“What Remains?”: A Persuasive Story Telling Game to facilitate Alzheimer patient intake in care homes

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Abstract “What Remains?” is a prototype that facilitates the intake of Alzheimer patient in care homes. The prototype generates storytelling and is based on co-creation principles involving the patient, the family-members, and the care givers. “What Remains” consists of three consecutive phases. In the first phase, family members of the patient collect pictures which are supposed 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 patients behavior and to personalize care. Additionally, the stories are be used by the family for remembrance purposes. The present paper describes the “What Remains” prototype and its design process from the perspective of Persuasive Game Design.

1 Introduction

‘What remains?’ is a design research project within the CRISP G-Motiv project that investigates how to design game element to change human behavior. In *‘What remains?’* the challenge was to stimulate storytelling of Alzheimer disease patients by designing game elements.

The context of this research project consisted of the nursing homes for older people, which was for this project represented by nursing home Careyn in Brielle, the Netherlands. Typically older people enter these homes when they cannot live independently any longer. Often this home will be their last. Many of the older people that enter the nursing home suffer from Alzheimer disease, which often is the cause for the impossibility of independent living. Alzheimer 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 Alzheimer will rise as well. Alzheimer is the most common form of dementia, and is characterized as an incurable brain disease that is progressive over time. Symptoms of Alzheimer include cognitive impairment, of which memory loss is the most notable, as well as behavioral impairment (e.g. unable to perform functional daily life activities or, in a severe stage of Alzheimer, being unable to move or eat at all). Alzheimer impairs communication abilities of the patient as well with regard to object naming, coherence or discourse production (Egan, Berube, Racine, Leonard, & Rochon, 2010).

The difficulties in verbal communication between Alzheimer patients and care givers affect the mental burden of the caregivers (Savundranayagam, Hummert, & Montgomery, 2005) as well as problematize the care giving as a whole (e.g. “They are unable to follow even simple directions”; “It’s difficult to get them to the tub room … you have to lie” (quotes from an explorative study by Richter, Roberto, & Bottenberg (1995)). Moreover, the 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 personal patient information available to the care givers when the patient enters the nursing home. Our interviews and workshops with caretakers showed that they use six weeks during the intake process in order to observe elderly with Dementia habits. After this observations caretakers have to write a digital dossier with all the information that they collected in six weeks based on observation. Despite these observations, the caregivers mentioned that it took at least half a year to get to ‘know’ a patient, understand the actions of the patient and to align communication with the patient. We suppose that when personal patient information (e.g. family, work, important life events, hobbies, etc.) is provided to the caretaker during the intake process, the communication between patient and caregiver will be improved resulting in better care and less burden on the part of the caregiver and patient. In this paper, we’ll present a cocreation based prototype that persuades patient to tell stories about their lifes which will be used by the caregivers to enhance their understanding of the patient and optimize their communication to the patient.

For the present design aimed at improving client intake we will rely on the Persuasive Game Design model (Visch, Vegt, Anderiesen, & vanderKooij, 2013) developed by G-Motiv. In this model the user experience is the core of the design process. The user is in this case the older person with Alzheimer disease. 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 bring the elderly into a game world experience that is *enjoyable*, *engaging*, *safe*, *free*, *and it provides direct feedback*, and which motivates them for storytelling. We aim to realize transfer effects of the story telling to the real world in terms of information sharing with the caregiver and adaptation of care– see Figure 1.

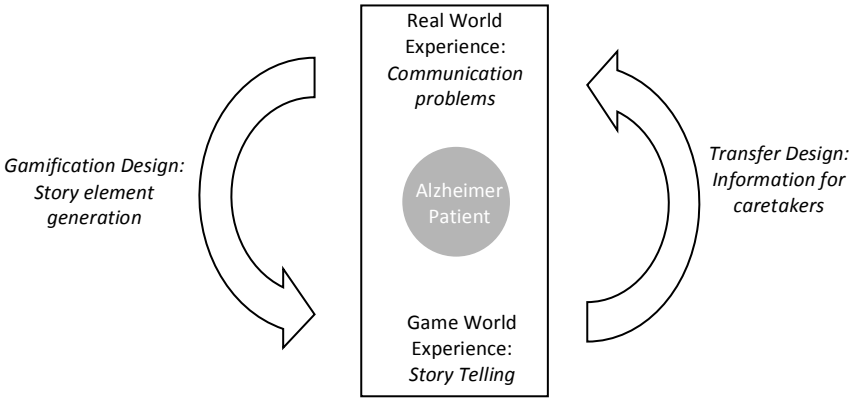

Figure 1: Persuasive Game Design model on present case.

2 Design process: Workshops

For this "What Remains" project we collaborated intensely with the nursing home Careyn, design agency Monobanda, Design academy Eindhoven, and Industrial Design dept. of the Technical University Delft. The collaboration yielded support for in-depth interviews and co-creative workshops between designers, patients, patient's relatives, and caregivers and elderly with Alzheimer's relatives. The ten workshops and co-design sections were organized during the morning since the elderly were more calm and active during that time of the day. It was decided that a number of three to four participants would have been appropriate. This decision was made to create a pleasant atmosphere that could make the patient comfortable, avoiding any form of anxiety-related feeling. The participants were: one elderly with severe Dementia, one elderly's relative and a designer. Furthermore, when possible, also a caretaker was taking part. immediately realized how Elderly with severe Dementia are normally very reactive and sensible to their environment and also to the emotions and behaviors of people who surround and approach them. Every co-design section used to start with a cup of coffee and soft delicate voices and smiling faces, after which we slowly started the workshops. The workshops consisted of the following content: in the first workshop we investigated probes for storytelling. In the second, the family members of the patient brought pictures that were supposed to be important for the patients. The pictures were presented to the patient to test their motivational effect on storytelling. In third workshop, not only to the research and concepts but also to the final design of the story telling game, including the appropriate materials for the realizations were discussed.

At the beginning the co-design sessions were twenty minutes long, while the last

one lasted almost one and half hours, due to the constant growing attention of the various patients. The participations of the elderly’s family members was fundamental for the understanding of the stories based on the images combined by the elderly. Furthermore, during the last phase of the project, the co-design method was extended non only to the research and concepts but also to the final design of the story telling game, including the appropriate materials for the retaliations.

Image 1-2,3: The first real story, pictures

3 What remains? – prototype and evaluation

The Prototype is composed of three elements: a computer application for generating story elements, a game for connecting these elements into stories and capturing and using the stories.

1. For the computer application, relatives of the patient are asked to pictures and life information about the patient. The pictures are divide in different categories: family of origin, new family, jobs, hobbies, pets, favorite food, things they did not like, thing they did and do likes, holidays and trips, memories. The caretakers are invited as well to upload pictures for instance regarding objects that are frequently mentioned by the patient or which provoke restlessness or negative behavior to their patients during the day. "Mindset", a digital mind-map and brainstorming application developed by Monobanda was used as a basis for this application. All uploaded pictures are accessible by the relatives as well as by the caretakers.

2. A selection of 25 to 30 pictures is printed by the caretakers on tangible spherical objects with a diameter of about 8 cm. Additionally, a picture of the patient is printed as well on a slightly larger spherical object. These objects will be places on a table before the elderly and serve a game-element for story telling, in the presence of the caretaker and family member. The elderly will move, group and connect these pictorial elements and though these interaction they will be provoked to tell stories connecting the pictures. If they don't start telling stories themselves, the caretaker might ask the elderly about reasons of their pictorial story element configurations and in this way provoke the elderly to storytelling.

3. The storytelling event consisting of verbal storytelling and picture configuration is captured by a digitally recording device inside the spherical object with the picture of the patient. This captured story can be used by the caretaker to analyse after the event and by the family member for remembrance of the older person.

4 What remains? – evaluation

During our evaluation of "What Remains?" the elderly to combine 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 in real stories. The evaluation resulted in the following two stories – see Figure 1 for related pictures.

A lady affected from a severe stage of Dementia 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 pictures of shoes and the pictures of his father. After several days and with the help of her sister, we finally understood that their father bought two pair of shoes for all of his children. One pair was supposed to be use during the weekdays and the other 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 bad behavior and started to become calmer and relax during the morning.

***Another patient** suffering from a severe stage of Dementia was combining the pictures of a guitar together with the pictures of her mother, father, sister and brothers and a photo of her home. She was often trying with to explain something about this but could not find a way to express her thoughts. After several stimulations 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 at use of the patient, where a playlist of Ukulele based songs was played at request.*

Image 1-2,3: The first real story, pictures

5 Conclusion

“What Remains?” showed that persuasive game design can be successfully applied to motivate people suffering from Alzheimer disease for storytelling and to generate material to increase caregiving. The gamification consisted of generating pictorial tangible elements that persuade the user to configure and tell – comparable to an pictorial ‘alphabet’. Moreover, the co-creation aspects adhered to the motivation of the user as well. The experience of being useful functioned as motivational self-efficacy related trigger that stimulated elderly with severe Dementia and their family members to use the “What Remains?”. Our evaluation showed that storytelling results led to adaptation of caregiving (providing extra shoes and a radio decreased patient’s restlessness) leading to a personalized care approach. During the early stage of the project the caretakers already indicated the use of personalized approaches as “the best approach that Careyn was aiming at”, since this is supposed to enhance the quality of life of the patient, even in the last stage of Alzheimer. However, in order to personalize the care, the caregivers need have personal information about the patient. “What Remains?” offers this information. For the family members the stories create a new channel of communication with their relatives, generating a deeper involvement within the nursing home’s life, as they would become an important active part of the game.

This game is a finally a shared activity, designed to stimulate a physical and emotional closeness between elderly with severe Dementia and their relatives.

We think that "What remains?" has generic applicabilities in that it is not limited to be used by Altheimer patients but can be used by in any context in which personal information is of value. For instance, "What remains?" may be beneficial for care giving during patient intake of in mental hospitals of people suffering from anxiety disorders or even trauma's, but it might be used to stimulate children or adults with communication impairments such as aphasia to tell stories.

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