1 'What Remains?': A Persuasive Story Telling Game

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Abstract "What Remains?" is a prototype that facilitates the intake of Alzheimer's disease suffering patients in care homes. The prototype evokes storytelling of the patient using pictorial game-elements and is based on cocreation principles involving the patient, the patient's family-members, and a caregiver. "What Remains" consists of three interactive consecutive phases. In the first phase, family members of the patient collect pictures which are expected to be of importance for the patient. During the second phase the patient configures and connects the pictures while telling stories about them. In the third phase, the stories are used by the caregiver to enhance understanding about patient's behavior and to personalize care giving. Additionally, the stories are used by the family members of the patient for remembrance purposes. The present paper describes the "What Remains" prototype, its design process and its evaluation from the perspective of the Persuasive Game Design model.

1 Introduction

'What remains?' is a design research project within the CRISP G-Motiv project that investigates how to change human behaviour by designing game elements. In 'What remains?' the challenge was to playfully persuade patients suffering from Alzheimer's disease (AD) to tell stories of the lives that could be used to facilitate the care home intake procedure and to personalize caregiving.

The context of the project consisted of nursing homes for older people, which was for this project represented by nursing home Careyn in Brielle, the Netherlands. Older people typically enter these homes when they cannot live independently any longer. Often this home will be their last. Many of the older people that enter nursing homes suffer from AD, which often is the cause for the impossibility of independent living. AD is a brain disease that is positively correlated with age (Brookmeyer, Gray, & Kawas, 1998). Since

aging is expected to rise globally over the coming years, the number of people suffering from AD will rise as well. AD is the most common form of dementia, and is characterized as an incurable brain disease that is progressive over time. Symptoms of AD include cognitive impairment, of which memory loss is the most notable, as well as behavioral impairment (e.g. being unable to perform functional daily life activities or, in a severe stage of AD, being unable to move or eat at all). AD impairs communication abilities of the patient with regard to object naming, discourse-coherence or production (Egan, Berube, Racine, Leonard, & Rochon, 2010).

The difficulties in verbal communication between AD suffering patients and care givers affect the mental burden of the caregivers (Savundranayagam, Hummert, & Montgomery, 2005), and problematizes the care giving process as a whole (e.g. "They [the patients, red.] are unable to follow even simple directions"; "It's difficult to get them [the patients, red.] to the tub room ... you have to lie" (quotes from caregivers of AD suffering patients by Richter, Roberto, & Bottenberg (1995)).

After several interviews with Marja Dijkwel, manager at Careyn, it was clear that memories play a very important role in the life of the patients living in care home. Mrs. Dijkwel experienced from observation that elderly with Dementia spend most of their life inside their own memories, completely disconnected from the present and everything around them. The sharp contrast between the patient experienced real world of the care center 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 . From several observations at Carey Care Home it was clear that negative emotions can deeply influence the behaviours of AD's patients and that, for this reason, caretakers and relatives have many difficulties in finding a suitable communication channel with them.

Moreover, communication between the caregivers and the patients is not only problematized by the impaired communicative skills of the patients but also by the lack of available personal patient information when the patient enters the nursing home. Our pre-study interviews with caretakers revealed that they observe the patients for six weeks after their entrance in the nursing home entrance to write a digital dossier about the patient. After this observation part, the caretakers need an average time of about six months of patient contact in order to get to 'know' a patient, to understand his/her behavior and to align their communication with the patient. We expect that when personal patient information (e.g. family, work, important life events, hobbies, etc.) is provided to the caretaker early during the intake process, the communication between patient and caregiver will be improved resulting in better care (understating of patient actions and optimizing communication)

and in less burden on the part of the caregiver. In this paper, we'll present a co-creative (Sanders, 2000) user centered prototype that provides this personal information to the caretaker by persuading the patients to tell stories about their lives.

For the design process we rely on the Persuasive Game Design model (Visch, Vegt, Anderiesen, & vanderKooij, 2013). This model is constructed around the experience of the user, i.e. the older person suffering AD. This person has a socalled real world experience consisting of communication impairment during contact with the caregivers. By gamification of the communication through the application of motivational game elements, we aim to let the elderly experience a game world that is *enjoyable*, *engaging*, *safe*, *free*, *and provides direct feedback*, which motivates the patient for storytelling about his/her life. We aim to realize transfer effects by applying the told stories in the 'real-world' care giving process – see Figure 1.

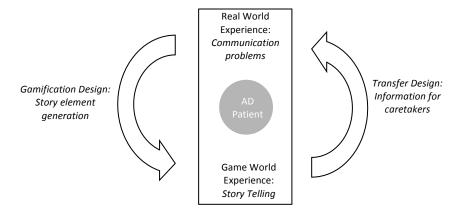


Figure 1: Application of the Persuasive Game Design model on the "What Remains?" case.

2 Design process: Workshops

For the "What Remains?" project we collaborated intensely with nursing home Careyn, design agency Monobanda, Design Academy Eindhoven, and the Industrial Design dept. of the Technical University Delft. The collaboration consisted in a series of in-depth interviews and co-creative workshops involving designers, patients, patient's relatives, and caregivers.

A total of ten workshops involving five diagnosed severe AD patients, four caretakers ,the manager of Careyn and fourteen families members, were organized during the morning since the elderly were more calm and active during that time of the day. During the workshops we realized how sensible the patients were to their social environment, especially to the moods and behaviors of people who surrounded and approached them. In order to create a pleasant and comfortable atmosphere during the workshops, the number of participants was limited to the following four: one elderly with severe AD, one of the elderly's relative, a designer (the first author), and a caretaker. Every workshop started with a cup of coffee, soft delicate tone of voice and smiles, after which we slowly started the workshops. The workshops were structured as follows: in the first workshop we investigated probes for storytelling. In the second and third one, the family members of the patient collected pictures from private photo albums and from the internet that were expected to be of importance for the patients. Over the next five workshops, the pictures were printed and presented to the patient to test their motivational effect on storytelling. Participation of the elderly's family members in the workshops was crucial for the understanding of the stories based on the images combined by the elderly. In the last two workshops, the final design of the story telling game was discussed. At the beginning the workshops lasted for twenty minutes, whereas the last ones lasted almost one and half hours due to the constant growing engagement of the various patients.



Figure 2: First picture: Impression of one of our participating patients configuring story elements. Second pictures: two pictures that were used during the evaluation.

3 'What remains?' – prototype and evaluation

The prototype is a mixed-media gameful storytelling tool that involves the following three interactive and consecutive phases: (1) a computer application for generating story elements, (2) a physical table game for connecting these elements into stories and (3) a diary that captures the stories and will be used by the caretakers and relatives.

- 1. For the computer application, relatives of the patient were asked to collect pictures that relate to the life of the patient. 'What remains?' proposes the following pictorial categories that may be extended by the relative: family, jobs, hobbies, pets, favorite food, religion, things they did not like to do, things they do like, holidays, memories. In addition to the relatives, the caretakers are invited as well to collect pictures, for instance regarding objects which are frequently mentioned by the patient or which seem to provoke restlessness to their patients during the day. The software "Mindset", a digital mind-map and brainstorming application developed by Monobanda, was used to upload the pictures. All uploaded pictures are accessible by the relatives as well as by the caretakers.
- 2. A selection of 20 pictures is made by the relatives and the caretaker. These pictures are printed in a round shape and inserted into tangible spherical objects with a diameter of about 8 cm. The spherical objects increase attention to the pictures by enhancing their visibility and 'liveliness'. They are made of a transparent plastic/glass material and contain a slot to insert the picture see Figure 3. In addition to these 20, a picture of the patient is inserted into a slightly larger round transparent object. All objects, 20 pictures plus patient, will be placed on a table in front of the patient and they serve as the motivational game-element for storytelling. The images in this context becomes the game elements that motivate communication. The patient will move, group and connect these pictorial elements and this interaction motivates them to tell the stories that connect the pictures. The caretaker might prompt the patient for storytelling by asking for the reasons of the made pictorial configuration. "What Remains?" allows a high level of control to players but the stories and outcomes are unpredictable and a little bit out of control. This triggers elderly relatives and caretakers in understanding AD patients thoughts and autobiographical stories buried in the patients minds.
- 3. The story telling sessions are captured by the caretakers and relatives in a diary: a small booklet that is provided by the prototype. The caretakers can

analyze the diary afterwards to personalize the caregiving process and diary will serve as a remembrance for the relatives of the patient.









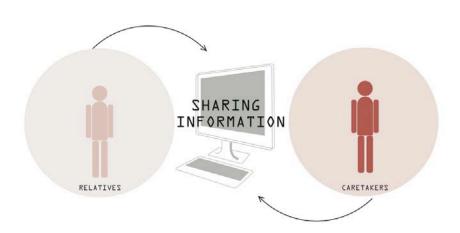


Figure 3: Top picture: What Remains? Table game prototype.

Bottom pictures: Info-graphics computer application

4 What remains?' - evaluation

During our evaluation of "What Remains?" the elderly combined the same pictures over and over again. At the beginning it was difficult to understand the intimate meaning of their choices, however with the help of their families it has been possible to translate the images into real stories. The evaluation resulted in several stories.

In order to explane the value of the prototypes we present the following two stories – see Figure 2 for related pictures.

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 very difficult for the caretakers to understand the reason behind her behavior. During a few story telling 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 bought 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 behavior and started to become calmer.

Another patient suffering from a severe stage of AD combined the picture of a guitar together with a picture of her family and a picture of her home. She was often trying with to explain something about this combination but could not find a way to express her thoughts. After several story telling attempts it was possible to understand that she was trying to inform us that she did not play the guitar, but the ukulele and she was used to play it together with her family when she was a kid. With this important information the nursing home provided a radio to the patient, that could play a playlist of Ukulele based songs at request.

5 Conclusion

'What Remains?' shows that persuasive game design can be successfully applied to motivate people suffering from AD for storytelling which can be effectively used to increase caregiving. The used pictures represent important elements/ events of the patient's life as a kind of personal pictorial 'alphabet' for storytelling. By presenting the pictures to the patient, the patient will enter the world of memory and is able 'play' with the pictures as story elements in a Cailliosian paidiatic sense: the magnifying glass represent the pictures in a slightly hallucinating perceptual manner contrasting from the actual perceptions of the care clinic and motivating the patient to enter their world of memory. Moreover, the tangible objects containing the pictures motivate the patient to connect the pictures matching memories of life events (that can even be understood as being narrative in structure c.f. Bruner, 1991). Both design features of the 'What Remains' objects, the perceptual story world-representing magnifying glass and the tangible story connecting elements are expected to cause the found motivation of the patients to tell and share stories of their lives during the gameplay.

The co-creation aspects of 'What remains' is expected to improve the patient's self-efficacy since the patient has the leading role during the interaction: only the patient can make the correct configurations and explain them. Additionally, for the family members of the patient the processes of picture selection and story generation creates a new channel of communication with their relatives, generating a deeper involvement within the nursing home's life and caretaking process. This game is a ultimately a shared activity, designed to stimulate a physical and emotional closeness between elderly with AD, their relatives, and the caretakers.

Our evaluation showed that storytelling led to adaptation of caregiving (providing extra shoes and a radio decreased patient's restlessness) leading to a more personalized care approach. During the early stage of the project the caretakers already indicated the use of personalized care as "the best approach that Careyn was aiming at", since this enhances the patient's quality of life even in the last stage of Alzheimer. However, in order to personalize the care, the caregivers need to have personal information about the patient. "What Remains?" offers this information. Summarized, the transfer effect of 'What Remains' consists of tailored caregiving, increased

social relatedness between patient, family members and caretaker and eventually increased self-efficacy.

In the present research we only tested the potential of these transfer effects which was successfully. A large scale evaluation study, involving more patients and different care homes institutions should be carried out to validate the transfer effects and the precise motivational effects of the used game-elements. We think that "What remains?" has generic applicability in that it is not limited to be used in the intake process of AD suffering patients but it can be used in any context in which shared personal information is at stake. For instance, "What remains?" may be beneficial for intake of patients suffering from anxiety disorders or trauma's, but it might as well be successfully used to persuade children or adults with communication impairments such as aphasia to tell stories.

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