, patients, caregivers and elderly with Alzheimer's relatives.

The research behind the project has been conducted from the starting point of observing the daily life of patients living in care homes, with the scope of stimulating co-design activities. Such an approach was not only fundamental for the designers but it also provided caretakers and relatives with new tools to better understand the multiple reasons behind specific behaviours of each patient.

As a result, this research approach has led to the design of a product service system that helps caretakers and the elderly's family members to constructively interact with this disease and personalize the type of offered care.

Keywords: Co-Design, User-centered design, Empathic design, *Dementia disease*

Introduction

'What remains?' is a design research project, which is part of G-Motiv, initiated by the CRISP (Creative Industry Scientific Programme) platform. The purpose was to investigate how to stimulate positive behavioural changes in elderly patients affected by Dementia through designing a Product Service Systems based on the use of innovative game elements. To do so, the Designer initiated a collaboration with Careyn - a social enterprise dedicated to the health and welfare of older people based in the Netherlands - which provided a valuable research context and made available useful information concerning the Dementia disease and any related therapies.

Through long-lasting observation sessions, including conversations with psychologist, care givers and manager working at Careyn, it became clear that older people with Alzheimer are used to spend most of their days within the walls of the centre. The environment of the care homes at Careyn is therefore designed to be as much as possible stimulating, reason for which also the staff places much effort in trying to be friendly and making the patients feeling comfortable. This seems to be a fundamental quality for most of the successful care homes that offer special environments for handling Alzheimer. According to Kytä (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".

By following the patients during their everyday life - in order to study their behaviors - it also started to become visible how the disease can negatively influence the life of older people. In fact, as there is no therapy or efficient treatment for this neurodegenerative disease, people affected from Dementia worsen as they progress, and the illness eventually leads them to die. The severest impact on patients' health, on the most common form of Dementia, is that the sufferer is robbed of the ability to speak, move, remember and even eat. The difficulties in communication and understanding between patients, caregivers and the elderly person's relatives, also provoke in the patients a deep state of anxiety and aggression during their everyday life. Furthermore, they tend to regress together with their memory, reason for which past events very often become their present reality. At that point, completely unplugged from their present and detached from their more recent memories, abilities and families, these people quickly lose the capacity to direct their lives. In most of the circumstances their responsibilities fall back on their loved ones, care homes and on society at large. For this reason it is necessary to respect the dignity of the sufferers as individuals and, to do so, it becomes fundamental to constantly provide for their needs.

Co-Design and Empathic design approach

To better understand how dementia affects people's lives and consequently to get to generate possible solutions, this research proposed an approach where collaboration and co-creation were considered as pillars, doubtless necessary for creating the connections between the designer and a small representation of the people who will use the products - or services - in the future. It is therefore understandable that the difficulty finally stands on seeking for the correct manner to enter into people's lives, with the aim to create a good synergy and mutual trust. This is one of the reasons why establishing a group to co-design with can be an activity that takes a long time and requires patience and good preparation. Careyn had never experienced an interaction with designers before, thus it has been very important to involve them from the very initial research phase and empowering them thanks to their professional knowledge. At the same time this project showed them the

potential of a multidisciplinary collaboration for designing new possible services and solutions for the care of dementia patients. Mattelmaki and Sleeswijk Visser (2011) stated that "co-design activities typically aim at searching new potential directions and producing design ideas and solutions." This quote was taken into account from the initial step of the research until the last prototype phase, where every Co-design activity were designed not only with caretakers but also with dementia patients and their relatives.

Working with people suffering from a severe stage of dementia required a very unique approach to co-design due to the delicate health conditions and neurological impairment. Furthermore difficult emotions are involved in the relationship between patients and their relatives, all of which cause painful interactions and difficulties in communication.

As a consequence of the extremely delicate research context it became fundamental to make use of an empathic approach, which could gain better chances to encourage mutual respect for the different emotions of each patient and stimulate a deeper understanding of tacit needs. As Koskinen stated, "Empathic design starts with a need to understand user experiences in the early phases of the design process" (Koskinen et al, 2003).

Such an approach to this research also helped achieving new awareness concerning the reason behind specific negative behaviours. Together with caregivers and elderly relatives we could finally understand that the painful emotions of patients, their restlessness and frustration, was caused by the impossibility to express thoughts and desires. Moreover, it became clear that their almost complete detachment from reality and confusion between past and present could generate fear, disorientation and even aggressiveness.

Marja Dijkwel, manager at Careyn, could indeed confirm that memories play a very important role in the life of the patients living in care home. From her observation she experienced that elderly with Dementia spend most of their time inside their own memories, completely disconnected from everything around them. The sharp contrast between the patient experienced real world of the care centre and the recalled fragmented memories of the patients generates very often negative emotions that can provoke feelings of anxiety, fear, aggressiveness in the mind of the elderly. Moreover – very important – the communication between caregivers and patients is not only problematized by the impaired communicative skills of the sufferer but also by the lack of available personal information on each patient when they enter the nursing home.

For this reason during the co-design activities with dementia patients, we started to make use of personal pictures belonging to each patient life-story and, by doing so, we discovered a very important communication and co-design tool to drive the research with. At that same research stage the elderly's relatives covered a very important role in collecting and sharing all the available personal pictures about their loved ones affected from the disease.

The collected autobiographical photos were afterwards shown to each patient with the purpose of testing their reactions. The outcomes were absolutely encouraging and the enthusiasm that we found pushed us to collectively decide to continue with that type of sensorial stimulations.

Each patient started in fact to perceive personal and autobiographical pictures as well as photos of everyday objects as important direct translations of their thoughts. For the very first time it was finally possible to establish a communication channel with each patient using a new visual communication tool made of personal photos.

In our project experiments, most of the time the patient would start shifting pictures from their belonging groups, to create physical connections between them: behind such actions there are autobiographical memories that – in the mind of the patient – obtain a

translation into new images. From the group of patients that collaborated to this project, it became clear that each connection carried a specific meaning and a real – however sometimes hidden - memory. Even if the meaning behind the pictures' combinations was sometimes a complete mystery to the eyes of relatives and carers, the fact that there was a sort of "enigma" to solve triggered them to investigate into the 'hidden memories' of their charges. This autonomous and unconditioned desire for finding the key to solve the enigma became itself a very interesting element that was added to the project. In such a way, in fact, carers and relatives co-designed "*What Remains?*", having self generated a solution to a specific issue.

In order to explain the value of the experiments it is important to present the following story:

A lady affected from a severe stage of AD was restless because she was looking for a second pair of shoes that she did not have. It was obviously very difficult for the caretakers to understand the reason behind such a strange behaviour. During a few co-design sessions the lady was combining the picture of a pair of shoes and the pictures of her father. After several days and by the help of her sister, we finally understood that her father was used to buy two pair of shoes for all of his children. One pair was supposed to be used during the weekdays and the other one was for Sundays and special events. Knowing this story the lady's son bought a nice new pair of shoes and placed them next to the bed of the lady. From that moment the lady stopped her nervous searching behaviour and became calmer.

This approach was not only fundamental for the designer, that could stimulate a personal interaction with each patient, but it also provided a new tool to caretakers and relatives, useful to gain a better understanding of the reasons behind each specific patient's behaviour. The numerous evidence and stories collected during the research contributed and inspired the design of the prototypes, which was time by time directly tested with the group of patients.

"What Remains?" Prototype

The first prototype comprises of two stages and two mixed-media tools, which both strictly depend on each other. The first stage involves a computer application whose features are shared between the patient's relatives and the care home. This computer application works as a mind map tool, which the relatives of the patients are asked to use for collecting and uploading pictures that can offer important life information about the patients. Pictures and information are divided in different categories, including family, jobs, holidays, memories, hobbies, pets, religion, favourite food, things they do/do not like to do, and other categories that may be extended by the relatives. The carers are also invited to collect pictures and information centred on objects that the patient frequently mentions or which seem to provoke restlessness during the daytime. All the information uploaded to the computer application is accessible by the relatives as well as the carers, and each patient has his own file.

The *What Remains?* application should initially be used during the intake phase of elderly people in a care home, providing the carers with a good understanding of each new patient. Immediately after intake, the app can be used to consult the personal information of the patient to quickly personalise the type of care. The interface of the application is also designed to continuously facilitate the update of pictures by carers and relatives of the patient, through new and more detailed information and discoveries. As a consequence, the application becomes an important tool to support the work of the carers, who can

quickly memorise visual information about the patients.

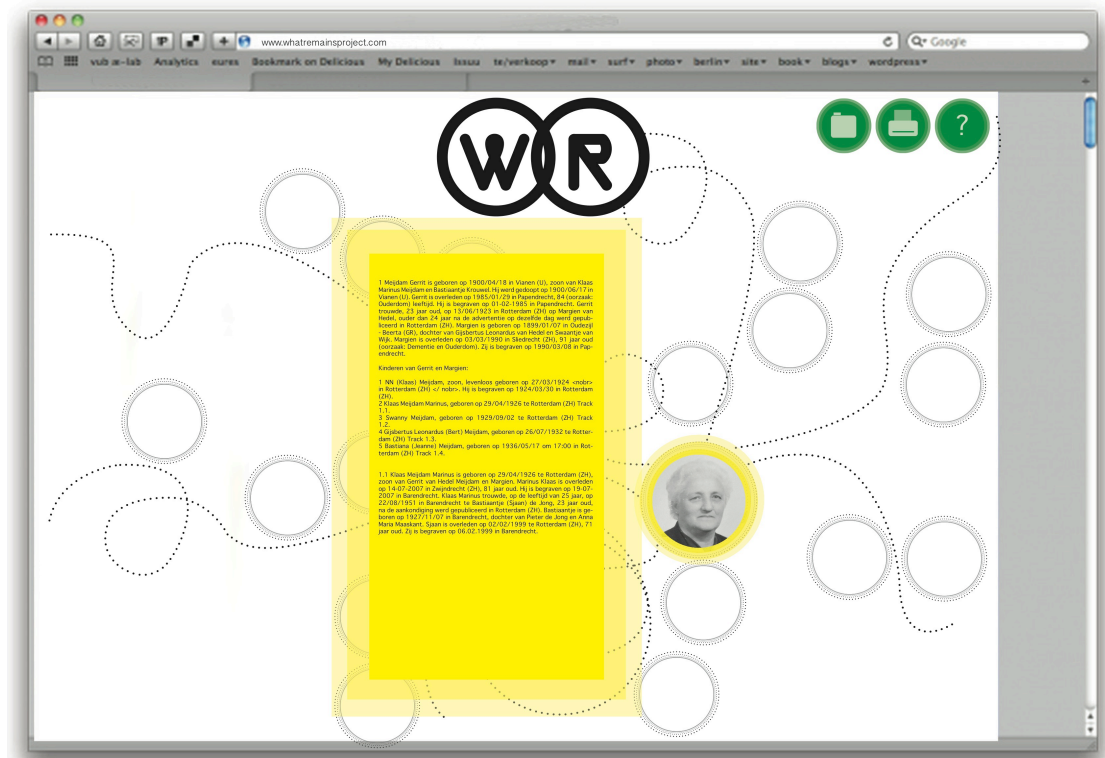


Figure 1: *What Remains?* Computer application

The second phase only starts once the patient's relatives finish uploading the majority of the pictures and information related to the patient's life. The relatives and the carers make a selection of 40 to 50 pictures based on the scenario offered by the application, which allows the pictures to be selected one by one from the categories and printed in a circular shape. The pictures are then cut out and inserted into the game's twenty spheres, which become the triggering elements for the elderly patient, their relatives and carers. The shape and materials for the game's spheres were designed as a result of the multiple co-creation sessions, where abilities and deficits of the patients were tested to create a triggering, playful experience. For example the game pieces increase the visibility of pictures that had been inserted, as the glass spherical shape magnified the pictures' size.



Figure 2 and 3: *What Remains?* Table game elements

Conclusion

"What Remains?" generated meaningful changes to the lives of the patients as well as their carers, who took full part to the design research and tested the prototype. From the side of

the professional carers it was immediately noticed how a deeper understanding of their patients could be beneficial for their work, due to the meaning added by a better understanding of a patient's tacit needs. The care home could in fact become a more human environment, incorporating at the same time a better, easier and more effective delivered service.

Looking at the side of the elderly's relatives the improvement was surprising, as they started to perceive the importance of their role in the cure of the patients. *"What Remains?"* changed – by simplifying - the communication channel between elderly and their relatives becoming a meaningful activity to share within the whole family.

Last but not least, this activity proved to stimulate dementia patients, strengthening at the same time the bond with their loved ones. Of the same importance are also the improvements that patients can self-generate by respecting their own dignity and personal attitudes without conflicts and oppositions that led to negative behaviours.

Finally, thanks to a multidisciplinary approach to the research project it was possible to meet some of the real needs of dementia patients and the health care environments focusing on older people. As Ezio Manzini (2011) stated, in order to stimulate and establish collaborations between the different subjects, the designer's role was fundamental: "Traditionally, designers have been seen and have seen themselves as the only creative members of interdisciplinary design processes. In the emerging scenario this clear distinction blurs, and they become professional designers among many non-professional ones. But even if this distinction blurs, it does not mean that the role of design experts is becoming less important. On the contrary, in this new context, design experts have the crucial function of bringing very specific design competences to these co-designing processes. That is, they become a particular kind of process facilitator, who uses specific design skills to enable the other actors to be good designers themselves."

For designers, and especially those working in sensitive areas such as the one of Dementia, sensitivity and humility are important attitudes that help them to create trust and respect, both important pillars able to support collaborations between different people with different knowledge and difficult life experiences.

In conclusion *"What Remains?"* demonstrated to be a significant co-design project, where Real life stories and intense collaborations with patients, their relatives and caretakers, could generate important Ethical value and life benefits.

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