## **INTERACT 2011**

# Promoting and Supporting Healthy Living By Design

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### Analysis, Design and Evaluation of an Interactive System to Support Dementia Patients and Integrate Carers

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**Abstract.** mobileWAY is an application for both tablets and smartphones which enables carers of dementia affected persons to remotely display dynamic, customized and illustrated information directly on the television of the dementia patient. In particular, mobileWAY enables caregivers to provide information about their identity, their whereabouts and the time remaining until they return to the home of the patient and thus supports dementia patients at home in situations of temporary lonesomeness and absence through information.

Keywords: Dementia, AD, Older adults, HCI.

#### 1 Background

In 2025 every fourth European will be older than 60 years [1]. This number is immense and will continuously grow in size in the upcoming decades. Nowadays, senescence poses a threat to the already limited capacities of medical health care systems and economically exhausted governments. Age-related, long-term chronic conditions are both psychologically burdening and financially challenging for the patients and the caregivers. Since the number of cases are expected to double every 20 years [2], dementia, one of the most common chronic conditions, is going to play a significant role in the caregiving management of the 21<sup>st</sup> century worldwide.

Innovative use of technology may have the potential to bridge the gap between exploding costs of long-term caregiving and assisted living at home of a dementia patient. To improve this situation, this paper presents the development of mobileWAY (mobile Where Are You), an interactive system to support early stage dementia patients and their families in a home caring environment.

#### 2 Understanding dementia-affected persons and their carers

This project reviewed the state-of-the-art regarding dementia affected persons, their technology affinity and existent skills and furthermore benchmarked the available solutions and research projects around the scope. Exploratory interviews with 9 informal and 2 professional caregivers, respectively totaling 213 and 80 minutes of audio record, enhance and complement the theoretical research and outline a broad bandwidth of problems of dementia patients and their caregivers while living together and dealing with the disease.

The user research revealed that dementia affected persons are most of the time older adults [60+] with a late dementia diagnosis and multiple other age-related diseases. Furthermore, concealment of the disease causes a loss of hobbies and social withdrawal. Technologicallywise, the television is the only widely known and accepted device in the dementia patients' environment while the ability to use a phone – if existent – gets lost early.

Regarding the caregivers, the user research outlines major life changes when a dementia case appears. Struggling psychologically- and socially-wise on one side in between preservation of their own responsibilities in life e.g., school, job, hobbies and friends and taking care of their ill family member on the other side is a problem. Therefore, continuous stress and emotional problems while coping with the new situation are observed. Also the fear of leaving the patient temporarily alone is one of the main causes of caregiver distress.

Additionally, the research indicates that family members in home caring environments organize their life around the patient and rarely forget disease-related tasks or appointments due to the use of phones as well as paper calendars and notes.

#### 3 Support patients and integrate caregivers: mobileWAY

The outcomes of the user research shaped design alternatives which concluded in an interactive and integrated system for caregivers and relatives. It is nearly impossible to introduce an "alien" artifact to a dementia patient - e.g. a smart-phone - since the current generation of dementia patients has little experience with information technology besides of the television and occasionally regular landline phones.

In this context, the television offers limited, but unexploited possibilities as a passive interface to support a dementia patient in cases of temporary lonesomeness. In broad, the general idea of the solution consists of using the television to display dynamic, customized and illustrated information in the house of the dementia patient in situations of temporary lonesomeness (Fig. 1).

The information displayed on the television is defined by the caregivers in "mobileWAY", an application that enables carers to display very simple information about: i) who they are (provided by her name and portrait), ii) their whereabouts (illustrated by a picture of the place or activity they are occupied with); and iii) the time remaining until the caregiver is back in the house of the patient (due to a dynamic time metaphor). Organizational helps, even if secondary, are considered by offering multi-caregiver accessible calendars, To-Do lists and a Forum for exchanging themselves (Fig. 2).

Follow-up usability tests with 2 dementia patients and 4 caregivers indicate patientsidewise partial to full comprehensibility of the information displayed on the television. Memory stimulation due to association and usage of real images of locations and persons of their individual environment is also observed.

Caregiver-sidewise, usability tests revealed high effectiveness and efficiency in using the system controllable from a mobile tablet or smartphone and also reported that the solution would likely improve their life as well as the life of their dementia-affected person.



**Fig. 1.** mobileWAY for a dementia patient.



Fig. 2. mobileWAY for a caregiver.

#### 4 Conclusions

The avoidance of adopting new hardware within the dementia patient's home, little to non-existent acquisition costs of additional infrastructure as well as a small amount of training or other prerequisites of either the patients or the caregivers are positive characteristics of the designed and tested solution.

Moreover, the involvement of caregivers in the patient's tests has been as a valuable addition for the conduction of usability evaluations with dementia affected persons and is a side result of this work. By way of illustration, a high-fidelity tablet interface of mobileWAY has been created. Ultimately, a demonstrator video [3] visualizing the possibilities of the system in a typical use case completes this project.

#### References

- 1. ENABLE Newsletter, Volume 1, Issue 1, 3 (2007) URL: <a href="http://tinyurl.com/6k2yvvi">http://tinyurl.com/6k2yvvi</a>
- 2. Alzheimer's Disease International: World Alzheimer Report 2010. The Global Impact of Dementia, 15 (2010), URL: <a href="http://tinyurl.com/3zbdkuv">http://tinyurl.com/3zbdkuv</a>
- 3. MobileWAY Demo, Fraunhofer Portugal (2011), URL: http://tinyurl.com/6duefm5