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Creating Interactive Experiences together with People with Dementia – an Inclusive Design Story

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1. Abstract

As dementia will seemingly become one of the most common conditions in our aging world and no viable cure is on the horizon, novel forms of care focusing on the quality of life and well-being of people with dementia are needed.

In order to create such novel interventions, the Furtwangen University initiated an interdisciplinary student design course together with the LUCA School of Arts (Belgium) and the St. Cyriak dementia care home (Furtwangen).

This paper showcases the inclusive design approach with the aid of two notable examples, an interactive "seated dance" music system and an augmented Memory card game, to illustrate the course's results and the lessons learned.

In summary, the students have overcome interdisciplinary challenges, gained a broad understanding of participative User-centered Design and the close cross-institutional collaboration has laid the foundation for future projects. The designed systems are still in use at St. Cyriak's to this day.

2. Background

Being the most common form of dementia, Alzheimer's Disease finally leads to, among other things, severely impaired memory, communication and orientation functions (Alzheimer's Association, 2016). While there are efforts and plans to find a cure by 2025, no remedy has yet been found (Prince et al., 2015). Therefore, it is imperative to approach the situation in a "care now – cure later" way of thinking and focus on non-pharmacological interventions, as these might improve the quality of life and well-being of people with dementia (PwD) (Cooper et al., 2012).

Already having made positive experiences with the scientific project InterMem (Interactive Memories, see Klein & Uhlig, 2016), the Furtwangen University faculties Health, Safety and Society (HSS) and Digital Media (DM) started an interdisciplinary effort to co-design creative interactive systems for PwD together with the local dementia care institution St. Cyriak and experienced researchers from the LUCA School of Arts from Belgium. Groups of students from two entirely different faculties with varied focal points would work together with the "extreme" user group PwD and their carers to create unique quality-of-life-reinforcing designs to ultimately benefit all cooperating parties.

In order to ensure a common level of contextual and technological understanding, the practical part in St. Cyriak was continuously accompanied by lectures regarding the specifics of design for PwD.

3. Design approach and prototypes

Subsequent to receiving the theoretical input regarding the needs, characteristics and potential difficulties of the target group as well as the code of conduct, the students were given the opportunity to observe and experience (i.e. "deep dive" into) the daily lives of the PwD in St. Cyriak first hand.

After having built up a sturdy context-related knowledge foundation and a trusting relationship with the PwD, the proposed course of action was to adhere to the principles of Person-centered Care

(Kitwood, 1997) from the personal/social perspective and User-centered (Systems) Design (UCD) (Norman, 2013) from the design perspective (see Figure 1).

Hence, the PwD themselves and their (socio-personal) environmental factors were put into the center of the design process. The PwD and their caregivers were directly incorporated in iterative designing activities and workshops following the spirit of Participatory Design (Carroll & Rosson, 2007).

Figure 1. User-centered Design: Participating in "seated dance" (on the left) and drawing sessions (on the right).
(fig-1.jpg)

The diverse interactive products ranged from an augmented photo book, a memory (reminiscence) box, an activity plan and a "seated dance" music system to an augmented Memory game. Although all systems were good combinations of aesthetic, functional and social design, we have chosen two of them as notable prototypes to represent the practical high quality outcomes of the course.

The first group used a Makey Makey interface electronics kit (Beginner's Mind Collective & Shaw, 2012) to create a tangible surface that encouraged the PwD to engage in movement and with that independently play their favorite songs by foot- or hand-tapping on the sensory surface, whether being in a "seated dance" session or in front of the personal desk (see Figure 2). Hence, the system aimed to prevent future immobility of the PwD in the long run. The co-creative steps included a thorough observation of the environment of the PwD, insightful discussions with the PwD, creating an Empathy Map as well as sketches, electronics prototypes, music creation and Wizard-of-Oz-testing throughout the whole process.

Figure 2. Interactive Makey Makey music system: Sketching (on the left) and user testing (on the right).
(fig-2.jpg)

The second notable project (see Figure 3) was an interactive music version of the popular "Memory" (aka "Concentration") card game with real haptic objects (i.e. wooden blocks) as cards. The prototype consisted of a Raspberry Pi micro-computer, a pair of speakers and a camera used to optically detect paper code tags glued to the underside of the wooden blocks. The top sides of the blocks showed engraved graphics of potentially meaningful themes for the PwD (e.g. Black-Forest-related cuckoo, mill, leaf and tree). If a block was placed on the camera device, it would play a matching sound. This system's basic idea was to foster the cognitive and haptic abilities of PwD. Similar to the first system, the creative team created (paper) prototypes, handcrafted the wooden blocks, prototyped the electronics, programmed the software and tested their final design in the dementia care institution.

Figure 3. Interactive Memory game: Prototyping (on the left) and final result (on the right). (fig-3.jpg)

4. Challenges and lessons learned

One of the biggest challenges was to be always patient and open for alternative solutions. Since it was unusual for the students to engage with PwD, the teams directly wanted to start to create prototypes for the first "points of attack" they noticed. Moreover, it was challenging to decide on which observation or problem they should focus as the next step.

Likewise, the interdisciplinary teamwork required a well-organized communication among the students. It was difficult to make appointments on which all members of a group could work together on their prototype since everybody had different schedules. As the close coordination between DM and HSS students was essential for the ongoing development of their prototypes, they had to "break through" the "classic" parts of their roles. E.g., the DM students had to accept to visit the care facility and interact with PwD on a weekly basis. Also the HSS students had to accept that they were confronted with technological problems. To solve the issues at hand, whether they were of technical (designing the triggers and coding) or of participatory ("How can we encounter PwD in an acceptable way?") nature, the students were encouraged to develop skills and know-how in completely new areas.

Throughout the process, achievements and positive experiences outweighed the initial difficulties. As expected, all teams encountered particular challenges in identifying working triggers that could activate as well as uphold the intended activity and motivation of the PwD. Eventually, the setbacks were compensated by positive reactions of the PwD as they laughed, sang along and engaged in interested conversations with the design teams. In order to further learn from their experiences and prevent the build-up of latent knowledge, each student wrote a final reflection concerning the lessons learned.

Regarding the above mentioned Makey Makey and Raspberry Pi projects, several design- and implementation-specific problems eventually occurred. To find songs that work well as triggers, several aspects had to be tested, ranging from music genre to the parameters of the tune (e.g. tone, harmony). The Interactive Memory game group found it difficult to define suitable game mechanics and to appropriately explain/convey them to the PwD. Furthermore, one of the most difficult tasks was the appropriate construction (e.g. regarding subtleness as well as robustness) and programming (e.g. camera-based recognition, audio output) of the prototypes.

As PwD are very heterogeneous individuals, their experiences and forms on the day had to be taken into consideration. The students had to learn to live with "certain uncertainties" and that there is no definite "wrong" or "right" when interacting with and designing for PwD. In addition, the students improved their social competency, learned how to approach the PwD and their caregivers in a highly empathic way and include the audience's needs into the design.

Last but not least, some important insights could also be gained regarding the cooperation with the dementia care institution. At the beginning of the process, the mere concept of using technology to augment the lives of PwD was not present in the carer's minds. Thus, they had to be brought close to and sensitized for the subject matter at first. Also, the high number of small "scattered" student teams posed a challenge, especially concerning the setup of the design and the evaluation appointments. In one particular case, a PwD's relative, who came to visit his loved one and saw the design team testing him,

seemed to be a bit unsettled believing that his protégé was used as some kind of "guinea pig" – even though informed consent was obtained from all test persons.

In contrast, the final feedback from St. Cyriak was very encouraging: The caregivers perceived the cross-generational exchange as well as the resulting products as an enriching experience. Up to now, the prototypes remain in the institution for continuous use (and evaluation) with PwD and some of the students have pledged to further improve their systems.

5. Conclusion

In summary, the participating students learned to take the individual needs and personal traits of real-world PwD into consideration and thus identify potentially meaningful starting points for their designs. The initial ideas were developed in participative drawing, modeling, discussion and narration sessions together with the actual target group as well as their caretakers. With that, a change of perspective between all design process stakeholders could take place, leading to a better social understanding of the involved parties.

The essential need for participative collaboration with the target group (and also between the project group members themselves) became evident, as a high trust and collaboration level creates opportunities to effectively work together, but also have fun as well as gain appreciation for each other. Reciprocally, fun and appreciation are leading to mutual well-being, interest and a higher acceptance of the design product.

On the competency level, the student designers have developed a heightened problem solving capacity for the given context. They gained a better understanding of human-technology-interaction with the particular user group, learned to creatively think of alternative designs and ultimately to use all resources at hand to make the product better in the next iteration step. Additionally, the interdisciplinary project work, documentation and teamwork skills were also stimulated and new cross-institutional contacts were made.

As this particular course deepened the bond between the involved scientific and practical institutions (as well as their members), new inclusive design projects in the context of dementia care will hopefully be sparked in the future.

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