Improving Daily Life for People with Dementia – An Observation Study

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Abstract. Residential nursing homes will face an increasing percentage of People with Dementia (PwD). In order to understand the needs and desires of this user group, an observation study was conducted in a nursing home near Würzburg, Germany. The observation data, conversations with relatives and caregivers of PwD were clustered into an affinity diagram. The results showed basic needs of PwD, their daily life at a care facility, and problems they are facing. In this paper, we describe ideas for designing assistive technologies that encourage PwD to do exercises and to walk in a certain direction, which were expected to improve the quality of life of PwD.

1 Introduction

Due to demographic changes [1, 10], the number of People with Dementia (PwD) is increasing dramatically [9]. In Germany, the majority of residents living in nursing homes suffered from dementia [5].

To date, most technological approaches focused on people with mild dementia [7] and the use of touch screens [3], aimed at facilitation of caretaking [2] or security issues [6]. Our target group otherwise was people with moderate and severe dementia, who were living in a care facility, and were not able to use smartphones or tablets according to pilot usability tests. We focused on fostering PwD' independence, self-esteem and quality of life using user-centered approach, which got PwD involved in both gathering information phase and designing phase.

Our study was to determine the main factors, which impair PwD' daily life at the nursing home and to find designing ideas to counteract these factors. The data collected from this study was clustered using the affinity diagram method to find the critical and valuable aspects for designing process. The method is an enhanced way of brainstorming [4].

2 Methods

Setting: The study took place in a 26-bed nursing ward, where half of residents suffered from different stages of dementia.

Participants: We had 8 participants, who got dementia and had mobility. Their ages ranged from 82 up to 94 years. A statement of informed consent were given and signed by a family member or legal guardian of each participant.

Observation: Participants were observed by two bachelor students who had learned how to observe unbiased and were experienced in user-centered techniques. Two weeks of full-time ethnographic observations was conducted in October 2014. Observation continued in the following four to six weeks besides conducting another study, which focused on visual orientation cues.

The observers first spent two days for getting familiar with environment, caregivers, as well as letting PwD get used to their presence. In the following days, they started communicating with PwD as they slowly began to lose their shyness.

Collected Data: General behavior and procedures of activities of PwD as well as conversation data (with PwD, their relatives and caregivers) were noted down.

The observers also recorded participants' habits, likes and dislikes, biographies, typical daily routine, movement patterns (e.g. PwD moved faster when they were going to the toilet), and strange behavior. All of that information will be useful for the intelligent system to recognize current activity and state of PwD, and their intention.

Affinity Diagram and Design Ideas: Data was clustered using the affinity diagram method [4]. During the process, every fact about or comment from the PwD was written down on yellow Post-its® (first level). Each note needed to be understandable on its own. The notes were read through by two researchers independently to gain an overall understanding. After that, the data was clustered and grouped into higher levels (blue, pink, and green) by theme. For example, a blue note "I am restless" was moved to be near another similar blue note "We run around and interrupt our meals for it". The higher level of affinity notes contained information of all subordinate notes. The highest level groups (green) normally consisted of one or two keywords per category, e.g. "loss of personality". Finally, for further refinement and verification, the two researchers critically discussed and reviewed the diagram until they reached an agreement.

After finishing the affinity diagram, design ideas addressing the most important problems stated in the diagram were noted down. The most promising and innovative design ideas were worked on by iterative drafting and building of prototypes.

3 Preliminary Results

The observation data, which was clustered by the affinity diagram, showed following insights. On the subject of navigation and orientation, the data revealed that the PwD in the facility were unlikely to move to a specific location by themselves as they were always accompanied by a caregiver. They used the handrails on the sides of the corridors almost all the time, even when holding a person's hand or sitting in the

wheelchair. The handrails seemed to be an appropriate place to incorporate a navigational aid (*Handrails as Guides*). Due to existing hints that light could serve as navigational cue, the idea that the handrail with an LED-Strip emerged. The LEDs should be enlightened brightly in front of the PwD and deactivated after them in order to guide them in a primitive and effective way.

The PwD apparently did not engage in any activity by themselves except for dining. They sat around most of the time but seemed much more active when others started conversations with them. Also, they mimicked exercises during a weekly gymnastics session and sometimes imitated examiners' movements. They obviously needed to be activated by others, either through direct approach such as conversation and touch or passive approach by watching others being active. This was especially successful if the counterpart was younger and lively such as children, visiting dogs or the experimenters. The assumption arose that PwD liked these "activating counterparts" because PwD probably felt that these younger and less harmful counterparts would not judge, insult or scold them for behaving inappropriately. The PwD also reacted much more actively to movement such as people or animals running around or gesturing a lot while talking to or standing near PwD. These observations led to the idea of a human-like avatar presented as interactive video on the walls of the facility similar to existing exercise programs (*Gymnastics avatar*). In order to be successful, the avatar should create the impression that it would never judge a person with dementia for making mistakes. Instead, it should motivate PwD to join in their exercising to activate them. Furthermore, the avatar needs to address the people to refocus their attention. According to the observers' experiences, this is best done by doing movements and calling the person's name (e.g. "Mrs. Smith, come on, let's do some exercises). An avatar would allow PwD to do exercise independently at any time they want without a need for instructors or caregivers.

4 Discussion

As opinions of caregivers and relatives were sometimes contrary to observations made in this study, we believed that designing ideas based on information from caregivers and family members were not sufficient. We suggested that the end-users (PwD) clearly need to be involved in the designing and evaluating phase. Through the studies using user-centered approach, we tried to address PwD' needs and desires, and implement assistive technologies to solve those issues.

Our designing ideas addressed the need to activate the PwD doing gymnastics and to help them navigate in the facility independently. Other ideas concerning appropriate caretaking (i.e. ensuring appropriate hydration, medication and food supply) are being refined and built into prototypes. Those ideas will be tested and evaluated with caregivers and PwD.

5 Acknowledgement

We would like to thank the Bayerische Forschungsstiftung for funding the work presented in this paper.

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