Since 2011, the Dementia Lab has been working in the space between design and care for (and with) people with dementia. In all of its iterations, the idea of design brings with it expectations. It is seen to inhabit a spectrum that places designers either as islands unto themselves on one end; the image of the designer as the “brazen hero, working in defiance of society” (Kvan 2000) on through to design being part of the consumerist machine (Papanek & Fuller, 1972) on the other. Looking to offer design alternatives within this spectrum, Papanek called for designers to take into account his/hers environmental, social and moral responsibility. More recently Victor and Sylvia Margolin (2002) suggested that design education has not given the attention it needs to or made changes to equip student designers to “to design for populations in need rather than for the market alone.” Along this same path is Nieusma (2004) who looks at the agency a designer possesses; the “designers’ ability to work in ways that confront dominant design outcomes and empower marginalized social groups”. It is this awareness of and involvement of marginalised groups that has continued to inspire and inform the design practice of the Dementia Lab in both our research practice as well as our educational one.

Much of our approach is grounded in participatory design. This link between marginalised or resource weak groups and participatory design (PD) is not surprising. Early forms of PD were highly political and ideological, striving to give marginalised groups such as workers, a say in their own work processes. Although many still feel that PD should
tackle the larger political issues or focus on collective action, others find an application domain for PD in smaller contemporary social or cultural issues (Steen, 2013). Steen suggests that it is not purely about politics but about ethics. He sees participatory design as the more ethical road for a designer involved in design projects to take and that the designer can and does make ethical decisions in their design process. This ethical positioning means that the designer is pre-occupied with “an accountability of design to the worlds it creates and the lives of those who inhabit them.” (Robertson & Simonsen, 2013, p. 12). A chance to be pre-occupied with a design’s purpose, users and context is what we offer our students our educational modules. This paralles what Van der Velden and Mortberg (2014) refer to as accountability; by training young designers to be mindful of power relationships, thinking about the ways participants are involved in design and reflect on how allocations of resources and method selection affects the participation.

We feel that combining this ethical perspective and furthering PD’s extension into other domains such as dementia is worthwhile. It furthers discussions into what domains, industries, communities, social groups and individuals can benefit from the type of real involvement that PD can offer.

When the Dementia Lab Event began two years ago as part of a design and education initiative supported by the Robert Bosch Foundation, our focus was initially on design education; raising awareness in young people (design students) of the potential for design to contribute to what contemporary care for people with dementia looks like and how it operates. However, since the first edition in 2016, it has grown to have a wider reach. Besides our educational focus, the event itself has grown to include participants from design educators and design students to industry professionals and designers of all backgrounds to design researchers and healthcare professionals.

What the Dementia Lab Event has become, is a place that continues the discussion about challenges designers face working in this area. In this second volume of the conference proceedings, Dementia Lab Event 2017: Stories from Design and Research, the authors represented as well as those who participated in the event actively debated, discussed and furthered the points raised by Papanek, Margolin and Nieusma. In these pages you will find papers reflecting on design’s taking a more active role in the social and moral issue of dementia (against, or better, in parallel with existing research on design working in a utilitarian way) and looking at how design research can be an enabler within the context of care and dementia. We are very proud of what the Dementia Lab event has become and are excited about future editions.

For more about the event, please see: http://www.dementialabevent.com
For more information about the Dementia Lab, see: http://www.dementialab.com
Make-Believe, Make-Feel, Make-Act. Truth and Deception in the Design for Dementia Care

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1. Overview of the Workshop

Residential dementia care is currently flooded with high- and low-tech interventions that aim to improve the quality and efficiency of care and to support the well-being of people living with dementia. Camouflaged doors reduce the need for physical constraints while securing safety. Sociable robots offer companionship and stimulation. Personalised photoprints on doors and other dementia-friendly design solutions support orientation. VR installations and nostalgic interior designs are expected to ensure meaningful and enriched experiences.

People with dementia are increasingly dependent on their social and material environment for care and retaining a sense of self. At the same time, many of the objects mentioned contain elements of make-believe. They can help caregivers respond to other realities that people with dementia regularly experience (e.g. by ‘going along’ with a person’s experience), but often they also involve the pro-active creation of different (e.g. ‘enriched’) realities for people with dementia. As such, these objects and environments are potentially deceptive.

The workshop discussed the proper place of material innovations that involve aspects of make-believe in person-centred dementia care. When can practices with these objects be seen as supportive of a person with dementia as a unique individual, and when do they count as deceptive or manipulative? What does this mean for the design of these objects?

The workshop started with a presentation, introducing the moral grey area around truth and deception in dementia care and five crucial values that are at stake when deceiving a person: the autonomy and the dignity of the person with dementia, the authenticity of his/her life and relationships, the possibility of trust in the social and material environment, and the integrity of caregivers and designers involved. These values were related to concrete cases on three levels:
Workshop: Make-Believe, Make-Feel, Make-Act. Truth and Deception in the Design for Dementia Care

› Make-believe: make/let a person with dementia think something that is untrue or that cannot be realised;
› Make-feel: have someone sense and/or feel ‘different realities’;
› Make-play: support interaction and play with and in ‘different realities’.

In a first interactive round participants worked in parallel groups on three different case-descriptions, involving objects with aspects of make-believe, make-feel and make-play respectively. They were provided with concrete tasks to help articulate and weigh the normative issues at stake with selected artefacts. In a second interactive round a layered case was discussed that involved all three levels: an imitation bus stop. At the same time, participants were invited to develop alternative design solutions.

Authors’ Bios

Ruud Hendriks (PhD Cultural Sciences, 2000, Maastricht University) published on inclusive approaches of people with Autism spectrum disorder and on normative aspects of a specialized form of clowning in dementia care. His research is situated on crossroads of Science and Technology Studies and Disability studies.

Ike Kamphof (PhD Philosophy, 2002, KU Leuven) published on networks of telecare in nature conservation and elderly care, and on assistive robotics for people with dementia. She specializes in the aesthetics and ethics of new media and technology.
What makes a good death for dementia patients?

M. de Haas¹, G. T. Jun¹ and S. Hignett¹

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Dementia is a terminal disease. The fear of suffering dementia may lead to many people signing an Advance Euthanasia Directive to make provision for health care decisions in the event that, in the future, he/she becomes unable to make decisions. However, Advance Euthanasia Directives are rarely adhered to in the case of dementia. This is because the symptoms of dementia conflict with the due care criteria; a person requesting euthanasia must be able to confirm this request at time of death and must be undergoing unbearable and hopeless suffering. Once dementia has been diagnosed, the euthanasia ‘wish’ can no longer be confirmed, and assessing suffering in a person with dementia is nearly impossible. Additionally dementia symptoms may include personality change whereby the person signing the Directive is no longer the ‘same person’. All these issues create great difficulties for physicians trying to support patient wishes in the Advance Euthanasia Directive; they are dealing with complex moral decisions.

This workshop explored the dilemma between having an Advanced Directive, and actually executing an Advance Directive using speculative design. This designed speculation proposes a solution: an implant that, once the conditions are reached that are described in your Advance Directive, triggers a swift and painless death (http://aed-plug.com/).

In the workshop three questions were addressed:

1. What factors, other than patient autonomy, should be considered for end-of-life decisions in dementia?

   Opinions differed greatly for this question. Was dementia really that bad? Shouldn’t we make sure people wouldn’t want to die? Participants felt that The Plug could be an option for those who wanted a choice, but it should not be obligatory.

   “Living with dementia doesn’t have to be negative – but I, for myself, would like to have a choice. And I, now at this point, don’t want to be that person [with dementia], no matter how happy I am going to be at that point, because that is not me.”

2. Who should be involved in making these end-of-life decisions?

   We debated the difference between a planned death and artificially keeping people alive. We discussed how secure a system would be if an AI would make these decisions.

   “You could hack the Plug... Kill them... Or keep them alive!”
Concerns were also raised about the possibility of changing your mind once the Plug was implanted

"the problem with the human heart and the human mind is that it’s not constant and we change our minds and I’m afraid that I might change my mind and someone is not going to [help me]”.

3. Is Design Fiction a useful tool to further this debate?

The speculation triggered interesting and relevant debate, but did not offer any solutions. It was clear that the speculation did help participants to understand a complicated moral dilemma.

Authors’ Bios

Marije de Haas is a PhD student with a commercial background in design. Her PhD studies are investigating if it is possible to have a good death in dementia.

Professor Sue Hignett is the Associate Dean (Teaching) and a fellow of the Chartered Institute of Ergonomics and Human Factors (FCIEHF), Certified European Ergonomist (Eur.Erg) and Chartered Physiotherapist (MCSP).

Dr Gyuchan Thomas Jun is Lecturer in Human Factors and Complex Systems and Chartered Ergonomist and Human Factors Specialist (C.ErgHF). He has been working in a broad field of participatory design, service design, design for behaviour change and system safety. He is a producer of two highly-engaging animations on systems thinking: Systems Thinking – a new direction in healthcare incident investigation; Two Contrasting Views of South Korea Ferry accident.
1. Overview of the Workshop

Manifestations of (at times) several different physical handicaps and diseases in addition to different types of dementia and isolation are among the main reasons for elderly people to enter long-term stationary care institutions. Since the ability to make decisions drops in the progression of the diseases, both the care staff and family members step in to decide in the name of the vulnerable. This applies not only to choices of furniture and interior design, clothing, and other commodities, but also to everyday life and leisure activities. Next to basic medical care, facilities fortunately take into account socio-psychological needs of the high-aged residents and try to satisfy them as much as possible. However, due to the lack of expertise, those institutions rely on the collaboration with designers, architects, gerontologists and other experts to fulfil the non-medical needs of the people in care. In order to design a successful product, designers cannot circumvent a direct exchange with people who are affected – which are both the staff and the elderly.
After drafting a possible design product according to the need of a fictive case, the participants had the opportunity to test it in an exemplary scenario depicting the interaction with accordingly affected people. The main question this workshop tackled is how to create the bridge between the designer, the institution and the consumers in need. In this workshop, the individual experiences of the participants with people with dementia have been discussed in relation to relevant criteria for a potential collaboration with the staff and residents of care institutions. Reflecting the participants’ experiences with the presented three fictive cases of people with different manifestations of dementia, factors and challenges when planning to design an appropriate, dementia- and facility-friendly product have been discussed and collected in the group. Those criteria, are for example the intersectionality of the affected people, biographical relevance, communication structures within the institution, hierarchical structures and most importantly, how the disease affects not only the perception, but also capacity to interact with and use a product. The workshop has shown the importance of participation of affected people in the design process in order to create tailored solutions helping people with dementia in their everyday life.

Authors’ Bio

Evelyn Duerschlag works on the intersection of participatory design and activation therapy in care facilities in Germany and Switzerland. Holding a degree in Art Education from the University of Essen, she was later among the first to be trained in Cultural Geragogy at the Fachhochschule Münster. She is the founder of Art for Care, a concept for participatory design, which is dedicated improving the life of people in care facilities by evoking collective urban memories.
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 further the creation of 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 “sitting 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 (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, Society (HSS) and Digital Media (DM) started an interdisciplinary effort to co-design creative interactive systems for persons with dementia 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 people with dementia and their carers to create 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 individuals with dementia.
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 people with dementia at St. Cyriak first hand.

After having built up a context-related knowledge foundation and a trusting relationship with the people with dementia, 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 persons with dementia themselves and their (socio-personal) environmental factors were put into the center of the design process. The people with dementia and their caregivers were directly incorporated in iterative designing activities and workshops following the spirit of Participatory Design (Carroll & Rosson, 2007).
The interactive products ranged from an augmented photo book, a memory (reminiscence) box, an activity plan and a “sitting 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 outcomes of the course.

The first student group used a Makey Makey interface kit (Beginner’s Mind Collective & Shaw, 2012) to create a tangible surface that encouraged the people with dementia to engage in motoric activities (e.g. within the scope of “sitting dances”, where people with dementia repeat sequences of rhythmic hand and foot motions introduced by the caregiver). With this, the persons with dementia could independently play their favorite songs by foot- or hand-tapping on the sensory surface, whether being in a “sitting dance” session or in front of the personal desk (see Figure 2). Hence, the system aimed at maintaining the mobility of people with dementia in the long run. The co-creative steps included observations of the environment of the individuals with dementia, formative and summative discussions with people with dementia and the creation of an Empathy Map, as well as sketches, prototypes, music and Wizard-of-Oz-testing throughout the whole process.
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 people with dementia (e.g. local Black Forest culture- and nature-related themes like a cuckoo, a mill, a leaf and a 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 persons with dementia. Similar to the first system, the creative team conceived (paper) prototypes, handcrafted the wooden blocks, prototyped the electronics, programmed the software, and tested their final design in the dementia care institution.
4. Challenges and lessons learned

The greatest challenges were to maintain a certain patience as well as an openness for alternative solutions when creating products for people with dementia. Since it was unusual for the students to work with this particular user group, they wanted to start creating prototypes for the first “points of attack” they noticed – without engaging in further thoughts. In the following process, it could thus become difficult to decide on which observation or problem the next step should focus.

Likewise, the interdisciplinary teamwork required well-organized communication among the students. It was difficult to make appointments at which time 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 people with dementia on a weekly basis. In the same line, the HSS students had to accept that they were confronted with technological problems. To solve the issues at hand, whether they were of a technical (designing the triggers and coding) or of a participatory (“How can we encounter persons with dementia in an acceptable way?”) nature, the students were encouraged to develop skills and know-how in 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 people with dementia. Eventually, the setbacks were compensated by positive reactions of the persons with dementia 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 reflection concerning the lessons learned.
5. Conclusion

In summary, the participating students learned to take the individual needs and personal traits of real-world people with dementia 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 created opportunities to effectively work together, but also to have fun and gain appreciation for each other. Reciprocally, fun and appreciation lead to mutual well-being, interest and a higher acceptance of the design product.

On the competency level, the student designers 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.
References


Authors’ Bio

Alexander Bejan is a scientific researcher and engineer in the area of Assistive Technologies at the Furtwangen University’s faculty of Health, Safety, Society.

Ramona Kienzler is a scientific researcher in the area of Applied Health Sciences at the Furtwangen University’s faculty of Health, Safety, Society as well as a former staff member of the St. Cyriak dementia care home.

Markus Wieland is a student researcher in the area of Digital Media at the Furtwangen University’s faculty of Digital Media and one of the student designers involved in the interdisciplinary design course described in this paper.

Matthias Wölfel is professor of Interactive Media at the Furtwangen University’s faculty of Digital Media.

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I see I see, what you don’t see

A. Coumans¹ and H. van Hoogdalem¹

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“All that has value, is vulnerable.” Lucebert¹

For the last two years, students from Minerva Art Academy have worked on portraits of people with dementia. By making a personal connection with their extraordinary models, the most personal and poignant portraits have come into being. The concluding exhibition offered a first glimpse into the confusing world of mostly alternating moments of clarity and emotion.

The project has an important educational value. In the project, not only the portrayal of a model is taken out of the context of the art academy and placed within social reality, but the students are also confronted with a very special model: a person with dementia. As a result, the students have to deal with the tension between their identity as a human being and their identity as an artist, between their social presence in the world of people with dementia and their artistic presence there as an artist. This tension lies at the heart of the project as an educational program. We expect that the students’ struggle, recorded in a number of video interviews, will be essential as part of their artistic identity for the rest of their lives.

The project also has important social value. The portraits work inside and outside of the care centers where they were made, as talking pieces that make the effect of dementia

¹ Famous Dutch quote from a poem of the poet Lucebert De zeer oude zingt (1974) Verzamelde gedichten, Amsterdam, De Bezige Bij, 2002
more understandable and easier to discuss. They have been repeatedly exhibited with exactly that intention. First within the care centers themselves, for the people with dementia, their environment, and the neighborhood. Then within an artistic educational context outside of the care centers, where the general public could get acquainted with the subject. Because the portraits in words and image testify to a personal encounter, the exhibition has a big impact on the visitors. In the coming year, the exhibition will also be held in a school of nursing, where art students and nursing students will enter into a conversation together about the different ways they as a professional relate to the person with dementia.

The project can also be evaluated as a research project in which the teachers, visual artist Herman van Hoogdalem and professor Anke Coumans research the impact of art on the institutional care context. Where a nurse wants to help and care for a person with dementia, an artist wants to meet that person and discover how he also encounters himself in that meeting (Coumans, 2017). In this way the arts bring another space into the ever-protocolled environment of the care institution, a slower space in which it is not necessary to immediately take action, and in which you have to dare to put yourself at stake.

This research is part of the larger study Designing the Social, in which the new roles, methods and strategies of artists and designers in social design transition processes are developed and described in institutional and public contexts.

**Authors’ Bio**

Within the research group Image in Context, professor **Anke Coumans** develops projects in which artists and designers give shape to new roles in a social, political, educational or intercultural context. The research group Image in Context is part of the research centre Art & Society, and is liaised with Minerva Art Academy, Hanze UAS, Groningen. More: hanze.nl/ankecoumans-eng.

**Herman van Hoogdalem** works as a visual artist and teacher at Minerva Art Academy (Hanze UAS Groningen). In 2009, he started to paint large portraits of people with dementia. The portraits became known in the Netherlands because they were exhibited (for instance at The Drents Museum), but also due to the broadcast of the complementary short documentary ‘Faces of Dementia’ (made by Herman van Hoogdalem and Gijs Wanders) on national television.

**References**

Sensory design for dementia care: 3 stories

A. Jakob¹, H. Manchester² and C. Treadaway³

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Introduction

The three stories told here represent results of three research projects investigating design for dementia care and its impact. Each of these individual projects (‘Tangible Memories’, ‘Sensor e-Textile’/LAUGH, ‘Multi-Sensory Environments in dementia care’) has been led by one of the three authors and received funding from the Arts & Humanity Research Council (AHRC) in UK.

With “Experimenting with sound” sociologist Helen Manchester reports on the impact of the ‘immersive sound’ rocking chair, created together with experience designer Heidi Hinder and computer scientist Peter Bennett. The chair provides the experience of nature for people living with dementia who might find it difficult to go outside. Its design emerged from the ‘Tangible Memories’ research project (tangible-memories.com). The project has been working on co-designing a set of new digital tools and explores how tangible technologies might be developed in a co-design process to enhance democratic community building and to engage residents in care homes in multi-sensory experiences.

In “Bill and Elaine’s story”, designer Cathy Treadaway shares her experience of co-designing a sensory blanket for a person living with advanced dementia who was chair/bed bound, almost blind and without verbal communication, and his carer. The blanket, developed together with textile designer Helen Watkins and computer scientist Stephen Lindsay, is one of the outcomes from the ‘Sensor e-Textile’ project completed in 2016 which is now informing current LAUGH design research (laughproject.info).
Within the latter, the research team is developing a number of playful objects that stimulate, engage, soothe and give pleasure to people living with the advanced stages of the disease. Methodologies involved include co-design and participatory Compassionate Design approaches.

“Paradise room” is a story about a care practitioner working in a care home in London which participated in research investigating the design and use of ‘Sensory Rooms’ – also called ‘Multi-Sensory Environment’ (MSE) – in dementia care. Designer Anke Jakob, together with occupational therapist Lesley Collier, explored how the performance and success of such spaces can be improved through design interventions to the benefit of care home residents, especially people in late stages of dementia, their relatives and care givers (kingston.ac.uk/sensoryroom). Based on the outcomes of the project’s ethnographic study, which included observations of environments and facilities on offer in 16 care homes and semi-structured conversation with care staff, the research team developed initial design guidelines on best practice regarding multi-sensory engagement of residents and sensory enriched spaces that meet the specific needs and preferences of people living with dementia, their families and the care homes they live in.

Experimenting with sound

**By Helen Manchester**

As an ethnographic researcher interested in lifelong learning, more tangible ways of knowing and stories, I wanted our work to acknowledge the different material and immaterial prompts, responses and forms of sense making that older adults engage in through recognising our connections to ‘things’ as well as people, to the evocation possible through visits to places, through smells and through music. I wanted the team to appreciate and encourage the creative acts of cultural collection and production through which people make sense of their own lives and identities and make connections with the lives of others. Through our developing relationships we hoped to enhance opportunities for older adults in ‘the fourth age’ to share and make sense of their lives and their sense of self now, and to think together about their possible future lives, perhaps better coping with the often intense feelings of loss and instability that they may experience as they move into and live in care home settings.
In a facility for those with more advanced dementia we were often greeted by residents asking us to ‘let them out’ or by others walking along the corridors with coats on or over their arms, looking to leave at the first opportunity. This is, of course, partly a symptom of their illness, but we also noticed a disconnect from the outdoors and nature for these residents, although these aspects of their previous lives were often discussed in conversations with us. For instance, Barry would discuss his cycling holidays and Enid her days out on the coast. As a result of these conversations and observations we worked alongside residents and staff to develop a prototype that enabled us to bring nature into the care setting, which we felt could be a therapeutic experience for those unable to get outside and experience nature first-hand. The prototype is an ‘immersive sound’ rocking chair that plays sounds from nature, music and poetry, played through speakers in the chair’s headrests, and activated by the rocking motion (Figure 1). As the residents gently rock and listen to the dawn chorus, or to crickets singing on a summer’s evening, their journeys of the imagination can rekindle past memories and help to assist story sharing.

Residents’ reactions to our prototype chair were varied and left lasting impressions on all involved. Margaret, a former pilot, spent some time exploring the surface of the chair through touch, commenting that it reminded her of the cockpit of an aeroplane. Then, listening carefully to the different sounds emitting from the speakers embedded in the rocking chair’s headrests, she identified a woodpecker and an owl’s call among the chorus of birdsong, and she even cooed back to the owl in reply. As she heard the rhythmic sound of someone walking on snow, she lifted her legs up and down in time, keeping apace with them and describing a vivid story to us about what was happening in her imagination: ‘The farmer’s on his way”. Jean, who usually doesn’t speak or sing, sat in the chair and sang ‘Rock a Bye baby’ from beginning to end, causing an emotional response from the care staff present. Further testing of the immersive sound rocking chair in additional settings has suggested a positive therapeutic benefit for those living with more advanced dementia through sensory engagement with the natural world.
Bill and Elaine

By Cathy Treadaway

Bill and Elaine lived near Swansea in South Wales. Their shared pleasure had been to walk together in the grounds of Abergasney House, an impressive historic building set in beautiful gardens. Even after Bill had been diagnosed with dementia their walks continued, until Bill became so disabled by the disease that he could no longer be taken out of the nursing home. The care staff in the home suggested to our research team that Bill would benefit from a sensory object to help calm him. His wife Elaine spent several hours every day in the care home and was keen to tell us about Bill’s preferences and provide a short biography to help inform the design process. In particular, she explained the pleasure Bill had walking with her in natural surroundings – particularly through the formal gardens at Aberglasney. He loved the trees and wildlife and Elaine longed to be able to take him back to the sensory experiences of nature that they had shared together.

Our research team focused on developing design concepts that would use embedded technology to provide highly personalised sensory experiences. Materials experts, computer scientists, engineers, textile designers, health professionals and carers were brought together in a series of co-design events in which the ideas were discussed, formulated and prototyped. Using the formal gardens as an inspiration for the layout of the surface pattern, fabric was selected with appropriate colour and stimulating texture and stitched to construct the base layer. The textile designer used specialist stitch and print skills to develop tactile embellishments including a stitched tactile fabric book, zippers, buttons and embroidered sections. Simple touch sensitive electronics were developed using a Touchboard microcontroller attached to metal clothing buttons to add nature sounds: birdsong, running water, wind in the trees etc. A textile designer with some understanding of electronics used conductive stitch techniques and snap fasteners to integrate the electronics into the base textile. The electronics were positioned in a leatherette pouch that could be removed from the blanket and wiped clean using antibacterial wipes; the base textile was fully washable.

Bill and Elaine were given the blanket and within twenty minutes the research team observed that Bill was able to deliberately reach out and touch the buttons to operate the sound (Figure 2).

Figure 2. The personalised sensory blanket (right), and Bill and Elaine using it (left).
(Photo © C. Treadaway)
Video recordings made at the time evidence that the textile immediately provided stimulation and interest. Elaine commented on how the blanket rekindled for the couple a sense of intimacy. Hand in hand they could go for a walk at Bill’s bedside and once again experience nature sounds together. For Bill, the sensory experience provided in the moment pleasure and for Elaine reminiscence of good times walking together. Elaine treasured the blanket and chose not to leave it in the care home but to take it with her when she visited Bill every day. It became a special activity that she alone shared with her husband.

The design for the blanket fits with the key components of Compassionate Design; it is personalised, sensory and designed to stimulate connection between Bill and his wife. The pleasure experienced was shared and their enjoyment together continued until Bill’s death. The textile remains as a treasured reminder to Elaine of their lives together and has become a memorial object that is helping her to come to terms with the death of her husband.

‘Paradise room’

By Anke Jakob

During my first visit, Lydia, in charge of coordinating and organising activities for the residents of a care home in London, took me around introducing me to other members of staff as well as to some residents. I immediately noticed her enthusiasm, empathy and passion for the residents she provided for and for her work. Proudly, she showed me the improvements she had achieved to make the communal areas more interesting and inspiring for the residents. However, she also voiced her frustration about numerous critical issues and the slow progress she was making in initiating change regarding the environment. She was particularly frustrated about the home’s ‘Sensory Room’, complaining about how this room had become nothing more than a ‘dumping space’, where unused furniture and other items were placed (Figure 3). Lydia knew that she and her colleagues would need to provide something better and talking to me seemed to have an inspiring as well as reassuring effect on her. Our lively conversation, a semi-structured interview using a questionnaire, about sensory enrichment and meaningful activities lasted more than 2 hours. It provided valuable insight, knowledge and data for our research. For Lydia, our meeting was the instigator to act – encouraging her to make this room an accessible and positive experience for her residents.
After 9 months Lydia invited me to visit again and view the newly transformed space what was previously the ‘Sensory Room’. During my first visit, the room had been cluttered with furniture and various items, some broken or dysfunctional. Although a spacious and bright room with direct access to the garden, its appearance was uninviting and confusing. Most of the time it was locked. The situation after the refurbishment had significantly changed to the better through few but effective implementations of suggestions I had made regarding the spatial arrangement during my previous visit (Figure 4). After decluttering, one side of the room was transformed into a pleasant lounge featuring wallpaper with a life size image of a 1950s kitchen and new, elegant furniture and curtains with colouring matching the colours in the image. As advised, a LED projector and a new sound system had been added replacing the low quality transportable CD player. Further, Lydia had plans to install a sensory enriched curtain for dividing the space and adding flexibility in terms of multiple use. The open door now invites the residents to stay and from here to stroll into the garden.
According to Lydia, feedback from residents has been very positive. Liked for its stimulating, yet calm and soft atmosphere, a destination has been created that is regularly frequented by the residents as well as staff members and relatives. It is often used for relaxation, helping to reduce agitation and stress. This applies not only to residents with dementia but also to residents with other mental health issues and Asperger’s Syndrome. Remarkably, the new room is not called ‘Sensory Room’ by the residents, rather ‘quiet room’, ‘beautiful room’, ‘lovely room’ etc. Lydia was particularly pleased about a resident who used to express his distress by shouting and abusive behaviour, and who feels better and calm when spending time in the new space. One day she was especially moved by his response to feeling overwhelmed and distressed as he said to her: “I cannot take it anymore; can I go to PARADISE ROOM now?”
Acknowledgement

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Authors’ Bio

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Beyond privacy – reflections on a self-study of technologies to support people with dementia

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1. Abstract
The impact current technologies have on the autonomy and privacy of people with dementia is highly debated. In this essay I go beyond these abstract concepts and reflect on the impact, or rather lack of impact, technologies had on my everyday life. In a self-study of a reminder app, a GPS tracker and a house sensor kit I undertook during my PhD project, I gained a new perspective that influenced both my research project and led to new impulses for design. The reflections and insights in this study can be relevant to both researchers or designers who are interested in novel views on the use of technology around dementia.
2. Reflections

Within this paper, I report on my experiences of using monitoring technologies made for people living with dementia, as a healthy participant. I reflect on the challenges and limitations of undertaking such a study as well as the insights I gained for my PhD project and my design work.

2.1. Have you ever read a paper about the ethics of technology for people with dementia?

If you are engaged in the subject, the probability is quite high. The topic of ethics and values might not be on the forefront when talking about innovation or current practice in this area, but debates are led. A strong focus is whether technologies can support independent living or might undermine autonomy. Monitoring technologies take a special place in this debate as they also touch on privacy due to their constant monitoring of health data, environmental data or behaviour to alert caregivers to potentially critical events. Is it acceptable for people with dementia to give up their right to privacy to gain more independence? Is human surveillance better or worse than technological monitoring? Are we just overthinking this and do people with dementia not care at all? It is likely that you have come across, thought about, and discussed any of these questions as part of your research work.
2.2. But do you know how these technologies make you feel?

Do you know what it feels like to give up your autonomy to some extent? Do you know what it means to respond to reminders you have not set yourself? Do you know what it feels like when your partner knows where you are every hour of the day? I do not mean, do you know what others have told you about, I mean do you know how these technologies make you feel? I do.

2.3. So, what did I do?

As an exploratory, initial study of my PhD project at the UCL Interaction Centre, I undertook a self-study of three devices made for people with dementia – a reminder app for my mobile phone, a GPS tracker and a house sensor kit. I am aware that there are more innovative and creative tools out there and in development, but I wanted to test what was commercially easily available. I wanted to learn how these considerations that I had read so much about played out in practice. I wanted to learn what it feels like. Each device was used for about a month and reflected on in free form, exploratory and openly – whenever something outstanding occurred. I noted down something at least once a day in the evening,
Figure 1. Screenshot of reminder app during study, own screenshot, 2016

Figure 2. Myself wearing the GPS tracker, own photography, 2016
2.4. Do I know what it feels like to live with dementia?

No. The study could not give me any insights into this and was not planned to do so. I know about dementia from academic literature and from caring for my grandmother when she lived with it. I am aware how individual, changing and personal this illness is. I did not try to mimic this experience during the time. I still do not know what using these technologies may feel like for someone with dementia. But I think there is little to suggest that their experience is very different from mine. Their reflection, their framing, their understanding might be different, but the experience might be similar. Not everything I experienced might be applicable, but at the same time it could not be suggested that people with dementia would not experience the anger, guilt and confusion I went through. Because in the end these were my main concerns about the technology.

I did not like to be monitored, but the intrusion was not as strong as I suspected. I trusted my partner to do the right thing and use the technology responsibly. Which he did most of the time. Until the point where he did not.
Until the point where I got angry and confused when unwritten rules were broken and he tracked me. Even though I was aware that this was an option I surprised both of us by the anger and anxiety I felt. He felt guilty. I felt guilty for making him feel guilty. I knew he was doing me a favour. I was angry nonetheless. That was not easy.

But the biggest concern was that I could not alter the technologies myself. When things went wrong, I did not know why. I was not even sure if something had gone wrong or if something was supposed to happen. I contacted my partner, who fixed it and then again: guilt. The technologies were overly complex by trying to avoid being complex. Battery status and connection with the satellite of the GPS tracker were indicated by blinking lights whose meaning I had not fully understood by the end of the study. Lights I found annoying, but did not want to switch off as they were the only indicator that the GPS tracker did anything. When I tested the devices, it became clear to me that the main reasons why I struggled with the technology were not abstract ethical concerns, but the lack of engagement with the device. It did not offer any tangible benefits but only promised protection from dangers I could not really imagine anyway. I am not so naïve about dementia that I do not fully understand that there will be in most cases a point at which people affected might not want to or might not be able to interact with technology. But the experiences during this study led me to question the currently quite common approach to design for a stage at which the caregiver and/or the technology take over. As a designer myself, I started to think about my responsibility to make technologies that could grow, develop and take over only where necessary. I have not yet an answer on how to achieve this, but this study led me to interesting new ideas and impulses. If people with dementia struggle with devices, should it not rather be my task to develop technologies they can use rather than avoiding engagement from the start? If dementia is a progressive illness, should technologies not be flexible and changeable? If monitoring is a sensitive issue, should devices not be overly open instead of – quite literally – black boxes? I do not have the answers yet, but this is something I want to explore further in my PhD project. The sketches below were used to capture initial ideas that came directly from the engagement with the current technologies. I thought about ways how the process could be less hidden, but enable a shared decision-making process that could help people discuss their values at an early stage and thereby take control rather than let technology take over.
2.5. Could I have learned the same from engaging with people with dementia

A self-study cannot replace the engagement with people with dementia. But it can add to the experience and prepare the researcher or designer for future work. I see that there cannot only be these kinds of studies. There is enough literature out there to convince me that engaging people with dementia into research or design is not only necessary, but also possible. During my career so far I have met a wide range of people who, willingly and with great reward, engage with people who have dementia and push the methods and means further every time they do so. It is a long and stony way, but I am convinced people with dementia will become equal partners in research and design throughout a wide range of subjects. The self-study was not easy. Nor did I expect it to be. This was not an easy way out of avoiding long and complicated ethical clearance procedures or avoiding the hassle of finding participants and taking time to engage their trust; nor was it a means to avoid finding ways of gathering feedback in a way that would make it meaningful for the participants. It was a way of pushing my understanding and my boundaries. A self-study is costly, not only in terms of time, but also emotionally. I felt like I was fighting repeatedly with the device, regularly with my partner and with myself at times. I am strongly against surveillance, how could I use these devices? Could my work lead to more of these? Are better monitoring technologies really what I want out of this? Questions were piling up whenever I was tired and upset and struggling to understand what was happening. Getting this insight myself has been a useful driver for design work and added a sensitivity to my approach to research that I did not have before. I am not thinking about privacy in general anymore but look beyond it and into the conflicts that arise from these technologies in general and how they might be overcome. Even more so I am thinking about the responsibility of the designer and how I can transfer my experience of using these devices into useful tools for designers and those interested in the topic.

2.6. What is next?

I have already used my understanding from this study to write critical stories, so called design fictions around dementia, technology and autonomy, both for an academic and a lay audience. During my upcoming PhD
work I want to use critical designs to see whether it can influence the way designers engage with the topic and whether and how it can be used to break open the debate around these technologies. Self-studies are one of many ways to gain insights into the everyday use of technologies. The study presented in this essay reflected on the use of a reminder app, a GPS tracker and a house sensor set. While it cannot represent the full experience of what it means to live with dementia and use these technologies, it conveys the experience of the technology with a directness and intensity that can – and has – led to inspiration for new designs and approach research or design with a new sensitivity. In this essay, I reflected on the process of undertaking this kind of study and outline new directions for design.

Acknowledgement

I thank my supervisors in supporting me in undertaking this study and writing this story as well as all colleagues who gave me feedback. Thanks to my partner who took part in this study so patiently.

Authors’ Bio

Building on her experience as a fashion designer, Britta F. Schulte explores how technologies can be developed that support people holistically, specifically in the context of dementia. In addition to design projects, she uses writing, both for an academic and a lay audience, to propose alternatives and stimulate debate.
Rituals of Farewell

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1. Abstract
Funeral rituals are in place to help those who remain to understand and accept that their loved one is gone. What if there were different rituals for different departures? It has been studied that it’s easier to accept a loved-one’s death in the case of a prolonged illness – the death is not sudden, but expected. There has been a chance to say goodbye. With sudden deaths, peaceful or violent, the grieving process is very different. Those who remain struggle much more with the loss. There are things left unsaid. There was no chance to say goodbye. In the case of Alzheimer’s disease, biologically, the patient may take a long time to die, however, we have to accept the loss of their identity during this biological process. Again, there is no chance for goodbye. This is particularly hard to accept and understand, as the biological individual is still around. Could we help the carers of people with dementia by designing rituals of farewell for memories or skills lost?

2. Rituals
There are spectacular cultural differences between how people ritualise loss. The Torajan people of Indonesia for example, keep the dead in their homes. For Torajans, the death of the body isn’t the final event of the West. Instead, death is just one step in a long process. Late loved ones are tended at home for a long time after death. For Torajans death is just another step in the process of being alive. Dead and alive people are not disconnected but separated (Bennett, 2016). The New Orleans jazz funeral is a typical image of New Orleans, Louisiana: fusing West African, French and African-American traditions. The funeral guides the mourners from grief to joy by a marching band. The Aboriginal have an elaborate funeral ritual, starting with a smoking ritual in the deceased’s home, to drive away their spirit, followed by a feast with dance. Then, the body is traditionally placed on a platform and covered in leaves and left to decompose. (May, 2013)

A study by Norton and Gino (2014) looks at how people cope with extreme loss. They found that those who overcome their grief more quickly all have
something in common. Following the loss, they performed ‘rituals’. These rituals were not the public or religious customs. Most of the rituals people did were personal and performed alone. One woman whose husband died still washes his car each week, as he had done when he was alive. Another woman who lost her mother would play a certain song and would cry each time she heard it. A man who lost his wife would continue their hairdresser’s visits, as they used to do together. Although these rituals sound very emotional, Norton and Gino found that the people performing these rituals would actually be less depressed than those who had experienced loss, but had no personal ritual. Public mourning rituals have a clear purpose to strengthen social bonds. Private rituals don’t do this, but Norton and Gino found that private rituals help people overcome grief by counteracting the chaos that follows loss. The privately constructed rituals can help to give the bereaved a sense of control (Norton & Gino, 2014).

As a carer it is hard to witness the slow decay, and the on-going series of small deaths of your loved one. In my personal case it is interesting to reflect, now that my mother is dead, the path that my grief has taken. I found it hard, but along the course of my mother’s illness I clearly learned to accept the small losses, one by one, until really there was nothing left. The final departure was not so painful anymore. There was a sense of relief, and an opportunity to celebrate what was good about my mother’s life.

3. A personal ritual

My mother was a sculptor and a collector. She collected many things, but her holy grail were rocks with holes. She collected many over the course of her life. Being diagnosed with early onset Alzheimer’s was a curse. The disease she feared most. She had witnessed her own mother’s dying in this way. It hit her hard. It hit the family hard. She wished for a dignified death, to not have to experience, and for her family to witness, the undignified deterioration that is Alzheimer’s disease. We would have loved to be able to grant her this wish. Instead we all experienced her gradual and terrible decline.
My mother lost her sense of humour first. Then she lost the skill to learn new things. She lost her optimism. She lost her excellent problem solving abilities. She lost her beloved skill to read. She lost her disgust for milk. She lost her friends. She lost her kids. She lost her dignity. She lost herself. Slowly and with much delay we learned to accept these losses. We had to deal with this grieving these losses over many years. Each rock symbolises a part of my mother we lost. Together we put her back together again, and can remember her as the beautiful being she was.
Authors’ Bio

Marije de Haas is a PhD student with a commercial background in design. Her PhD studies are investigating if it is possible to have a good death in dementia.

Acknowledgement


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Lessons learned from designing a tool for identifying and alleviating needs of people with dementia and their informal caregivers

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1. Introduction

A wide range of assistive technologies for coping with dementia is offered in Europe; yet, research and practice show that people with dementia and their caregivers have difficulty in accessing these products and services which can support them in their everyday challenges (Meiland et al., 2017). This is because they are not aware of the availability of the solutions (Donath et al., 2011), information provided about the solution is unclear (van der Roest et al., 2009), or the solutions are insufficiently adjusted to individual needs and contexts (Lauriks et al., 2007). There is a clear need for a means that can help people with dementia and caregivers find out about the available and relevant support. In project FIT, we aimed to develop a digital decision aid for clarifying the specific personal and contextual needs of people with dementia and their caregivers and offering customized advice about available assistive technologies and care services that can alleviate unmet needs. In other words, we aimed to provide a “fit” between the needs of people with dementia and existing product and service solutions.

Project FIT is a collaboration between two design research institutes, three research institutes in healthcare, three care organizations, and two SMEs in the Netherlands. Together we examined how preconditions for participatory design work out in the practice of designing a decision aid for people with dementia in the Netherlands. We first conducted focus groups, interviews and diary studies with people with dementia and caregivers in order to investigate their needs, and then created a comprehensive inventory of the product and service solutions in the Dutch market.
In an iterative procedure, we created a conceptual structure that matches these solutions with the needs and developed several prototypes for the digital decision aid. People with dementia, professional and informal caregivers and domain experts contributed to the development and refinement of the design. User experiences with the decision aid were collected by means of structured questionnaires and focus groups among informal and professional caregivers (the development process of the FIT decision aid can be seen in more detail in Cila et al., 2017).

Below, we will highlight four of the most important lessons we learned in the design process as design researchers working closely with different experts in the field of dementia.

2. Lessons learned

2.1 Break the problem down

The insights we gained from the diary studies and interviews with the people with dementia and their caregivers made it clear that it is impossible to talk about “one fit” between users’ needs and solutions. There existed multiple potential users of the tool who have different motivations to use it. We identified the primary users of the FIT decision aid to be informal caregivers and care professionals (i.e., GP, case managers, district nurses, social workers). Informal caregivers can use the FIT decision aid together with their partner/parent as a communication tool to explore met and unmet needs, or use it to find solutions for relieving their own situation. Care professionals can use the FIT decision aid to become informed and transfer this knowledge to their patients (Lauriks et al., 2007). We considered the people with dementia to be the secondary users of FIT because we found out during the interviews that the participants who are in the early stage of the disease (and still cognitively able to use FIT) do not always acknowledge their illness and the need for support, and the participants at a later stage of dementia may not be able to use a digital aid. For this reason, we did not target people with dementia as autonomous users of FIT, however, we designed the tool to be accessible and inviting for them so that caregivers and care professionals can use it together with them.
Apart from the target group, our research also revealed four user behaviours that affect why they would use the decision aid: (1) people who are not aware that they have unmet needs and are therefore not in the search of solutions; (2) people who are aware of their needs but never realized there could be solutions to alleviate these; (3) people who are aware of their unmet needs and know of a potential solution, but do not know where to find it; and (4) people who want to explore all the existing solutions to prepare themselves for future possibilities. Different “fits” are needed to get from one situation to the other. For instance, the FIT tool should make the users who are not aware of their needs able to identify their needs (from user behaviour 1 to user behaviour 2), or people who do not know that there could be solutions for their problems become aware of the type of solutions that can help (from user behaviour 2 to user behaviour 3). These behaviours were translated into a conceptual framework that starts from a higher “need” level, proceeds by specifying a “goal” to fulfill that need, and ends by finding the “product category” that can realize that goal (Figure 1).

In the end, breaking the main design research problem into smaller problems and reframing it after each user study really helped us to create a tool that various users can use according to their specific needs and expectations, which is also the core of typical design thinking processes.

Figure 1. The conceptual framework of the FIT decision aid
2.2 The power of design probes

In our user research and design process, we observed that people with dementia had difficulties in expressing their needs regarding independent living and were not able to recognize or acknowledge the things they cannot do alone anymore. For this reason, we designed sensitizing booklets to support people in need of articulation and prepare the participants to talk about topics such as safety, mental wellbeing, health, and social relationships. These booklets turned out to be a good means for starting the conversation about needs because they helped to focus the conversation and felt familiar and comfortable to the participants. The healthcare professionals in our project team were first hesitant about this approach due to their affinity of working with questionnaires and quantitative research methods. However, they also became enthusiastic about the rich picture these booklets provided regarding the everyday lives and needs of people with dementia after they saw the booklets in action.

One year after this user study, the healthcare institutions involved in the project are still using the booklet for their intake interviews with new clients. Before the design of the digital decision aid was complete, we created a card set in order to investigate if the needs we covered were comprehensible enough and observe the conversation of nurses and their patients so that we could design the digital tool accordingly. In this first paper prototype, each card represented a need category on the front side and some related products that can support that need on the back. These cards were very well received among the nurses since they can put them on the table and talk about them one by one. Also, they can leave them behind as a reminder to think about their needs every now and then. Even after the design of the digital tool was complete, we realized that some of the nurses kept on using these cards to start the conversation with their patients. For this reason, we redesigned the cards in the style of the website and now offer them as an accompanying product of our FIT decision aid (Figure 2). Although digital tools are comprehensive and can support people with dementia, it is still imperative to have supporting physical means that users can engage with.

Figure 2. The FIT cards set for starting conversations about needs
2.3 Living with dementia is not about sadness

In our project, we particularly aimed to look beyond the stigmas and gloominess that dementia is known for. Although our decision aid addresses many challenges that people with dementia encounter, we aimed to appoint them as “things you would like to improve” rather than “problems”. The tool starts with the question “What would you like to talk about?” and the topics to choose from are neutral and not symptom related, i.e., *Daily activities, Health, Household, Care relationships, Information, Finances, Mental wellbeing, Pleasurable activities, Social relationships, and Safety*. Also with the illustrations, we aimed to show an optimistic, non-stigmatizing and all-encompassing image. If one chooses for example “Social relationships”, s/he is asked which topic describes their need best (i.e., “sub-needs” in the conceptual framework): *Intimacy, Company, Communication, Contributing to society, Social support, or Balancing caring for and loving*. If s/he chooses “Company”, then s/he is asked to specify the thing s/he would like to accomplish (i.e., “goal” in the conceptual framework), such as *Meeting like-minded people, Having someone (or something) to care for, Having someone around you, Having someone to talk to, Having someone to listen to, Doing something together* (Figure 3). These are all concrete goals that people can easily act upon compared to for example saying “I feel lonely”. We aimed to make the language positive and activating. As designers, we believe it is in our hands to empower people with dementia, either by the tone of voice and/or images you use to describe them and their situation. Therefore, we are required to use this impact wisely.

2.4 Health care professionals as ambassadors

We collaborated closely with nurses in the design process since they are the experts in supporting people with dementia and communicating with them (Figure 4). They had very good suggestions on the content of the decision aid, as well as the wording we should and should not use. Although at the beginning it was difficult to ask their time and involvement, we observed that their enthusiasm grew immensely once they realized that their input was taken into account in prototype development. We listened carefully to their feedback and made sure their comments were materialized in each version of the prototype. Right now, the nurses
who participated in the co-creation sessions consider themselves as “the ambassadors of FIT”, as one of our nurses stated. They wrote a short document about the usefulness of the decision aid and how to use it; they pass this document to their colleagues and promote FIT in their institutions. They have become co-owners of the end result, which they are proud about. The involvement of healthcare professionals is crucial for the development and implementation of the design solution.
3. Conclusion and next steps

FIT is being used in three healthcare institutions in the Netherlands for half a year. The informal reports of the nurses indicate that the decision aid meets the needs of the informal caregivers and care professionals to get tailored information about products, services and support that can reveal and fulfil unmet needs of people with dementia. We aimed to co-create the tool with healthcare professionals to be able to implement FIT into existing healthcare infrastructures, as well as accommodate different user groups and make the tool usable in different stages of dementia. One of the long-term aims of our project is to create a sustainable business model that can keep the information on products and services up-to-date and include new products and services launched in the market. We are also busy with investigating the long-term effect of using FIT on increasing the quality of life of people with dementia and their informal caregivers.

As any other field of care, dementia care also requires a holistic, person-centred approach that builds upon people’s strengths rather than focusing on cognitive deficits (Kitwood, 1997). We aimed to achieve this in FIT, and hope to inspire other designers with our work.
Acknowledgement

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Authors’ Bio

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References


How do we want to live as we age? Millennials’ reflections on aging, collections, and participatory design through technology

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Overview of Story

Asking, “How do we see ourselves as we age?” two MFA graduate teams explored aging through a focus on participatory design, and collections. For the purpose of this study, we describe collections as a group of objects or ideas accumulated by the participants for some purpose. Examples are: collections of sports memorabilia, family photos, record albums, personal journals, etc. The two stories you are about to read explain the experiences each team had, the lessons they learned, and how their research may be applied to people living with dementia.

Story 1: Amorphous

New Experiences, Frustrations and Lessons Learned

How do you create something that harnesses collective human resources to solve problems dealing with aging using the parameters “collections”, “participatory design” and “aging”? Where do you even start? What possible role can visual designers play in this kind of problem solving?

Team One tackled these questions as part of a required second semester MFA graduate class in Visual Communication Design course at Kent State University. What they discovered was the power of extracting crowd-sourced questions, answers, memories and nuances of experience; and of delivering this valuable “street-
level” data to experts in various fields for evaluation and solution generation. Hemidreza, an Iranian male student in his early 30’s, Lisa, a British mother and student in her 40’s and Vanessa, a Nigerian woman in her 20’s, powered the team. I was their instructor.

In the first few weeks of the semester, the team struggled to see a way forward in tackling the problem at hand. Eventually, they started with what they knew—the design process, and dove in with secondary and primary research. Hemidreza, Lisa and Vanessa interviewed 12 people from diverse cultures and backgrounds, male and female, with ages ranging from 18–67. Abstract and conversational questions included:

- When you look into a mirror what do you see? How do you feel?
- Imagine being in an older person’s shoes, how do you see yourself aging?
- We are constantly bombarded by new technology. Do you feel pressured to keep up or are you a willing participant? Do you collect things?

They surveyed participants and found that 51.9% of people do not know how they want to be cared for when they are older, while 29.6% would prefer independent living. 92% of participants thought about growing older but only 16% talked about it with their families. 45% of people surveyed listed health as being their main concern about aging.

They found in their interviews that 66% of people felt that creating new opportunities for themselves was important, and the same percentage recognized the value of making adjustments as they aged. 58% of people felt it was important to, and had the desire to make decisions and remain independent if they were physically capable.

Themes from coded interview data on aging began to emerge. Themes on aging included: fear and worry; age as a state of mind; the need for financial stability; accomplishing life goals; reinvention and staying up-to-date. Themes on collections were: emphasis on future planning; living space as a reflection of sense-of-self; collections as physical objects; collections as an abstracted notion. Themes on participatory design were: the receptiveness of technology; remaining independent for as long as physically possible; entrepreneurial freedom; and the structure of a professional career path. In general, they found that the most pervasive feelings associated with growing older were fear and worry.

Team One had plenty of data, and knew how to categorize it, but the daunting task of finding a solution set in and the team became frustrated. As second year MFA students, they hadn’t expected to find themselves in this position. After all, they were working designers and professionals. They knew design! But this was something else.
Out of sheer frustration, Team One turned to what they knew how to do—brainstorming possible solutions. No matter how absurd or implausible, they all knew how to throw out ideas, and that even bad ideas are ideas. Somewhere in that mess, the team began to connect the dots — even bad dots — and discovered that “systems thinking” was the only basket large enough to hold their incredible range of ideas. Several more weeks passed, and finally, they sheepishly asked if they would be permitted to make up something that doesn’t exist yet but could possibly exist someday, in a society that may be receptive to new ideas.

It was Amorphous. They called it Amorphous because ideas from all parts of the globe would organically converge to solve problems, starting with the experts, then moving to general public, then back to the experts. The team defined their creation this way: “Amorphous is a strategic tool that addresses the need to improve the quality of people’s lives as they age. The importance of Amorphous is that it addresses the need for data analysis by taking a people-centered approach that empowers the delivery of positive change.” Amorphous can help address concerns found in the data by making a “positive difference through shared stories, experiences and interdisciplinary collaboration…. The location of this system is not so much a single artefact, rather the system that exists everywhere. It is not confined by the boundaries of the here and now. It is a multi-dimensional idea that can be reshaped at any given stage.”

A Prototype with Potential Dementia Testing

The system works by asking a question such as, “What are your fears about aging?” The team described this system in the following way: “The public is presented with the question and then give their opinions through the appropriate mode for them. Their responses are collected and the data is then organized through a statistical analysis software. Researchers and professionals are given access to the organized data. Researchers then individually or collaboratively compile, back up and translate their data with more external research and if the research is inconclusive, researchers can go back and ask more targeted, specific
questions. Comprehensive research is then enough to prototype solutions. A solution or outcome is presented to the public through the applicable channels.” (Team One)

The Amorphous system can be used by a variety of people working through varied channels. Based on personal surveys, the channels emphasized by the team were magazine ads, interactive posters and websites. Distribution modes would be uniquely designed for people who use only print, for those who get information in public spaces and use some technology, and for others who strictly gather information through technology—specifically through social media outlets (Figure 1).

So far, it has been primarily dementia experts who have been involved in exploring opportunities for people living with dementia. What if some of the challenges and opportunities for people with dementia could be collected by the public and then returned to the experts to analyse answers, try new things, and use the collective ideas gathered by this system to test out possibilities that haven’t been considered before? What if both old and young populations can have a voice in this matter? Given the potential of this tool, it would be interesting and valuable to do a test sample with a focus on memory loss. Tapping into a wider community of voices rather than using only traditional research allows unlikely people to be heard as we search for ways to treat and approach memory loss issues.
Story 2: The Memory Collective

From rough start to a smooth finish

Mahlon and Natalie, a relatively small two-member team, struggled mightily with the whole concept of aging, collections and participatory design, just as Team One had. In the end, however, they did an incredible amount of work and came up with a unique solution that has potential applications in dementia. Both ambitious young people, Mahlon (of mixed background and race, and in his 20s), and Natalie (a white female in her 20s) collected information from 78 people of varied ages and ethnicities! Like Team One, Team Two started with what was familiar to them; secondary and primary research. Dividing the work based on personal strengths, the two-member team produced surprisingly large volume of work.

Their primary research included: 70 surveys, 8 interviews and 3 photo-ethnography sessions completed in less than three weeks. Their research findings indicated that a majority of participants owned collections of some kind, ranging from rocks to guitars. Their main findings indicated that “if people are disabled and can no longer live actively, they value being near to family, followed by proximity to nature, then convenience of locale.” One interesting tidbit in their surveys was the response to: What does ‘old’ look like? which the team summarized as, “Something or someone who has gone through its lifetime and experienced a collection of things.” Old also ‘looks like’ “understanding and lack of fear for whatever the next experience, day or moment holds.” Their interviews indicated that 87.5% of people believed that participatory design involved the act of coming together, that it required communication between a multitude of different people. Somewhat surprising was that 62.5% of people had collections of objects! 62.5% people mentioned a love of nature or doing activities in nature. 50% of the people were willing to share their memories, while 100% wanted to hear other people’s memories. Not sure what to make of that. People are generally voyeuristic?
On to the prototypes!

Team Two settled on the final prototype, The Memory Collective, based on the premise that “We are more alike than we know.” In their own words, The Memory Collective “exists to bring people together through an empathetic sharing of mutual experiences. It serves as a virtual collection, not only documenting the personal narratives of populations as they age, but also the universal human experience.” Memory Collective is a traveling installation that invites participants to record a personal memory. Memories are uploaded to a virtual collection, which can ignite inspiration, empathy, and joy in the viewer. It works through 5 ‘E’s: Entice, Enter, Extend, Exit and Engage” (Figure 2). Their design goal was to “create an inclusive space that can be moved easily and exist in different environments.”

What does this have to do with dementia?

The booth, as we ended up calling it, has the potential to stimulate memories in people living with dementia. For example, at the onset of dementia, people would reflect and record something personal, such as a collection they knew or even loved. Subsequent watching the video of themselves, or of other people who may have the same collections, may serve as a bond that helps them remember the objects of specific collections and circumstances, or stories revolving around those collections (Figure 3). If the stories they share are about what it’s like to grow older, that too has the potential to impact how they feel. The videos also may stimulate emotions, memories, feelings or ideas by showing them people in their lives, such as relatives and friends, whom they may enjoy thinking about again.

![Figure 3. Memory Collective process; entice, enter, extend, exit and engage](image-url)
Utilizing the memory collection of a person’s ‘younger self’ may be another way for people to recall parts of themselves. Memory and display of valued collections may play a role in triggering that recall.

Finally, seeing younger people share stories of their own collections may trigger a connection to the collection, and create an enjoyable experience which can be shared by persons living with dementia along with their family and friends. All these triggers or stimulations are intended to allow people to savour their memories and to appreciate the stories that may emerge along with them.

Conclusion

Both the Memory Collective and Amorphous are unique tools which can be used to hear the voices of, and gather information about aging and memory loss populations. As visual designers dive further into exploring problems that require research, design thinking, and creative solutions based on target audiences, I believe they can make a significant contribution in a number of areas where their expertise hasn’t been utilized in the past. It is my hope that these two stories can contribute to a larger body of work collected by designers who wish to advance research and testing in dementia and to move the needle to make a difference in the lives of the people living with dementia.
Acknowledgement

Special thanks to members of the Amorphous project: Lisa Cook, Hamidreza Sohrabi and Vanessa Okojie. For the Memory Collective project, I extend many thanks to Natalie Snodgrass and Mahlon Rhodes. Both teams worked diligently on research, analysis, design processes and methodologies, prototypes and final presentations which were featured in this paper. This story would not have been possible without their creative vision and perseverance throughout the semester. Also, thanks to my Graduate Assistant, Jordan Kauffman, who took photographs and video, documenting the project and was invaluable in providing his unique perspective during the semester.

Author Bios

Sanda S. Katila completed her B.F.A. at the University of Akron, M.F.A at Kent State University and worked as a professional designer for 13 years. Professor Katila began teaching in 1993 in the School of Visual Communication Design. She’s been actively involved in administrative roles at the university serving as the Internship Coordinator, Graduate Coordinator, Associate Director and Acting Director. Her research focuses on aging, healthcare communication, socially responsible design and graduate service projects.
Evaluating Art and Design projects for Dementia

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Abstract
When designers engage in art and design research projects with people living with dementia, they often have difficulty evaluating the project outcomes. This is in part because while outputs are often explicit, the desired outcomes remain implicit, or because the design study does not take into account the multiple agendas that are often present. Drawing on the findings from an evaluation of an Arts Access Program for People living with dementia in Australia, this paper will suggest that it is essential that the values providing the rationale for the project, and the overall experiences of participants, who may have difficulty articulating their views, are not lost because of inappropriate methods. While the paper focuses on arts engagement, the findings are transferrable to co-design and participatory approaches that prompt emotive and emotional responses to objects, activities, processes, interactions and engagement.

Keywords: Dementia, Evaluation, Qualitative

1. Introduction
The Art Gallery of New South Wales (AGNSW) in Sydney, Australia has permanent collections of international and Australian art; hosts national and international touring exhibitions; runs outreach programs; and engages in research. Over 1.3 million people visit the Gallery annually. In addition to its exhibitions, the Gallery supports lectures and symposia, film screenings, music recitals, and performances, and offers a range of access and education programs that engage with diverse audiences and people with different access requirements.¹

The Gallery is funded by the NSW government, through corporate sponsorship and from donations from private benefactors. It is currently undergoing a period of change. An important element of the transformation is ensuring that the Gallery continues to evolve opportunities for diverse

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audiences to engage with its permanent collection and temporary exhibitions. Through education and access programs, the Gallery aims to break down social barriers and promote inclusion for people with different physical, sensory, and intellectual needs and enable disadvantaged community groups to actively engage and connect with art (Art Gallery of New South Wales, 2015).

The Gallery has been running Art Access Programs for people living with dementia, carers, family members, and health care professionals since 2010. The program supports the Gallery philosophy of lifelong learning, enrichment, and inclusivity through engaging with art, and through this approach aims to contribute to reducing the stigma associated with dementia. It caters for a wide range of people with different physical and cognitive capabilities and is inclusive of people with early-onset dementia, in early stages of dementia, and those in more advanced stages. Attendees of the program come from residential aged care facilities (RACF), community groups, and people living in their own homes alone, with family members, or with carers.

The program has now received funding to enable the introduction of art and design making activities and to extend the project further into the community, as part of NSW Family and Community services Liveable Communities scheme. As a result there are a greater number of stakeholders in the project, including the NSW Government; philanthropic benefactors; gallery board of directors; gallery Staff, program producers; artists and designers engaged in the making activities; ageing and care organisations; formal and informal carers; and people living with dementia. Many of these stakeholders already are required to carry out evaluation in their day-to-day activities and often have an opinion on the type of evaluation they believe should be undertaken. Therefore, the next stage of the project involves setting up a negotiated evaluation framework. However, for the purpose of focussed discussion, this paper will focus on the evaluation undertaken in the first phase of the project, and while it focuses on arts engagement, it has relevancies for design processes that engage with people living with dementia in co-design and participatory approaches and projects that aim to understand emotive and emotional responses.
Participants on the Arts Access Program were introduced to 3-4 artworks per visit. Trained art gallery facilitators contextualised the artworks being observed and opened up opportunities for general discussion. Program attendees and accompanying family members, primary carers, or professional care staff were all encouraged to share their views, experience, knowledge, or associations arising from their engagement with the artworks and interact with the facilitator and peers. The engagement of all persons in the space of the gallery was part of the evaluation process. This approach builds on the concept of a 360-degree approach to dementia, which recognises that all stakeholders in dementia care have knowledge and expertise that can inform our understanding because of their proximity to the disease (Kenning, 2017).

As with evaluation of co-design and participatory projects for those considered part of a ‘vulnerable community’, evaluation of the impact of arts engagement for people living with dementia is still very much in an early stage of development. While clinical, medical and health care professionals are able to draw on an array of scales and measures that have been developed and validated to evaluate physical and intellectual abilities, assessing the impact of social, cultural and emotional engagement of art and design is in its formative stages. This means that researchers often look to other fields and disciplines for guidance. However, the importance of the choice of the artwork, and the contribution that design materials and style choices make to the experience may be not taken into account in some evaluation frameworks. Similarly, how objects are introduced, scaffolded, or contextualised and impact
the viewing of artworks or engagement in design processes, may be overlooked. Furthermore, in arts engagement and design projects for people living with dementia, the importance of the person retaining any information after the event can be a divisive issue. Therefore, this evaluation study, commissioned by the AGNSW, used a mixed methodology approach involving qualitative and quantitative research to gain an understanding of the impact of the AGNSW Art Access Program on people living with dementia.
2. Background

2.1. Ageing and dementia

While many people continue to live healthy active lives and remain independent long into old age, the incidence of age-related conditions such as dementia will increase as people live longer (World Health Organisation, 2012). By 2050 it is predicted that the percentage of the world’s population over 65 will double to 16% and the number of people living beyond 80 will have quadrupled. An unprecedented number of people will live to be 100 years of age and more than 131.5 million people worldwide will be living with dementia, many of who may be undiagnosed (AIHW, 2013; National Institute on Aging, 2015; World Health Organisation, 2014, World Health Organisation, 2015). Dementia impacts cognitive function and can affect memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement. However, consciousness is not affected (World Health Organisation, 2015).

2.2. Art and design for people with dementia

People living with dementia who have been regular attendees at galleries and engaged in cultural events may, as they pass through the various stages of dementia, no longer remember details about artists and artworks, designs or events. However, consciousness and emotional memory persist. This means that even in the later stages of dementia, people can experience pleasure and all of the benefits that come from ‘feeling good’, and that includes engaging with cultural artefacts and in social and cultural activities and the types of events that are often taken for granted by the broader population (Cohen, 1988; Cohen-Mansfield et al., 2012; Guzmán-Vélez, Feinstein, & Tranel, 2014; Sabat, 2006;
Satler & Tomaz, 2011, Zeisel, 2009). Art Access Programs primarily focus on the ‘here and now’ and provide opportunities for individuals to experience ‘in the moment’ pleasure and the benefits and enjoyment of social interaction. In this we can draw parallels with the immediate types of engagements that occur in many participatory and co-design approaches used with people living with dementia.

2.3. Evaluation of the Art Access Program

Evaluation of the impact of people living with dementia engaging with art has often focused on the long-term benefits and the extent to which art experiences, treated as ‘interventions’, alleviate stress or manage so-called behavioural problems and psychological symptoms. Understanding long-term benefits and/or the impact of an activity on physical and mental good health are important aspects of caring for people with dementia. However, such approaches only partially address the social and cultural aspect of how arts engagement impacts on health and wellbeing.

![Figure 2. Viewing Australian beach pattern, Charles Meere. 1940](image)
Long-term improvement is an unrealistic outcome for people living with a degenerative condition such as dementia. Kitwood (1997) argues for a change in the way we understand dementia and calls for a focus on wellbeing. He suggests that rather than thinking in terms of deficits or perceived problem behaviours, we should address the person as a whole recognising the impact of their social context, their personality, social relationships, physical health, life experience, and neurological impairment. Sabat (2006) suggests that positive emotional experiences can have an ongoing impact on people with dementia. He argues that a “person may not be able to recollect consciously some previous experience, but his or her actions will reflect a memory of that previous experience nonetheless” (p.11). Therefore, positive emotional experiences can contribute to wellbeing (Cohen et al., 2006; Cohen-Mansfield et al., 2012).

Understanding the responses of people, particularly with advanced dementia are complex and difficult to evaluate. But addressing and responding to the person as a whole, while providing pleasurable experiences that can reduce depression, stress and tension, can facilitate communication and improve self esteem (Kenning, 2016; Kenning, 2017). Similarly, in co-design and participatory design projects it is important to recognise that the person, who may not be able to articulate their interests and concerns, has a wealth of experience and can communicate if we are patient and observant enough. Therefore, in evaluating the impact of the Art Access Program we sought to understand and establish a framework to examine the extent to which arts engagement can prompt the type of ‘In the moment’ pleasure and ephemeral joy that can give rise to the intense emotional experiences that Sabat (2006) suggests have an ongoing impact, explore how individuals experience ‘in the moment’ pleasure, and understand the context in which it arises and exists.

3. The Study

Researchers at the University of Technology Sydney explored whether engaging with artworks and discussion about artworks facilitates and promotes ‘in the moment’ pleasure and thereby contributes to positive wellbeing. The research project undertaken sought to gain an understanding of the environment and context in which people experienced the artworks, the responses
of the participants in the arts engagement program, and the views of stakeholders caring for them. The study used a range of research methods including observation, interviews, and surveys of those involved in arranging, delivering, and experiencing the program in the Gallery space. It draws on best practice evaluation of music, drama, and the visual arts (Flatt, Oakley, Gogan, Varner, & Lingler, 2014; Killick & Allan, 2001; Mittelman & Epstein, 2006; Thomson & Chatterjee, 2013), as well as social science methods generally. While not specifically focussed on evaluating communication, communication theories and communication evaluation methodologies also informed this evaluation (Bauman & Nutbeam, 2014; Beard, 2012; Cutlip, Center, & Broom, 1985; Flatt et al, 2014; Killick & Allan, 2001; Lindenmann, 1993; Macnamara, 2012; Mittelman & Epstein, 2006; Thomson & Chatterjee, 2013). The evaluation model used in this study contributes to a growing body of research and evaluation that focuses on the extent to which people living with dementia can have meaningful interactions and engage in activities that impact on subjective wellbeing and enrich their lives. The study investigated the experience of people living with dementia and relevant stakeholders participating in the AGNSW Art Access Program during 2015. Specifically, it explored:
- The context of the visit – that is when, where, who and how;
- Verbal or non-verbal communication and behaviours;
- Behaviour that suggested joy or ‘in the moment’ satisfaction or pleasure, or negative responses;
- Signs of engagement or connection with facilitators or art Gallery staff; Peer to peer; With the artwork; With the Gallery space;
- Signs of anticipated pleasure prior to the Gallery visit or reflective pleasure after the visit;
- The response of Gallery staff and program facilitators, family, carers and care staff;
- The overall mood of everyone involved in the visit to the Gallery;
- Pre- and post-visit self-assessment of quality of life and self-esteem through participant questionnaires.
4. Methodology

This evaluation primarily used an interpretivist qualitative approach. The methodology used was informed by findings from the evaluation of the Meet Me at MOMA program carried out in 2006 (Mittelman & Epstein, 2006) and contributes to the emerging field of evaluation of programs for people with dementia. Evaluation of arts engagement is in a developmental phase. Models are currently being developed to explore the impact of ‘in the moment’ pleasure (Macpherson, 2009) and how focussing on associations and the ‘reverberation’ of the experience can provide an alternative to focussing on memory of the experience (Muller, Bennett, Froggett, & Bartlett, 2015). Evaluation of arts and leisure activities in relation to people with dementia are increasingly recognising the importance of seeing art experiences as ‘intersections with’ rather than ‘interventions in’ people’s lives – the latter being terminology commonly used in Random Controlled Trials (RCTs) in clinical, medical and psychological studies (Vogelpoel & Gattenhof, 2012).

Evaluation of arts engagement for people with dementia such as Memories in the Making and its analysis by Kinney and Rentz (2005) and the Meet me at MOMA program and its evaluation by Mittelman and Epstein (2006) employed modified self-reporting questionnaires to assess individuals’ quality of life. However, as they reported, there are inherent limitations in using self-reporting questionnaires among people with dementia because participants may have lost access to memory, language, writing skills and lack confidence and decision making skills. Nevertheless, with careful consideration of factors such as the length, the number of questions, and how and when the survey is completed, self-reporting questionnaires can be a useful tool for gaining insights into individuals’ perceptions and reactions, particularly when specialised scales are used. The evaluation also took into account carers responses as proxy for people living with dementia, but importantly, this data was always differentiated as someone speaking ‘on behalf of’ and not taken as representative or equal to the person with dementia responding for themselves.

The methodology was further informed by social science research methods literature. In particular, interpretivist approaches.
identifying the value of data collected through interviews with participants and relevant experts, and direct observation when possible (Neuman, 2012). As language may be partially or entirely compromised for people living with dementia, the nuances of non-verbal communication also offered valuable insights into the experiences of the individual (Zeisel, 2011).

4.1. Methods
Accordingly, this evaluation used the following methods with analysis based on triangulation of data collected through:

- Ethnography incorporating both personal observation and video ethnography;
- Interviews (formal and informal) with carers, facilitators, and Gallery staff involved in the program. This provided a level of expert review; and
- Pre and post-visit questionnaires distributed to attendees, care staff, facilitators and family members of the AGNSW Art Access Program.

4.2. Sample
The study used a purposive sample and researchers were introduced to a number of organisations in the process of arranging visits for people with dementia to the Art Gallery of NSW. Prior to undertaking the research, the researchers met with representatives of three organisations whose clients were scheduled to attend the Gallery – a government funded community centre, a program for younger onset dementia (YOD) through a public hospital, and a residential aged care facility (RACF). This provided researchers with background information about the organisations and their roles and afforded a broader understanding, on the part of the researchers, of the current program. In this sample selection and preliminary stage of the study researchers also met with professional care staff and volunteer guides who accompanied people with dementia on their visits to the Gallery. This provided further ‘immersion’ in the field of study and enabled the completion of consent forms for all participants.

4.3. Ethnography
The study used ethnographic approaches, which afford the benefit of first-hand observation of an individual or group by a trained observer looking at individuals’ experiencing, behaviour, patterns of behaviour, vocalisation, physical positioning, and interactions. This approach provided additional data and context to participants’ self-reporting questionnaires, which may be affected by, for example, self-consciousness, shyness, nervousness, and, or cognitive or physical limitations.
4.4. Questionnaires

Specialised questionnaires were developed for the attendees, family members and primary carers, care staff, and facilitators and distributed pre- and post-attendance. Pre-attendance questionnaires provided benchmark data for comparison with post-attendance questionnaire data.

From the literature, the study identified a number of measurement instruments including family assessment measures (FAM), quality of life measures (QOL), self-esteem scales (Logsdon, Gibbons, McCurry, & Teri, 2005; Ready & Ott, 2003; Rosenberg, 1965; Skinner, Steinhauer, & Santa–Barbara, 1983), and adaptations of these scales used in the evaluation of the Meet Me at MoMa program by Mittelman and Epstein (2006). As a result, the AGNSW evaluation questionnaires used a series of scales further adapted from quality of life (QOL) measures, self-esteem scales, and pictorial self-rating mood scales. Modification of the instruments was confined to shortening some questions, eliminating questions not considered relevant for this study, and adapting language for an Australian audience. Thus, these instruments provided criterion validity for the study.²

Gallery staff, facilitators, care staff, attendees, and family members were all included in the sample for questionnaire and/or interviews. These ‘experts’, from a range of experiences, could provide insights in terms of understanding and assessing the mood, demeanour, and responses of the attendees. They also provided a level of face validity.³

Attendees, family members and primary carers were invited to complete QOL and self esteem questionnaires in relation to their perception of the attendee and to make additional comments.

Attendees were asked to complete a pictorial mood survey and were invited to make additional comments.

Facilitators were asked about their experience of the program and completed a pictorial mood survey.

Professional care staff in attendance at the Gallery were asked to complete a survey about the program and a pictorial mood survey.

Immediately after the Gallery visit all participants (Facilitators, care staff, attendees) completed mood surveys.

Attendees’ families had been given a questionnaire to be completed after the visit with the same questions relating to the quality of life, self-esteem, and mood of the attendee. Each form was returned by mail to a specified post office box address.

² Criterion validity is established when an instrument used has been tested and shown to be valid (Frey, Botan, & Kreps, 2000 p. 116).
5. Findings relevant to co-design and participatory approaches

While there are methodological challenges in evaluating the cognitive, affective, and conative outcomes that can be achieved by and for people with dementia, this intensive period of study and analysis led to three key findings, as well as further findings that inform operational processes in the Art Access Program for people with dementia, and others in relation to evaluation methodology that can inform future research and inclusive design research projects and is available in the full report.

The three key findings in relation to participants that are transferrable to participatory and co-design projects are:

Affordance of normalcy — based on the rights of every individual to be treated with dignity and respect and accorded the rights and privileges of all citizens regardless of abilities or perceived disabilities (Chenoweth et al., 2014; Killick, 2013; Kitwood, 1997; Treadaway, Kenning, & Coleman, 2014).

The importance of context surrounding visits to the Gallery, including preparation and logistics such as administrative arrangements, length and method of travel, etc.; – Factors such as the length of the journey to the Gallery, the atmosphere on the bus or other transportation used, the seating of the chairs in front of the painting, noise levels in the Gallery, etc. can create discomfort, confusion, or even rejection and withdrawal. Such factors can mean that individuals may not arrive in the Gallery space in a condition to engage with the artwork. For some, this does not mean that they will not have a positive outcome from the visit, but it can potentially be an added difficulty for care staff and facilitators, and impact on group dynamics.

The need for provision of social scaffolding – Understanding the importance of social scaffolding has grown out of psychology applied in education, such as the work of Russian psychologist Lev Vygotsky (1978), Jerome Bruner (Wood, Bruner, & Ross, 1976), and Barbara Rogoff (1990). Social scaffolding refers to individuals’ support structures ranging from family and carer support to social interaction and collaboration, and this concept is now being examined in relation to people with dementia (Hydén, 2014) and in exploring how people with dementia engage with artworks (J. Bennett, personal communication, March 16, 2016).
6. Conclusions

While the three key findings relate to the research study which focused on arts evaluation, there are transferences and relevancies for design, and particularly design processes that are inclusive and engage with people living with advanced as well as early stages of dementia. Importantly, while the study reinforced the concept of normalcy building on personhood and individual dignity, it also revealed how normalcy is relational and takes into account the role of the individual within an ongoing social and relational context. This is important for reaffirming how design needs to take into account not only the individual, but all their relationships.

As designers and researchers we recognise in research studies and design projects that, study design, living lab and workshop environments remove people from, or impress upon their everyday lives. While we can gain important knowledge, that cannot be gained from observation of the everyday (such as responses and reactions to objects, activities, and people) it is important to acknowledge this as a differentiated space, presenting both possibilities and restrictions.

In the arts access program study it was apparent that how people living with dementia were brought to the space had an impact. That is not only the physical preparation that included comfort and logistics, but also how they were introduced and primed ready for the engagement activity. This transfers to both the co-design and participatory research space and to the reception of the design prototype or product. Carers and family members can model engagements for and with people living with dementia, and in the design space this may also be the role of the designer and researcher. This is not to suggest that it is telling people how to use, respond to, or engage but building confidence and offering reassurance that their response is appropriate and desired.

While this paper has set out the methodologies and processes engaged in an arts access program the methodologies and findings are transferrable to design practices that focus on inclusive designs working with vulnerable groups including those living with dementia. The study focused on the emotional everyday responses of people living with dementia and acknowledges that these responses are signs of our humanity and are ongoing.

³ Face validity is established when qualifications or experience of the researchers or collaborators means that, ‘on the face of it’, the research is likely to be valid (Frey et al., 2000; Neuman, 2012).
Authors’ Bio

Dr Gail Kenning is an artist and researcher at University of Technology Sydney (UTS); Honorary Reader in Design for Ageing and Dementia at Cardiff Metropolitan University, Wales; Design United Visiting Fellow at Eindhoven University of Technology, Netherlands. Her research interests are in relation to how creativity and innovation can impact wellbeing for people living with dementia.

References


The soft, sensitive way of interacting with people living with dementia

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Abstract
Particularly the developers of technical aids are often confronted with a low level of acceptance in the field of dementia disease. There is a large number of products and design artifacts which have failed to meet the needs of people with dementia, but why? How can a responsible-orientated design be realized, and which approaches and methods for the process of design and design research are useful? Consequently, which design strategies can help to develop solutions in the form of artifacts to support the daily life of people living with dementia?

In collaboration with the Alzheimer Association Berlin, I am investigating the possibilities of a sustainable design in consideration of social, ethical and ecological aspects. In order to facilitate a needs-oriented and human-centered design of wearable technologies in my case study spur, the affected persons and their relatives are included in the conception, development and design, as well as conventional experts: medics, therapists and technologists.

Keywords: Textile-and Surface-Design, Interaction-Design, Wearable Technology
1. Introduction

Especially in the case of dementia, for most of the people living with the condition, the acceptance of aids is low. In contrast the majority of relatives and caregivers recognise the advantages of technical aids, as these can provide life-saving, protective functions for people with dementia and have a positive impact on the daily lives of those affected and their relatives. Wearable technologies can support both user groups in the progressive and individual course of a dementia disease. The main advantage of these wearable technologies is the potential to provide support for people with dementia whilst not reducing their mobility. I am interested in this paradox, that people with dementia often choose not to use such aids, despite the fact they would potentially improve their lives and reduce their suffering (Mareis, 2014). If one could improve the acceptance level of people with dementia, it would be possible to increase the use of technical aids. Consequently, the burden for informal carers could be reduced, enabling them to continue caring for a longer time, and people living with dementia could therefore remain in their familiar living environment, thereby avoiding the potential stress of a transition to residential care. It is important to consider this topic because two thirds of people with dementia are cared for by informal family caregivers. It is necessary to reduce the burden on carers as early as possible, because many of them are affected by symptoms of depression. In the case study spur two research questions are examined. How can wearables be developed and designed to be sustainable in respect of social, ethical and ecological aspects? And how can technical aids be reconsidered to improve the situation for both user groups: people living with dementia and their relatives?
2. Background Information

Currently the technologies are predominantly developed through approaches focused mainly on the technical properties. In this respect, a number of aspects are not adequately considered. The consequence is often that technical aids are not easily accepted by users, and life-sustaining and life-facilitating functions remain unused. In contrast to the development of a separate device, often built as a monolith, a design-research-process led from a fashion and textile/surface design perspective is more interested in understanding human artifacts, such as familiar clothing or furniture, and involving the sensual perception of such artifacts into the design-research process (Milev, 2011).

3. Case Study: spur

In cooperation with the Alzheimer Society in Berlin, I examine the possibilities of a socially, ethically and ecologically sustainable development and design of wearables in the field of dementia (Brock, 2013). In order to facilitate a needs-oriented and human-centered design of the wearable technologies, the affected persons and their relatives are included in the conception, development and design-process, considered as equal “experts” alongside conventional experts such as medical professionals, therapists and technologists.

3.1. Case Study: spur – Methodology

In practice-led design research, the practical analysis of the iterative prototype development and the subsequent studies on interaction and acceptance are linked with an ongoing theoretical reflection. According to the design-theoretical concept of Alain Findeli (2000), a number of implicit design questions arise from the formulated research questions. These are answered by a research “through” design and then strengthen the corpus of knowledge with regard to the research questions. Methods of empirical research, which are composed of quantitative and qualitative parts, are combined with the methods of design research (Creswell, 2003). In this combination, quantitative survey results are supplemented with subsequent individual and focus group interviews. The individual interviews take place in several stages, from partial narrative to focused interviews.

3.2. Case Study: spur – Procedure

In this combination of empirical qualitative and quantitative methods I work with the experts stated above. That means the stakeholders (relatives, caregivers, people living with dementia, employees of the association and therapists) are involved into the process of research, concept design and development. The procedure of the case study is divided into three phases: hear, create and deliver.
3.2.1. HEAR

step: quantitative research – understanding use cases

Together with the psychologist Susann Garten, who at the time worked in the Alzheimer Society, we developed a specific part of a study based on the scientific paper “Caregiver Burden and Needs in Frontotemporal Dementia” (Hsieh, Irish, Daveson, Hodges, Piguet, 2013). In our study 65 relatives were questioned about significant stressors (Garten, 2015). Our survey was focused on the significant burdens of the relatives and should elicit information about meaningful functions beyond simply tracking people with dementia.

The quantitative results showed that the relatives often become overwhelmed by the burden of caring for people with dementia on a permanent, informal basis. For this reason, between 30 and 80 percent of relatives suffer from depressive symptoms, the number depending on the type of dementia (Gunzelmann, Wilz, 2012). In addition to the concern for one’s own social–life and private existence, the anxiety experienced by carers regarding people with dementia and their safety is particularly striking (Rapp, 2009). Most relatives are concerned about the fact that, the person with dementia may be involved in an accident in the home, since those affected often forget to switch off electronic devices after use, or that they may leave the home unexpectedly unaccompanied, or even if accompanied, may disappear and wander off in a crowded place. (Gutzmann, Zank, 2005) Relatives are afraid that they will not become aware or be able to alert emergency services quickly enough in the case of an emergency situation arising, or fear that the people with dementia may suffer a fall and the related injuries, which would be followed by a lengthy recovery process. In such cases it is possible that walking could not be fully learned again, resulting in a loss of mobility (Melton, Beard, Kokmen & Atkinson, 1994).
step: qualitative research

Subsequent to this quantitative survey, concrete application scenarios were developed in focus groups composed of stakeholders, employees of the Alzheimer Association and relatives. In this process 18 people with Alzheimer’s and Fronto-temporal dementia were included. For the development of a holistic design concept, the casual notes and marginal notes of the interview partners are particularly important. These provide important information for the requirements of the design concept, the handling and insights regarding the exact process of the use cases. This attempts to tailor the functions and design to the special needs of dementia.

step: understanding human needs and requirements for the design

Together with the focus groups relevant requirements were collected and information about trouble experienced with technical aids they had tried and failed to be accepted were also discussed. People with dementia reacted to technical aids which were worn on the wrist, belt or hip with a lot of uncertainty, strong negative behavior or in a few cases with aggression. These reactions negatively impact the informal carers’ emotional wellbeing, who are always concerned about the person with dementia and want to protect them. In some cases, due to the implementation of an unwanted aid, people with dementia have lost trust in their carers. The resulting scepticism shown towards their carers was particularly hard for the carers to bear. As my investigations have shown, the dominant visual presence of the technical devices is often the cause of the scepticism and the rejection of the devices, which results in low acceptance of the support offered in the field of dementia. In the case of an onset of dementia, those affected sometimes fear a loss of autonomy and that they may be subject to constant surveillance, triggered by the constant confrontation with the visible devices. Through this visibility, people living with dementia are permanently reminded of the presence of the technology. In the field of advanced dementia disease, this concern is often secondary. The main focus here is on the unpleasant feeling of permanently wearing a strange and unfamiliar object. Moreover, most of the devices currently available cannot be removed by people with dementia due to special safety locks. This causes frustration, often leading to rejection of the device and may trigger aggressive reactions against their caregivers. The ensuing confrontation is a particularly painful and burdensome experience for their caregivers.
**step: participant observation**

The results of interviews are supplemented by participant observations in the familiar surroundings of two people with dementia. Additionally, I collected extra information from a participant observation led by the psychologist Susann Garten, who worked in the Alzheimer association in a program with weekly meetings of affected persons. We documented the observations in photos, sketches or notes. We exchanged our impressions after the meetings and discussed the conspicuous observations with the focus groups of relatives and employees, and continuously collected the most important information. Therefore, it was important for me as a researcher to stand back after observations and compare my impressions with those of stakeholders, as I did not want to anticipate something or influence their impressions. Thus, characteristic actions, behaviors, and movements can be observed. Furthermore, the integration into the social arrangement and the handling of objects by people living with dementia can be observed. We identified objects or materials which triggered a reaction through sensual perception. This was helpful to generate first ideas about how we can involve them later in the “CREATE” process (sensory exploration testing). At the end of this “HEAR” process we collected information and gained a better understanding of the major burdens of relatives and caregivers, and also the needs of people living with dementia and their problems with technical aids. We defined important requirements for the design concept which could address the needs of both user groups and find a solution which works for all involved. The aim was to develop a design concept which is as subtle as possible. In that way, the aid should not disturb the user and should therefore be less likely to be discovered and therefore rejected. Thus the burden placed on people living with dementia (and carers), resulting from the uncertainty and scepticism triggered by the unfamiliar device, should be reduced in advance. Consequently, relatives’ concerns about the risk of confrontation with negative reactions, on the one hand, and the burden of keeping people with dementia safe, on the other hand, should also be reduced.
3.2.2 CREATE:

The combination of methods of social research and methods of design research attempts to develop and shape the technologies in a need-oriented and human-oriented way. The decision to heavily involve relatives in the study makes it possible to include valuable information about people with dementia and their preferences. Thus the preferences can be involved in the concept and can be triggered again by the design objects through sensual perception. Sometimes it is possible to evoke faded memories. The Co-creation with relatives enabled the implementation of technical aids into the familiar surrounding environment and existing artifacts, which are already accepted by people with dementia. These can be furniture, dishes, garments or accessories: objects which have surrounded them already for a long period of their life. These objects are meaningful in a context of milieu therapy.

Cultural probes: According to “Cultural Probes”, collections of pictures or sketches of the life-world of people with special needs are created by their relatives. The visualization of one’s own life environment is difficult for people with dementia with advanced disease. For this reason, it is beneficial to include the information of trusted persons, since the family members have often accompanied the person concerned for a long time. In close proximity to the “biographical work”, they can provide additional information about familiar and beloved items, clothing and one-time interests that can be involved in design development (Osborn, Schweitzer, Trilling, 2012).

Sensory exploration:
The design research methods are increasingly focused on sensory aspects. I have attempted to investigate the subjective perception of the surface sensibility of the skin on different positions of the human body and the individual feeling of different materials as perceived by people with dementia (sensory exploration testing). Due to the decline in the condition of the people with dementia it was not possible to test together as we had planned. The risk of overwhelming the participant is one of the biggest problems in design research (Branco, 2014). Most of the people with dementia preferred the materials with a soft surface, but due to the low number of participants in the test we came to the conclusion that this method can provide meaningful information for the design concept, but was not representative enough to support our concept. That is why we decided on a design concept which makes it possible for users to have a choice regarding the materiality of the device, as the inclusion of the preferred
materials and colors could achieve greater acceptance and have a positive impact on the emotional relationship to the design object (Cummings, 1997). A well-accepted design of the objects can help reduce the negative feelings or confusion felt by people with dementia in the case of “discovering” the device anew (Pullin, 2009). Especially the positive effects of colors are actually often discussed and investigated (Marquardt, Büter & Motzek, 2014).
co-design with relatives and caregivers
For the co-design process, we noted that functions are not tied to a particular object or visual shape. They are invisible, do not have a specific materiality and can therefore be implemented in any “substance”. In collaboration with the experts we chose an approach we call “making-absence”: the focus is not the development of an additional lone-standing device. The aid must be able to be customised, and should also be adaptive, invisible, comfortable and not disturbing for people living with dementia. We define the concept as a “modular assistance system”, which can be integrated into already existing, familiar garments.

modelling shapes: The shape of the modular objects was created together with relatives, because of their valuable knowledge about the people living with dementia and their perceptions. I created and used design-artifacts in different ways and for different purposes during the research process. The artifacts worked as tools to support the communication with focus groups, as an aid for visualization and the imagination and also as a solution to solve problems and answer design questions (Jonas, 2004). At the beginning of the Co-creation process it was not easy for the relatives to think about the possible forms of the separable modules. A lot of them had difficulty considering possible shapes, their ideas were often linked with existing and available devices. I proposed a range of several shapes: in that way we could model these in the following process. After every feedback about the identified, preferred position on the body and the way of wearing the form, the prototype’s thickness, dimensions, material and form were adapted. The positions on the body were tested, changed and redefined in an ongoing process. The positioning of the technical aid on the garment can be determined by each individual diseased person or the relative independently.
Modular solutions can enable an individual implementation and the direct integration of life-sustaining and life-enhancing functions into the respective favorite garment. In addition, a modular concept is positive for ecological reasons, since the recycling of wearables is still a critical issue. Especially in fully-integrated electronics, which are interwoven or interknitted, it is hard to separate the components after the life-cycle of the garments. The requirement to consider ergonomic factors was conceived from the outset as an integral part of the design concept. Thus I tried to design a versatile solution.

*integration:* The artifact should be inserted as subtly as possible into the living environment of the person concerned. The “devices” remain largely invisible and can act as a support to milieu therapy (Staack, 2004). In this way the described confrontation with the rejection and the skepticism towards the aid is to be avoided, which could also increase acceptance. The modules can be removed by the wearer themselves; this is a conscious decision, as ethics in design is the focus here (Brock, 2013). The user should not feel disturbed by or be aware of the modules during wear (Branco, 2014).

![Figure 6. Different ideas for integration were tried.](image)
3.3.3. DELIVER

The involvement of relatives who provide informal care is also necessary for the procedure of testing and iteration, as they are best at “interpreting” the reaction and can assist in the “DELIVER” process (Branco, 2014). That is the reason why we decided from the outset to test in the familiar surrounding environment of people with dementia, in their homes, and without observation by the psychologist or design–researcher. After each testing an iteration of the design followed. The material and color can be changed in advance according to the
preferences of people with dementia. Generally, the material evolved continuously from one overall solid material towards larger, flexible and elastic parts to be worn in a more comfortable way. Finally, I realized a soft solution in silicone, which is transparent and makes internal electronic components visible. That is again a decision in favour of an ethical solution, which consciously does not hide the electronics in a kind of “black-box”.

Figure 8. Electronics moulded in silicone.
4. Why it is interesting to focus on using garments in the design and design-research process?

4.1. Advantage: Movement

Design research from the perspective of fashion design focuses on the human body and its continual movement. Currently, it is well known how important movement and the physical activity is for people with dementia. Movement has a positive influence on the progression and course of the disease (Hölter, 2011). The major effort of the case study was to not restrain the affected persons in their movement and daily activities. By directly integrating additional functions into a garment, these functions can support the user in particular ways. Technical support allows an increase in safety for the person concerned. At the same time, the possibility of mobility is maintained.

4.2. Advantage: Sensual perception through surfaces

Characteristics such as the materiality, smell and color of clothing have an influence on humans’ sensory perception. This perception is primarily a tactile experience and can sometimes not be articulated. At the same time, tactile perception does not require so much specific knowledge and is often still possible when cognitive abilities are limited. Insofar as the surface sensitivity of humans is not disturbed.

4.3. Advantage: Familiar surrounding

No other artifact of human habitat is as implicitly and ubiquitously connected with the body as clothing. Therefore, it is often referred to as the second skin. Its presence resembles a sociocultural imperative of Western cultures, since the body of a person is almost always covered by textiles of some kind. Above all in the Western cultural circle, the wearing of clothes and the nakedness of a person are related to the level of intimacy between people. Without clothing, many people feel defenseless. For each person, a garment is often associated with a protective space and privacy. It is only in the course of the disease that people with dementia increasingly forget to put their clothes on. Even if they forgot to put clothes on, in most of the cases, they do not feel disturbed by clothing and easily accept their relatives dressing them.
4.4. Advantage: Textile memories

Items of clothing and their representation in photographs evoke memories of a bygone era. The representations can reveal a segment of a past life that presents itself through a certain style of fashion. This can particularly appeal to the memory of people with dementia, because many people with dementia particularly like to look at photographs. Textile body surfaces are part of one’s own identity and favorite garments can be remembered by them for a long term of the course of disease. The selected garments already have strong emotional relationships, as they have often been worn for many years. For two affected persons of the focus group, these were particularly soft garments. These were felt to be pleasant, because the people with dementia suffered more from cold after the onset of dementia than before, due to lower activity. For other persons of the group, items such as important jewellery (e.g. a necklace with a large pendant), or a well-worn leather-cap for an older man, were chosen. In the participating observations it became clear that a certain style of a garment had an influence on the person’s manner. A person who almost always wore high-heeled shoes before the onset of dementia became more self-assured when wearing shoes with a small heel. It was as if the heeled shoes triggered her muscle memory. Her posture became more upright and she remembered moments of the past, her working life and the daily routine with her children.

4.5. Advantage: Surfaces and implicit challenges

The use of garments for integrating electronics into the textile allows the design-researcher and designer to add functions, without creating an additional, independent device. They can be integrated in a subtle and invisible way, when it is an advantage in the use case. The meaning of the textiles shifts and become anticipated more and more as a kind of interface, to interact with the environment, other people or themselves. In contrast to conventional fashion design, which primarily has an aesthetic function, designers in the area of wearable technologies delve into the complex field of technology design and technology development. This results in an interplay between sociocultural, psychological, physiological, economic, ecological, political and ethical implications (Milev, 2011).
5. Conclusion

5.1. The Process

- methods: During this design-research it became clear that the skills of communication in the transdisciplinary exchange are most important (Krippendorff, 2012); it was necessary to adapt research methods in an ongoing process (Cohene, Baecker, Marziale, 2005). We noted that sketches are more practicable than descriptions, whereby three-dimensional objects functioned better than two-dimensional visualizations. A wide range of possibilities is not always easier for those involved to handle and requires them to possess a certain capacity of abstraction (Krippendorff, 2012). Sometimes they have difficulties to find words to express their ideas and to understand the ideas described by the other participants in the focus group.

- relatives: Using a wide range of various quantitative, qualitative, design-research methods and co-creation, it can be possible to get insider information about the needs and requirements of people with dementia from their relatives. Often the informal carers are unconscious about their knowledge. This information is valuable for designers and design-researchers to help them understand the familiar environment of people living with dementia, their former interests and favorite preferences, which are increasingly more difficult for the people themselves to remember, enabling the designers to move towards solutions for the concept and design of artifacts or services (Cohene, Baecker, Marziale, 2005).

- testing: In a general testing situation with people living with dementia, the relatives are heavily involved. This can help to ease the difficulty of entering into the familiar surroundings of people with dementia as a design-researcher (Jonas, 2004). Through the participation of the relatives in this process, it is possible to also perceive small differences in the behavior of people with dementia. For the relatives and informal carers it is easier to recognize the uncertainties in their faces.
and body language and to describe these. Additionally, relatives are able to quickly recognize changes in the affected person’s condition and can inform the researchers of these developments. These insights prove to be invaluable information for design-researchers, who know the people with dementia usually for a shorter time and do not have the long-term relationship and experiences of living with them on a daily basis.

- **challenges:** An examination of this critical topic of technical aids makes it essential to also reflect on the implicit risks of monitoring, control, the loss of autonomy and the intervention in the social arrangement of people living with dementia. The research into the disease of dementia is not just a challenging topic with respect to the dimension of the critically-evaluated development of artifacts as technical aids, but also with regard to the design research process, in that dealing with the topic is made more difficult due to the changing phases of the condition and the progressive nature of dementia (Hendriks, Truyen, Duval, 2013). Therefore, the constitution of people living with dementia have a great influence on the planning and realisation of the research project.

5.2. The Solutions

There is no doubt, an individual design made by Co-creation involving people with dementia addresses their individual preferences the best, but it is not always the most useful approach when you attempt to reach a larger number people with dementia (Zeisel, 2013). It can be helpful to define the concept and the design of technical aids so that they have adaptive and hybrid capabilities. This can be important since each case of dementia is unique in its course of progression, the form of the disease and its different phases.
Authors’ Bio

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References


Designing a Safe City Eco System for “Wandering”

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Abstract
This paper introduces a successful dementia care program in Omuta City, Japan. The program, SOS Training, was not originally designed as a co-design project. It achieved co-design characteristics as a result of trial-and-error practice among public and private enthusiasts for making a better and safer community for people with dementia. As a case of substantial co-design participation of citizens that involves people with dementia, this paper points out challenges and opportunities for making Omuta’s program scalable and sustainable. The newly established design team that includes the authors, investigates potentials of the Omuta way of helping people with dementia.

Keywords: Wanderings, Co-design, Citizen Participation

1. Introduction
The growing issue of people with dementia getting lost and unable to return home is pushing more regional communities to establish official as well as unofficial elderly support frameworks at the community level. Recently, the Japanese TV reported a case of a senior with dementia that received a lot of attention from Japanese citizens. The senior woman at the age of 67, suffering from dementia, had gone missing for seven years before the police found her and returned her to her nursing home. During seven years, the police could not identify her name, address or other basic information. Similar cases have occurred on a daily basis. According to the Japan National Police Agency, 15,000 elderly people with dementia were reported missing in 2016, up from 9,607 in 2012.

The Japanese strategy to keep people with dementia safe has just been initiated at national, local and family level. Even though Japanese authorities often are criticized for their slowness, there are several notable cases reported of advanced senior support at regional level. For example, Omuta city, Fukuoka Prefecture, Japan, started a couple of dementia care and support initiatives in early 2000s and have continuously generated
successful results. The care and support initiative for people with dementia in Omuta is characterized by its varied level of regional support as well as its wide group of stakeholders and its many program varieties (see fig. 1). The stakeholders range from people with dementia and their families to the whole local community. Programs for supporting people with dementia stretch from official support programs (e.g. regional living support services and regional integrated care and dementia coordinators) to grass root activities (e.g., dementia educational programs and Sunday Cafe). The Omuta regional care eco system has been evaluated to be one of the most advanced and well-organized success cases in Japan.
This article aims at discussing future opportunities for citizen participation on solving social challenges related to dementia, based on the case of Omuta city. In spite of a few success cases including the Omuta case, many regions in Japan face difficulties in applying the approach of these success cases to their own areas. Although Omuta City is often reported as a successful case, the practices accumulated in Omuta city are not well articulated and therefore not disseminated widely. Their success to an extend merely a result of struggles with trial-and-error rather than applying a straight forward step by step design process with strategical means and methods: This makes it difficult for other regions to understand and replicate the Omuta approach. Considering scalability and sustainability of Omuta City’s success, it is of critical importance to externalize Omuta’s lessons into a more visible, tangible and learnable process that enables a systematic replication.

In the beginning of 2017, two core members of Omuta City senior service division, a regional care center manager and a municipality personnel in charge of senior care, invited the authors and three corporate researchers from the telecommunication industry to investigate the feasibility of establishing sustainable senior care programs in the Omuta area. After a few meetings, we agreed to establish a cross-sectional design research team to analyze, reorganize and disseminate “the Omuta way”. We were confident that it was essential to co-create solutions with citizens and people with dementia strategically to overcome the current challenges in Omuta. We assessed that the co-design approach would be beneficial for the purpose. We also believed that dissemination of the Omuta way and Omuta experiences and failures would contribute to the wider dementia communities.

First, the paper introduces one Omuta case and its unique characteristics from a citizen participation aspect. Then, current challenges are introduced. Finally, we discuss potential contributions of the newly established design team to the Omuta city and the wider dementia community.

2. Omuta City

On a municipal level, many prefectures in Japan are tackling the dementia challenges with a tremendous help from their local communities. The city of Omuta is no exception. Omuta, once a city of coal mining, is a typical rapidly aging city in Japan. Since
the last coal mine, the Miike Coal Mine, was closed in 1997, the population has decreased drastically. Currently, the population of Omuta city is 119,098 in October 2016. This is about half of its peak population of 210,000 in 1960 (City Omuta, n.d.). The percentage of the aging population over 65 years was 34.4% in 2016. This is the third biggest aging ratio in Japan. The last decade, local citizens have expressed their worries of people with dementia who lost their way and failed to be found for a long time. Helping seniors with dementia who wanders has become one of the most urgent problems to be solved together with other worries such as an increase in isolated deaths among the city’s elderly.

Pre- and post-visit self-assessment of quality of life and self-esteem through participant questionnaires.

Facing its serious demographic change, the city played a leading role in making a unique political decision. By coordinating with related public organizations, local NPOs and private care centers, the old mining city set the goal to make Omuta a leading dementia care city in Japan. In 2001, the city and all private care centers in Omuta gathered and established a Dementia Care Society concept as a response to an initiative by the citizens and a care center. They agreed to turn the city into a place “where the elderly can feel at ease to wander around” (City Omuta, n.d.). After this top down initiative of Omuta city’s Dementia Care Community Promotion Program, varied public and private stakeholders collaboratively created several programs to match the needs of people with dementia and their families.

We investigated current programs in Omuta and found that local citizens in need initiated many initiatives and disseminated them into a wider area of the city with public support. Based on the preliminary investigation, we identified five key pillars of Omuta Dementia Care Community, which contributed to the success. They were: 1) their unique philosophy (normalization person-centered care), 2) educational program of dementia coordinators, 3) establishment of physical space for supporting sustainable senior life, 4) eco system of education, license and public care support regarding senior care, and 5) citizens’ participation. Among these, we focus on the last “citizens’ participation” exemplified with one prominent program, SOS Training. As one of Omuta Dementia Care Community Promotion Programs, SOS Training depend strongly on citizens’ participation. We utilize the case for our concluding discussion on scalability and sustainability of Omuta programs.
2.1. SOS Training

Started in 2004, SOS Training formulates the critical participatory activities for Omuta city’s dementia challenge. SOS Training is an annual program, where residents of Omuta city can practice how to approach confused people found wandering in the city. The participants can acquire some fundamental knowledge about dementia through practice and discussion. Before the training, citizens often had to deal with seniors who apparently were lost on a daily basis. Although the citizens often suspected that such seniors were in trouble, their knowledge typically was too limited to take any action and to understand how to deal with the wandering senior. The SOS Training expanded widely soon after its introduction. In 2007, all areas of Omuta city became appointed as training areas by the program, and in 2011 all regional communities started to organize the training sessions collaboratively.

Since a school district often defines the minimal administrative community unit of a Japanese city, elementary and junior high school students participate in the program and often play leading roles. School students with their active mindset often succeed to recruit their family members, friends, local institutions and organizations to the program, and disseminate their learnings and experiences in action, reports and booklets. They often become diplomats of the local community influencing the wider community positively. To this end, the local municipal office has created a network that includes the police, fire department, post office, local companies, local communities and schools. The number of participants for SOS Training which was 311 in 2007, became 3,127 in 2015.

The training is a one day program. Participating residents have role-playing scenarios in pairs, while a few members act as lost seniors. Before going out to look for a senior who wanders, the participants practice a few key approach-phrases such as “Are you OK?” for caring, and soft voice training to avoid scaring the lost person. They also learn the reporting process of a missing person to the police and related senior institutions. After the group training, the participants go out into the city to find persons who play missing seniors. The training session is closed with reflections, interactions among participants and warm dinner. Through SOS Training, the ability to identify lost seniors in the region has increased. This is important. More importantly, however, the program also nourishes an intangible reciprocal
support system in the community. Omuta has become a place, where “citizens can watch over each other, and cooperate with people with dementia and their families” (Otani, 2015). Furthermore, the program generates a mindset of ownership of the program among citizens. By having wider participation of citizens, the training framework and its activities have been polished and elaborated along the way.

Since people with dementia were also a part of the training, they also have a say. For example, the program name was changed reflected by the voice of people with dementia. Originally, SOS Training was called the simulation training for the wanderings. Later, people with dementia claimed it was not wandering from their point of view, and renamed the program as SOS Training.

3. Discussion of the Omuta Way

In addition to SOS Training, many other Omuta Dementia Care Promotion Programs were created and promoted as shown in Fig.1. Many of them are innovative and well designed. This has contributed to establish a favourable reputation of Omuta city. The programs influence each other and support each other with a weak–tie. They define an organic eco system that supports people with dementia, their families, and other citizens in Omuta city. The current success of Omuta city is a result of both top-down and bottom-up approaches. After 15 years with trial-and-error practice, Omuta city has involved many local citizens in different generations and at different participatory levels.

However, Omuta city has now questioned whether their dementia care system is sustainable. Although many parts of the Dementia Care Promotion Programs in Omuta were promoted and carried out through participation of citizens, there was a strong leadership of a couple of core members who made extensive efforts to realize the programs. Many of them were professional care givers, and now they are also aging. They stand on the other side of care service after 15 years of practice. In other words, the support community behind the Dementia Care Promotion Programs consisting of private as well as public enthusiasts and citizens with entrepreneur mind-sets are now in need of a generation change. The older members should give way to new and younger citizens. A certain kind of community of practice (Lave & Wenger, 1991) exists, and generation shift in the community is needed. For a sustainable community, it is important to recruit new citizens, educate them in leadership, maintain the programs, and take down practice to the new care citizens to make the support community sustainable.
4. Reflection and Conclusion

Several Omuta Dementia Care Promotion Programs such as SOS Training have strong potential for improvement and empowerment through co-design practice (e.g. Binder et al., 2011; Hendriks, Slegers, & Duysburgh, 2015; Hillgren, Seravalli, & Emilson, 2011). As mentioned earlier, some of the programs are already conducted in a co-design style with people who have dementia and other local stakeholders. The practice indicates the limitations of providing dementia care without presence of people with dementia. The approach of the Omuta Dementia Care Promotion Programs is characterized by its co-design mindset generated by trial-and-error experience in practice. People at stake need to have in-depth understanding of local conditions around people with dementia and knowledge from field observations and daily practices. This practice based problem-solving approach embodies one of the key aspects of a sustainable design community.

The Omuta case has similarities what European co-design projects for social innovation and social challenges in dementia care. Branco (Branco, Quental, & Ribeiro, 2016) shows the importance of stakeholder participation and the resulting personalization of the design artifacts when collaborating with people with dementia. Hendriks et al. (2015) emphasizes values to involve people even though they are with cognitive or sensory impairments in the process of designing social solutions for their life and within their local community. The Omuta case also exemplifies the necessity to involve local stakeholders since it is an efficient way to provide solutions to societal challenges with high complexity and uncertainty.

Based on the Omuta case, we see a huge potential in reformulating and making a theoretical foundation for the successful programs especially from a co-design perspective in order to sustain and improve their sustainability and scalability. For sustainability, it is an urgent matter to extract the essence of Omuta’s practice based problem solving approach and the tacit knowledge behind the success of Omuta. The co-design practices in Omuta were not intentional nor strategically designed with design researchers, but mere spontaneous responses to local needs through trial-and-error practices. In other words, the Omuta co-design mindset and field-based approach was constructed by ordinary citizens and social workers out of necessity. Currently, Omuta faces a generation change challenge. Hence, Omuta has to search for a way to maintain its own eco system without initial entrepreneur minded practitioners. Also for scalability, it would be beneficial to externalize Omuta’s approach to make it implementable in other socio-cultural environments. There are many aging cities and communities in Japan and the world with similar challenges. Some Japanese cities have tried to follow Omuta’s way, not all successfully. From Omuta’s approach, we have
learned the importance of stakeholder involvement. However, we do not know clearly what the essence is of the Omuta way, or what kind of methods and approaches that can be utilized to transition this successful story to other communities.

The newly formulated design team in Omuta that include the authors, is going to act for new potentials of sustainability and scalability of the Omuta way. We do so through co-design with senior citizens by utilizing living labs as a tool (Christiane, Winthereik, Malmborg, & Andersen, 2009; Kareborn & Stahlbrost, 2009). We believe that the advancement of sustainable safe city eco systems resides in co-design with seniors and other public and private stakeholders to which design researcher can contribute.

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Author Bios

Mika Yasuoka (Ph.D. Research Associates, Technical University of Denmark) has directed research projects applied design methodologies, especially stakeholder involvement methods (from in-depth user studies to co-creation) to design advanced IT systems and services for social challenges in collaboration with international universities, industries and local communities.

References


Person-Centred Design for Dementia: Design insights from three in-context case studies

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Abstract

Due to the ageing population, the number of people living with dementia increases rapidly. People in society sometimes conceive them as a problem or a burden. In this paper, we present a different perspective, where we aim to empower people with dementia to become more self-reliant through design.

Based on a person-centred care approach, this study presents three design cases that target people with dementia as the direct user. These cases are used to find which aspects work well to allow people with dementia to interact well and aim to stimulate the discussion on personalisation, enablement and using the capabilities of people with dementia in design.

In this paper, we present three case studies: Case study one focuses on a musical pillow for people with dementia. Case study two describes a personal booklet for people with dementia. Finally, case study three focuses on early stages of dementia and covers an interactive family radio to listen to family provided sound fragments and stories.

These case studies portray how we can design for persons with dementia directly, rather than only design for the people around them. With this work, we aim to inspire other researchers and designers to change their perspective on the development of new concepts for people living with dementia.

Keywords: Person-centred care, Design, Dementia, qualitative, case study
1. Introduction

Dementia is characterised by gradual deterioration of cognitive abilities such as memory loss, impaired language, personality changes and memory challenges (Prince, Prina, & Guerchet, 2013). The most common form of dementia is Alzheimer’s disease, accounting for about 70% (Prince et al., 2013). With the ageing society, the number of people with dementia is increasing rapidly as well. The number of people with dementia is expected to double by 2050 causing grand societal challenges. This challenge pertains to both costs connected to the care of dementia and the personally experienced quality of life by those with dementia.

The design of new (technological) interventions can be one approach to address this challenge, and improve the quality of life and increase the independence of people living with dementia. However too often people with dementia are not involved in such design processes (Mäki & Topo, 2009) or considered as direct users of interventions (Brankaert, 2016).

In literature, we see that technology can play an essential role in supporting people living with dementia. However, in the field of assistive technology, we know that studies often ignore the real-life context (Brankaert, 2016). Mäki and Topo (2009) only found five out of 66 papers to take a real-life setting into account when designing assistive technology for people with dementia. In this study, we discuss three examples of (technological) solutions designed for people living with dementia directly. Such design proposals can help to change the perspective on how to position people with dementia and promote the discussion of seeing them as equal stakeholders in dementia care and design. Furthermore, people with dementia each are different, just like every person is different. The design process should take this difference into account. Person-centred care can inspire us in how to achieve these goals.
2. Person-centred care enabled by design

Experts in dementia care consider person-centred care as a useful care strategy (Kitwood & Bredin, 1992). This approach focuses on the individual perspective of people with dementia as the starting point for care. Kontos & Martin (2013) argue for the body being an integral part of selfhood – to extend person-centred care – and introduces the idea of ‘embodied selfhood’, which stresses knowledge of the body’s ‘natural intercourse with the world’. These and other advancements in person-centred care have contributed significantly to improving the quality of dementia care (Dupuis, Wiersma, & Loiselle, 2012). ‘Bodily knowledge’ – the idea that the body knows how to respond without cognitive deliberation – can also be used in technology design for people with dementia.

Despite these advances in person-centred care, there is still need to apply this concept to increase the quality of dementia care (Dupuis et al., 2012). Trends such as staff shortages, high workloads and insufficient time are related to this deficiency in the quality of care. A literature review concerning the quality of life for people with dementia explicitly reveals the importance of experience. Various studies elaborate on the fact that the first-person experience of impairment, e.g. needs, support received and the concept of agency, affect the quality of life and thus increases the reliance on others (O’Rourke, Duggleby, Fraser, & Jerke, 2015).

By considering individuals and their experience in the design of their environment and care approach we can improve their situation. Moreover, technology and design can play a facilitating role in supporting person-centred approaches in dementia care. Three case studies portrayed below, show how we can design for a person with dementia from a person-centred perspective. With this work, we aim to inspire other researchers and designers to change their view on design for dementia as well.

3. Method

In this paper, we analyse three design cases, from student design projects at the University of Technology Eindhoven, Department of Industrial Design. The designers evaluated the concepts in context, and these results have been gathered and coded. Based on the shared qualitative themes that emerge from this data we formulated four design insights. Furthermore, we support the topics found with findings in the literature. Some of the subjects are already elaborately touched upon in other studies. However, some of the insights provide new perspectives to ideas of others. The aim is for this analysis to be explorative, allowing shared themes to surface from our dataset, and thus add to existing knowledge on design for dementia.

In total three cases are included: (1) Discover dementia experience pillow, (2) personal activity booklet and the (3) Stay-tuned radio. In each of these design cases we found
design aspects that are beneficial for the usability and overall quality of the design. Furthermore, these design cases show how people with dementia directly can benefit from interactive non-pharmacological solutions. The work shows aspects that are important to facilitate usability and adoption by people living with dementia.

**Case study 1: Discover Dementia Experience Pillow**

*Concept:* A strong example of person-centred care enabled by design is the Discover Dementia experience pillow, designed by Eriano Troenokarso (Bachelor’s graduation project, Industrial Design). The cushion (Figure 1) has twelve patches. By touching these spots, users of the system can play sound and music fragments. The sound fragments are personal and selected together with family members to elicit meaningful memories and responses from the person with dementia. The pillow can be used individually or with family members to explore the personal sounds.

*Evaluation results:* The designer created the system through an iterative design process, in close collaboration with care organisation Land van Horne. This partnership ensured that person-centred care values were actively present in the concept. Results from an informal evaluation with four residents with late-stage dementia were auspicious. Some of the residents responded with strong emotions to the sound fragments. For example, one person, who did not answer in 1-on-1 conversations, was enlivened by a piece of music and sang along with a smiling face.

*Reflection:* The pillow shows how people, even in the later stages of dementia, can be included in an iterative design process. Thereby, the focus on reminiscence of experiences benefits the design. Furthermore, the fabric sensors are very suitable for people with dementia. Overall the pillow is not only designed for people with dementia but also carefully considers the role of caregivers and family members in the use of the cushion. Overall, the evidence base for music interventions in the context of dementia is significant for its therapeutic effect on agitation and anxiety. This design facilitates interaction to stimulate use.

![Image of the Discover Dementia experience pillow in practice](image-url)
Case study 2: A personalized booklet

Concept: In this design research project Martijn Roza (Master’s project, Industrial Design) developed a personal activity for a person with advanced dementia. The first probe – a cushion with ten small ‘activities’ – delivered the insight that personal history and a mirror worked very well for this person as an activity. These were subsequently integrated into a booklet shaped design (Figure 7.3).

Evaluation results: The designer created the concept specifically for one individual, and therefore the booklet was only evaluated by this person. The design provided a personal activity for this person that occupied him for more extended periods. This occupation gave more freedom to the caregiver as more time became available due to this design.

Reflection: In this concept tangibility and familiarity proved to be essential aspects to engage the person with dementia. Moreover, the process showed that personalisation is a valid strategy to increase adoption of the design. The first iteration included many options (the cushion). The second iteration allowed for maintaining those that were successful for this person (history and a mirror, see figure 2). By probing the real-life context with an early design, the designer found a suitable concept in a relatively short amount of time.
Figure 2. Personally designed activity probe for a person with dementia.
It was found that communication improved, and the messages were perceived more directly by the person with dementia. The people with dementia enjoyed this way of keeping up to date with the activities of their family.

Reflection: The system allows people with dementia to stay in control and thus improves their self-reliance. The interaction is simple, as Orpwood and Colleagues (2004) show that a typical cd-player interface can already be problematic. Also, the interface and appearance are kept physical and familiar regarding interaction (buttons), aesthetics (radio) and presentation (pictures), supporting usability and adoption by people living with dementia.

4. Results

Based on an analysis of the qualities and evaluation of the design cases a set of design insights were found. Simplicity in technology for people with dementia is known as an essential consideration. Devices should be easy to learn and require little interaction (Orpwood et al., 2004). Besides, technology should avoid chains of action (Rosenberg, Kottorp, & Nygard, 2011). Because people with dementia are impaired, designers need to consider these aspects and implement them in design. In all three cases, simplicity is a critical factor in the interaction, showing how this is beneficial for interaction design for dementia.

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Case study 3: Stay-tuned radio

**Concept:** The Stay-tuned radio is a communication concept designed by Marjolein Wintermans (Master’s graduation project, Industrial Design). The device integrates WhatsApp® (a popular messaging application) with a simple 60s radio shape exterior (Figure 3). Family members, portrayed by small pictures on the front of the system, can record voice messages and send them directly to the radio. The person with dementia can listen to these sent messages by selecting one of the pictures. The interaction is therefore familiar and straightforward, one knob for volume and one to choose a person’s photo to hear their stories, in this way a person with dementia can interact with the system directly and individually.

**Evaluation results:** The designer evaluated the system in a ten-day in-context evaluation, with two people with dementia and their caregivers (Wintermans, Brankaert, & Lu, 2017).
Personalisation is another concept that works well for people with dementia. We have seen that the person-centred care approach promotes this quality as well (Kitwood & Bredin, 1992). In technology, however, this is challenging and only a few examples of electronic health (e-health) approaches encompass this. The discover dementia pillow amplifies this by offering personal music through a platform, much like an iPod delivers various kinds of music for different individuals. Additionally, the personal activity probe (booklet) showed how personalisation could become part of a technology design process for both early and late-stage dementia care solutions to increase usability and encourage adoption.
Personalisation is related to familiarity, as what is known and recognised by somebody differs per individual. In the literature, recognisability is considered as necessary in technology for people with dementia (Orpwood et al., 2004). We aim to elaborate on this aspect and extend the dimensions. In our thematic analysis, we found familiarity contains several levels such as recognition of the shape (such as the stay-tuned radio shape), the interaction (such as the stay-tuned rotating buttons) and recognition of oneself (such as through the mirror in the booklet).

Furthermore, the aspect of physicality was found, as a quality that supports clarity of both use and appearance. So, simplicity is related to physicality, making interactions more direct. Mäki & Topo (2009) mention clear visibility is important when designing technology for dementia. During the evaluation of the stay-tuned radio we found that physically distributed interface elements increases clarity and visibility. Also, in the Discover dementia pillow, we found that the aspect of tangibility contributed to the ability of people with dementia to interact with the design, and have a direct response to their action.

Finally, the theme empowerment contributes to the recommendation to improve the independence of users by the technology designed (Mäki & Topo, 2009). Besides, people should also become more self-reliant through such technology design proposals. The musical pillow demonstrates this by enabling people, even in the far stage of dementia, to interact with their favourite sound fragments. The Stay-tuned radio is another example. The system allows for people with dementia to directly keep up to date with the activities of their family. In this regard, we should not consider the impairments of people living with dementia, but rather the abilities they still have.

5. Discussion

Based on the analysis of our design cases we found five themes that were relevant to enable self-reliance and interaction in design for people with dementia. These were the following: Simplicity, Personalisation, Familiarity, physicality and Empowerment. Two of these insights were already familiar in the literature such as
simplicity and familiarity. However, the insights concerning personalisation, physicality and Empowerment brought new knowledge to literature.

5.1 How to use the design insights

We intend the design insights to be an addition to existing design principles in design for people living with dementia. The three specific design insights highlighted above might, however, not provide a complete overview of everything that is important as we extracted them from a limited set of design cases, however, they might offer new perspectives for others aiming to design for dementia.

We think these insights are useful in the exploration, design and evaluation phases of design and research processes for this specific target group. In the exploration phase, they are helpful to generate ideas and find new opportunities. In the design phase, these insights could enhance the experience and interaction design of technology. Finally, these insights could be used to reflect on a design proposal to find areas of improvement.

5.2 Conclusion

Through the paper, we have seen how the concept of person-centred care and our design insights can aid in design for dementia. By putting our proposals in context, we found solutions for people with dementia to be directly used by them, instead of for them. Some of the cases demonstrate a straightforward translation of the insights, such as the Discover Dementia pillow with which a personal soundscape is used to evoke a response, and seeing people with dementia to experience this allows us to reflect on the design and make decisions accordingly. Moreover, other cases show the importance of focus on the persons with dementia directly. The Stay-tuned radio, for example, enables a person with dementia to perform specific tasks they could not do before and thus increase their self-reliance. This approach is person-centred, as we developed these design proposals to be used by people with dementia themselves. Considering the personal aspects of the individuals stimulated and inspired the design process.

The perspective of person-centred care and in context evaluations allow us to focus more on the experience people have rather than the characteristics of the disease. This view contributes to the quality of life as indicated by people living with dementia themselves (O’Rourke et al., 2015). Such design proposals consider all of the involved perspectives. Our design insights support this reflection process, which enables us to improve the quality and increase the impact of design proposals we create for people with dementia now and in the future.
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References


Co-creating stories with people with dementia: experiences of using a cards game in familial and institutional settings

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Abstract

This paper presents the development and use of a ludic artefact, a cards game to co-create stories, that emerged from the collaboration with a person with dementia and her family. It describes the process of involving this family, who engaged in the definition of a design brief that responded to their needs and preferences, and how they experienced using the artefact. The artefact was also utilised in two different institutions for the elderly within the activities conducted by healthcare professionals. Based on direct observation, and on interviews with family members and healthcare professionals, these different uses are described and analysed, stimulating a discussion of how to promote an adequate and sensitive use of artefacts that are designed to be used in familial contexts, without the presence of healthcare professionals.

Keywords: codesign, dementia care, experiences of use
1. Introduction

Person-centred dementia care emphasises the importance of supporting people with dementia to communicate, building and maintaining relationships within a rich social environment (Allan & Killick, 2008; Brooker, 2007; Killick & Allan, 2001; Kitwood, 1997). The artefact presented in this paper is an output from a participatory design project that explores how design can provide personalised opportunities for people with dementia to communicate, and thus stay in relationships, particularly with their close social circle. In this research, personalisation becomes both as strategy and an approach to involve people with dementia and their families in a respectful manner, attending to their uniqueness and personhood. Several aspects of the project, such as the artefacts, the brief, as well as the process, are left open so that participants can redefine them according to their individual needs, availabilities, preferences and stories (Branco, Quental, & Ribeiro, 2017).

After a preliminary observational study in two care institutions, where the researcher participated and helped as a volunteer in several activities for people with dementia (Branco, Quental, & Ribeiro, 2015a; 2015b), three previously designed open artefacts were the starting point to invite people with dementia and their families to participate in the project. Participants were asked to personalise one of these artefacts in order to make it more adequate and engaging for them. In this paper, we describe the case of Laura (a lady with mild dementia who attends the day centre in one of the institutions) and her daughter Matilde\(^1\), who did not find any of the three initially proposed artefacts relevant and adequate for them, either because they did not suit their routines, were difficult to use due to the lack of common interests among the different family members, or did not correspond to their preferred activities. Alternatively, we proposed participants to collaborate in the definition and development of a new design brief that responded to their needs and preferences.

2. Definition of a new brief

Drawing on the person–centred thinking tools (Bailey & Sanderson, 2013), used by dementia services to gather information in order to deliver individualised care, two exercises were created in order to engage participants in the definition and personalisation of a design brief: one exercise about how a good day would be like, to understand what they

\(^1\) The real names of participants have been replaced to preserve anonymity.
like and dislike doing, their interests and preferences, and another one about their weekly routine (Branco, Quental, & Ribeiro, 2016) (Figure 1). The ‘good day’ exercise was conducted with Laura who revealed her constant need from being with others, and her enjoyment of conviviality, conversation and laughing. The ‘weekly routine’ exercise was done with Matilde. Since the family’s routine was rather busy, the activity was required not to imply too much time and effort. This exercise also prompted a long conversation about Laura’s difficulties and behaviours due to dementia. The diversity of interests among family members was clear, so it was agreed that the new artefact should encourage them to collaborate on an activity that was not focused on specific themes, enabling a feeling of creating something together. Due to Laura’s memory problems and difficulties in following precise rules, the artefact should not have right or wrong answers. Instead, it should trigger creativity and humour.

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**Figure 1.** The ‘good day’ and the ‘weekly routine’ exercises.
2.1. The story-making card game

The insights collected in both exercises and the observation of the very active and creative participation of Laura in the activities promoted by the institution she attended, influenced the idea of designing an activity where new stories could be co-created. The family agreed with the new activity proposal and was disposed to try it, but did not show availability to participate in its development. While doing the ‘good day’ exercise with Laura, we noticed that it was much easier for her to speak about her interests based on the multiple-choice suggestions. This is explained by Sabat (2014), who distinguishes recall and recognition as different ways of remembering, and affirms that the ability to recognise is commonly preserved longer in cases of dementia. In this way, narrative elements could be suggested for people to choose from, talk about and put together to create a story. The story-making card game was the result of joining these considerations in a familiar, tangible, economical and easy to use format. It is a set of cards composed of five different categories: characters, places, verbs, adjectives and things. Characters and places are represented with images and the other categories with written words (Figure 2).
2.2. Pictures and words
The decision to present some of the categories with pictures and others with words was related to the aim of providing different stimuli, which could result in different responses and serve distinct preferences and abilities. Allan (2001) describes her approach of using cards with both pictures (people and objects) and words (emotions) to elicit people with dementia to express their views, in their own terms, about the services provided to them. Pictures and words were used to support people to speak about their experiences indirectly or as direct triggers for discussion. Additionally, they were also used to spend time together and communicate with staff, which sometimes also helped people with dementia to relax. Although pictures are more commonly used as cues for conversation and storytelling (e.g. Timeslips, SeeWhatIMean), Allan (2001) observed that “it definitely seemed that having the words easily visible helped to promote the fluency of the conversation” (p.61).

Since the main goal was to stimulate creativity, the use of general (rather than personal) pictures seemed more appropriate to eliminate the pressure of recognising personal references. This influenced the decision to make simple illustrations, which also responded to the intention to reduce a picture to its essential (removing unnecessary visual inputs that could be too demanding or confusing) while allowing some degree of interpretation. Being aware that illustrations could be considered childish, there was an effort to make them as neutral as possible.

2.3. ‘Hidden’ personalisation
As already referred, reminiscence was not the focus on the activity. However, the materials were partially personalised with a few personal preferences and references to Laura’s life history, so that she identified with the content on the cards, facilitating recognition and conversation. For instance, Laura referred her appreciation of being by the sea, thus several sea–related cards were included. This decision was also influenced by Laura’s response to the ‘good day exercise’. Although not asked directly, the exercise materials triggered her to share personal stories. It was also envisaged that, after trying this prototype, a new one could be ‘more personalised’, involving Laura in creating her cards, with words and images chosen and drawn by herself and/or conjointly with family members.
3. Responses to first use

The prototype delivered to the family was accompanied by a proposal of use: each player gets a card of each category randomly (randomness could give origin to funny, non-sense stories, thus putting humour into play); then, in each turn, the player places one of the cards on the table, adding that element to the story that is being created. It was also explained that there was no right or wrong combination of cards and that players could freely add something to the story that was somehow related to their cards. It was suggested that they could add or reduce the number of cards if they found it necessary, and that the first player to finish the cards could be the winner.

3.1. Family’s response

Matilde reported that when they started playing with other three family members, Laura started participating inappropriately, diverting to things that were not in the cards. She did not respect the turn of the other players and made inadequate suggestions. Despite her initial interest, after a while Laura got tired from being there and left:

“I explained the game to my mother three or four times, that she should continue the story. I encouraged her to start, but she refused, so another person started…. But then she wouldn’t carry on with the story. She started talking nonsense and turned off.” (Matilde, 15.03.2017)

Matilde explained that for them it was difficult to entertain Laura, since she loses interest in most activities after a short while:

“The problem was not the game. The problem is that she cannot keep focused on anything. ... If she is talking with others, she might pay attention, but when there are some kind of rules, or that others need to intervene, it’s over. She loses interest.” (Matilde, 15.03.2017)

The family also recognised that maybe trying another day, another time (it was after dinner) or maybe with her peers at the institution the game could work better. However, in general, they did not believe that Laura would engage in the activity as intended.
3.2. Comments from the Health Professional

After the family’s unenthusiastic response to the artefact, we sought comments from a healthcare professional to understand the artefact’s adequacy and how it could be improved. The feedback about the materials was very positive. However, the game dynamics was probably too demanding for the person with dementia. In addition, since the family had the expectation that the stories created had some logic, they might have added even more complexity to the activity, which is likely to partially explain why the family found their relative’s participation inappropriate. Based on these comments, we proposed to both collaborating institutions to use the cards during their activity sessions, involving several healthcare professionals and people with dementia in trying, providing feedback and contributing to the definition of different uses for the story–making card game.

4. New definitions of use

The story–making card game was used in four activity sessions with people with dementia, conducted by healthcare professionals: two group sessions of cognitive stimulation in one institution, and two arts–based sessions involving small children in Laura’s institution. After the success of these intergenerational sessions, this nursing home organised an event dedicated to the story–making card game, where residents from other institutions and children from the nearby kindergarten were invited to participate.

Although all sessions were different due to the group dynamics and to how the activity was facilitated, it was possible to observe similar approaches. In general, healthcare professionals reduced the number of cards used in each activity (no more than two or three cards per category). They invited all participants to choose their card (only one) and encouraged them to speak about the chosen card. In smaller groups, they supported participants to work together to fit all the chosen cards into one story. In most sessions, there was also some emphasis on registering the stories through drawing and/or writing, or in telling it to the others. Based on these experiences, three new suggestions of use were defined:

1. using only the picture cards: choosing one card, speaking about it, and drawing or writing something related to it;
2. co–creating a story: choosing one card, speaking about it, bringing together all the cards in small groups to co–create a story, and sharing it with others;
3. associations: in a small group, choosing one card and making possible associations between all the selected cards. This approach emerged in a smaller group of four participants, who intuitively started using it in this way.
5. Responses to institutional activity sessions using the story-making card game

The following insights were collected in the observation and comments from healthcare professionals and people with dementia at the end of the sessions using the story-making card game, as well as in posterior evaluation interviews with five healthcare professionals (psychologists) who used the game.

5.1. Attention, interest and fun

All professionals who used the game were enthusiastic with the results. They highlighted the interest and attention of participants over a long period of time (around one hour or more), and the pleasurable and easy-going environment generated. In general, older participants referred to have enjoyed creating stories with the cards, except one participant who said the activity had no interest for him. Participants described the activity as entertaining, fun, novel and creative (Figure 3). Laura integrated the two sessions and the event organised at the nursing home. In all occasions, she demonstrated interest and participated actively, contributing to the stories and making drawings.

Figure 3. Written feedback from a participant about the event: “In this activity I felt happy because we all shared and lived things with animation. Thus, it was very good.” (13.07.2016).
5.2. Creativity and inclusion

Some participants considerably appreciated conceiving the stories, for being a stimulus to their creativity and imagination. One participant with early dementia also referred that “creating the story makes the activity more meaningful” (Fieldnotes, 17.05.2016). Some professionals reinforced this creative aspect, considering that the cards enabled freedom to make different interpretations and associations, many times unexpected and improbable. In this way, there was an ‘absence of error’, which is particularly important to promote a pleasurable, relaxed and inclusive environment when working with people with dementia:

“As the game progressed, the participants got more at ease and contributed more to the story…. I noticed that they felt secure about what they were doing, I believe they didn’t feel frustrated. I think they felt valued for having contributed to the story.” (psychologist A, 29.03.2017)

Another healthcare professional emphasised the collective aspect of the activity, which managed to bring together and include people with different abilities, who could contribute without being judged:

“Even if we were all in the same group, around the same table, …the activity doesn’t expose the capacities or difficulties in the task. The activity involves you regardless of what you can do.” (psychologist B, 14.03.2017)

According to another professional, this involvement occurs mainly due to the invitation to choose a card:

“the cards even managed to unlock the people with more cognitive difficulties. … In this activity of co-creating a story, obviously, there will always be some people that perform better than others, but the fact that we asked them to pick a card allowed everyone to be involved in the activity. Many times, in the activities, people lose attention. In this way, everyone was involved, even if they only picked the card and held it while they waited to see how it would fit in the story. They have a role in the activity. In this case, we don’t speak as much of individual cognitive stimulation, even if it has that potential, but about the group well-being.” (psychologist C, 04.04.2017)

It was also referred that the game encouraged participants to listen, accept and work with the choices of others, which can play a part in respecting everyone’s contributions and pace regardless of their condition (i.e. reinforcing inclusiveness of people with dementia). Therefore, some professionals highlighted the icebreaking qualities of the game, important to promote socialisation and comfort, which could also make people at ease to participate in other group activities promoted in the institution. Some participants with dementia also valued the collaborative aspect of the game, even if it added complexity to the activity:

“Mr C found the game entertaining and appreciated the coordination of everyone’s cards, the fact that all participants contributed to the same goal. Mr A agreed, but thought it was challenging because they were many people, thus many cards to bring together.” (Fieldnotes, 24.05.2016)
5.3. Flexibility and facilitation

Several participants found the cards interesting, simple, easy to understand, and mentioned that they facilitated the creation of stories, which worked as an encouragement of participation:

“It isn’t intimidating, and there are many things that are easy to recognise. In this way, we give the necessary encouragement to do the activity.” (psychologist A, 29.03.2017)

All healthcare professionals valued the multiple possibilities of choice that the game offers, both for the people participating in the activity, as well as for who is conducting it. Some professionals reflected on the effects of this possibility of choice. On one hand, since for some people with dementia decision-making becomes harder, it might generate some apprehensiveness. On the other hand, it can make people feel that they are in control of what is happening, thus more secure, creating proximity to the activity.

The use of words and pictures was considered stimulating, and helpful to unblock language and narrative:

Having both words and images was also instrumental in including of people with different abilities. Images were more flexible and easier for those whose language is weaker, whereas the words became stimulating for people with fewer difficulties, and even those without any cognitive impairment:

“It integrates two distinct realities, and this makes the game very complete. It is possible to easily adapt to people with and without cognitive impairment.” (psychologist E, 23.03.2017)

Although adding complexity, the incorporation of adjectives and verbs was appreciated since they instantly facilitated building a narrative. The pictures were found more appealing and captivating, having generated a positive conversation dynamics, which added to the fun and joyful environment.
5.4. Possibilities of personalisation

Since the story-making card game was partially personalised for Laura and the possibility to develop it in a more personalised way was taken into consideration, we asked healthcare professionals about their views on personalisation regarding this artefact. Even if the game had some personal elements of the participating family, these were general and diverse enough to be relevant for everyone. Most professionals did not believe that personalising the cards was beneficial since they already allow the activity to be personalised through playing:

“When I interpret an image, I am automatically personalising. My life history will have an influence on how I deal with the images or words and the associations I make with them. In that sense, the game is personalised at each moment.” (psychologist 4, 23.03.2017)

However, one professional also pointed out the potential of using a personalised version of the artefact to do more individual life history work. The fact that pictures and words are not personal allows the person to identify his/her own history without the pressure of recognising people or moments, and to speak about it in his/her own terms.

6. ...valuable in institutions, but how to ensure an adequate and pleasurable use at home?

On the one hand, the story-making card game was appreciated both by older participants and healthcare professionals for acting as an incentive to creativity, allowing great freedom in how people contribute to the activity by embracing improbable and nonsense associations, thus lessening the possibility of error. In this way, the game provided an inclusive activity that enabled people with different abilities and ages to take part, generating a pleasurable environment and well-being in the group. Professionals valued the quality, diversity, ease of use and versatility of the cards, which held interest and attention, and encouraged involvement among the participants. The combination of pictures and words contributed to the collaboration between different people and permitted professionals to adapt the activity to different needs. Images were considered visually rich, not infantilising and descriptive, and more adequate for people whose language is weakened. Words, namely adjectives and verbs, facilitated narrative. The story-making card game was found appropriate and valuable in institutional contexts, working well in small groups. Most professionals also highlighted the qualities of the game to work different cognitive domains, namely language, thus having a potential to be used therapeutically in cognitive stimulation programs. On the other hand, Laura’s family said they were unable to engage her in playing the game, thus not accomplishing its intended purpose of promoting a collective and convivial activity with their relative. New activity instructions were created and delivered to Laura’s family, based on the playing experiences in the institutions, but the family did not play it again.
The disparity between the experience of using the story-making card game at the institutions and at home, as well as the differences between Laura’s involvement perceived by her family and observed in the institution, initiated a discussion on how to ensure an appropriate and enjoyable use at home. Despite all the already acknowledged potential and positive outcomes that the game can provide, the cards are not enough to yield these outcomes. Professionals reinforced the argument that the success of the artefact highly depends on how the activity is conducted, as well as on the group, on the room setting, and on facilitator’s sensitivity to observe and adapt the activity to each person, taking into consideration their abilities and mood. In a family context, high expectations, fatigue, emotional charge, lack of sensitivity, and the attention centred on only one person with dementia can be some of the reasons that might lead to an unsuccessful experience of playing:

“What bothers me to play this at home is that there will only be one patient. Everyone will be focused on her deficits, on the disease. It might become more heavy than ludic. ... It also depends on how is the family dynamics, if they are worn out, if they don’t understand that some of the behaviours are symptoms and think the person is being stubborn or ill-disposed... if the family is not working well, then any strategy to implement at home will also be difficult.” (psychologist 3, 04.04.2017)

Professionals recommended that further guidance for using the cards should be provided, suggesting different possibilities of play, with various levels of difficulty, in order to demonstrate how the activity can be adapted to what is adequate and engaging to the person with dementia. This versatility might allow the family to adapt use throughout the progression of dementia, and suit different availabilities. It was also proposed that the artefact should be presented less as a game and more as an activity. While the idea of a game might be stimulating, families might associate it with having specific rules and becoming less flexible about their relative’s response to the activity. Instead, the creativity and humour prompted through playing should be emphasised, challenging the family to ‘lose their filter’ of rationality and logic. In addition, it was mentioned that it would be important to encourage sensitivity, possibly by including some guidance on how to communicate, pay attention to their relative’s reactions, adapting and responding accordingly.

After these interviews, the story-making card game was given to another participating family that was willing to try it. The different ways of playing used in the institutions were provided, and some of these considerations were shared with family members. This family reported that they laid out several cards, words and images, on a table, and asked their relative with dementia to pick a card and make associations:

“The themes were always very simple, like words related with home, money... In general, he reacted very well to the stimulus and was able to make some interesting relationships between words.” (family member, 26.05.2017)

The picture cards were mainly associated with his life history:

“For instance, starting from the card with the church, we spoke about my parents’ wedding.... Of course, he did it with lots of help and many memory lapses. The most important thing is that he was always, during about 45 minutes, very collaborative and participative.” (family member, 26.05.2017)
7. Concluding remarks

The development of this artefact—from the initial engagement with the family to define the brief and their unsatisfactory experience of use, to the collaboration with healthcare professionals and the inclusion of more people with dementia in the institutions to identify other possibilities of use—raised important considerations for the design of artefacts for people with dementia, namely if they are intended to be used in a home setting without the facilitation of a healthcare professional. Although the story-making card game emerged from the collaboration with a person with dementia and her family member, according to their needs and preferences, this was not sufficient to ensure an adequate and enjoyable experience of use at home. When designing for families, it is essential to take into consideration that familial contexts are many times loaded with fatigue, emotional charge, expectations, and there is usually only one person with dementia, all of which can bring pressure to the moment of play. Therefore, it is important to find strategies to lighten the activity. These can include the emphasis on creativity and humour, and the provision of different possibilities of use, that can be chosen according to what is suitable and enjoyable to the person with dementia, to her/his mood in the moment of play, and to family availability. In order to accomplish this flexibility, it was also suggested that the artefacts are accompanied with guidance on how to observe, respond and communicate with their relative, encouraging sensitivity.

Even if the collaboration with the family was inspiring and crucial to the development of a valuable artefact, the institutions were more adequate settings to experiment and define possibilities of use. Several healthcare professionals from different areas contributed with their sensitivity and expertise, inquiring, trying, evaluating and improving the artefact. People with dementia who participated in the activities also played an important part, through their engagement, their reactions and feedback about the artefact. This journey of developing the story-making card game revealed a productive synergy of involving individual persons with dementia and their families, groups of residents in institutions and healthcare professionals in the design process. Here, the designer responds and brings together all these voices to give shape to an artefact which is aimed to support families to include their relative with dementia in a collective activity, but also relevant in institutional contexts. Although the story-making card game is a prototype confined to the presented settings, this effort to experiment its use in different contexts is a step forward for it to become accessible and available beyond the research.
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Curating Conversations: Designing Personalised Media to Support Intergenerational Engagement in Dementia Care

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Abstract

Changes in communication can cause many social consequences for people living with dementia, often resulting in a restriction of the social roles they play in the lives of others. Although research is increasingly acknowledging the importance of socialisation in dementia, the important role that younger people can play in this sphere is not often highlighted. In this paper, we discuss two case studies that explore how designing for the curation of personalised media can support more meaningful communication between people with dementia, younger family members and student volunteers. We also discuss some of the design challenges and opportunities that we have encountered in our own research, with a view to encourage reflection on the importance of designing with and for people with dementia, in order to support them in more positive social roles.

Keywords: Dementia, intergenerational interactions, life histories
1. Introduction

As dementia becomes one of the biggest challenges facing our ageing population, design and technological research has focused primarily on symptoms, safety and compensation for cognitive decline (Cohen-Mansfield, Parpura-Gill, & Golander, 2006), arguably adding to an already over-medicalised view of dementia in research. In doing this, designers and researchers risk neglecting the lived experience of dementia, and further adding to the ‘discourse of loss’ that dominants the dementia narrative (Beard, 2004). The contrast between how dementia is experienced and how it is treated is highlighted in the body of research and design practises that explore the lived experience of dementia and changed the way we think about designing for and with people with dementia (Killick & Craig, 2011; Kitwood, 1993; Wallace et al., 2013). With the growing interest in the use of media in dementia care contexts, in this paper we share design processes which support spaces for sharing lived experiences along with the challenges and opportunities for future work within this space. Firstly, we discuss some current approaches to the use of media and their effect on social roles within the dementia care ecology. We then present two case studies centred on the effect of curated media on social roles within the dementia care ecology, through which we can share the challenges of carrying work out in this area but also the opportunities for future work.

2. Background and Related Work

2.1 Social Consequences of Dementia

Research exploring the experience of dementia sheds light on the ways in which the disease, and its accompanying preconceptions, result in unnecessary and often distressing social consequences for people with dementia (Brooker & Surr, 2005; Cohen-Mansfield et al., 2006; Moyle et al., 2011). A diagnosis of dementia impacts the various roles that have previously contributed to the construction of identity, including professional roles, familial life, hobbies and leisure as well as personal attributes (Cohen-Mansfield et al., 2006). Many of the previous sources of meaning in life are restricted and abandoned as dementia progresses, despite the fact that people with dementia report the maintenance of their identity through meaningful activities as pivotal to their well-being (Beard, 2004; Black & Dobbs, 2015; Ryan, Bannister, & Anas, 2009).

1 The real names of participants have been replaced to preserve anonymity.
People with dementia also report a sense of being of limited value to society, particularly as civic and volunteering roles are largely restricted once they receive a diagnosis (Moyle et al., 2011). Breakdown of communication with family members and familiar friends is one of the greatest losses reported by people with dementia as a result of experiencing dementia (O’Rourke, Duggleby, Fraser, & Jerke, 2015). While relationships with family remains central to the maintenance of identity, the adjusted role that they play in the family dynamic can also result in negative social consequences (Caddell & Clare, 2010).

A lack of opportunities to contribute to their social world, paired with a narrow focus on the illness, can result in a person with dementia acting in a more passive role in their social relationships (Moyle et al., 2011). Though cognitive impairments caused by the neurodegenerative disease often lead to communication difficulties, it is clear that lack of meaningful communication between people with dementia, carers and service providers can often lead to greater socio-psychological problems than necessary (O’Rourke et al., 2015). The next section will explore how design research can contribute to enriching this situation for those living with the condition.

2.2. The Importance of “Stuff”: Media and Communicative Objects In Dementia

The phenomenology of perception and embodiment as defined by Merleau-Ponty acknowledges that “stuff” is important to us because it tells us something about ourselves and the relationships we have formed:

“If we reflect phenomenologically on our involvement with our surroundings, we arrive at this conclusion: we are always already engaged with objects, and these objects simultaneously transcend us and yet ‘speak to us of ourselves’.” (Merleau-Ponty, 1945, p. 3)

For the purposes of this paper we suggest an opening of the term ‘object’ to include media of all kinds – texts, photographs, and film – in the particular context of dementia. With this, we can talk about how objects can be placed within relationships of care to open up conversations and allow new opportunities for socialisation and social roles. This is particularly important when thinking about intergenerational interactions in dementia. For a certain generation, receiving text messages may be something which evokes strong emotion and is returned to time and again, as described by McCarthy & Wright in their book “Technology as Experience” (McCarthy & Wright, 2007). For an older generation, that return may not be to technology but rather; letters, photographs, film, TV, and VHS tapes. Current media platforms such as YouTube, Pinterest, and Flickr can hold similar resources which, if carefully curated, could be hugely valuable for stimulating creative communication and sharing in dementia.
There have been several design studies in dementia care that have attempted to redress the notion of care homes as ‘placeless spaces’ (Twigg, 2000) through the use of certain kinds of media. Prime among these are “Tales of I”, concerning digital jewellery and dementia (Wallace et al., 2013), and “Photostroller” (Gaver et al., 2011). In ‘Tales of I’, set in a hospital unit which housed people with dementia, Wallace et al.’s design work culminated in an interactive art piece installed for the use of all residents. Similarly research by Gaver et al. produced The Photostroller, a waist–high portable unit which displays photos streamed from the online photo–uploading website Flickr. The Photostroller was intended to be used by any resident of the long–term care setting for conversational, reminiscence and storytelling purposes; and as such used a collection of generalised media.

Referenced above, Wallace et al. underlines the link between the loss of self and personhood in dementia and how objects (in this case, digital jewellery) can help to express a sense of self in a social context. With this in mind, Wallace et al. led a design inquiry into the experience of personhood in dementia. Focusing on a couple, Gillian, who had been diagnosed with dementia, and John, her husband, as a case study, Wallace used design probes to create several pieces of digital jewellery for Gillian. Wallace et al. reflects on the value of these digital objects and the use of design probes, concluding that the creative nature of the probes allowed for expression while also ‘scaffolding’ the process for the couple. More importantly, however, the design and wearing of this digital jewellery allows Gillian to retain a sense of self and aided communication in further stages of her dementia.

Interactions between carers and people with dementia has been supported with media for some time, often focusing on physical objects such as scrapbooks filled with old family photos, but also more recently moving towards digital media. McKeown et al.’s review of Life Story Works (LSW) explores the use of media in care homes, highlighting how the compilation of these works encourages interaction between staff, families, and the person with dementia, present the opportunity for improving relationships within the dementia care ecology through the act of curating media (McKeown, Clarke, & Repper, 2006). Opportunities to share their LSWs were seen as social occasions centred around sharing the experiences of people with dementia, leading to changed perceptions of the care home residents through these expressions of personhood. Media in care homes has not always been reminiscence but supportive of social engagements. Morrissey et al.’s shows how “SwaytheBand”, a baton which responds with glowing lights to a predefined list of music, can have a positive effect on residents’ social roles within in a care home (Morrissey, Wood, Green, Pantidi, & McCarthy, 2016). Creating group sessions using the technology with an accompanying list of songs
transformed stagnant interactions into one where residents actively engaged with each other and staff. In that moment, the authors describe how social roles change from fellow care home residents to friends and singing partners.

Finally, McNaney et al. explored how a curated set of media can act as ‘tickets to talk’ for younger family members to engage with an older relative with dementia (McNaney et al., 2017). They found younger people were keen to engage in everyday conversation with their older relative but topics of conversation were difficult to find given the intergenerational gap. McNaney et al. suggest the anchoring of conversation around a curated and personalised set of media such as photos, videos, and songs can support family social roles within dementia. Using this personalised media approach means that conversation is now specifically centred around areas of interest for the person with dementia, subjects which they have the opportunity to reminisce and share their experiences on, or instead enjoy songs, photos, and videos carefully selected for them. It therefore represents an intermediary between the highly personalised design approaches of Wallace’s digital jewellery, and the more generalised or scalable approaches to media selection seen in work such as the Photostroller. McNaney et al.’s work is built upon significantly in the second case study within this paper.

3. Case Studies

Here we present two case studies: ‘Life Story Boxes’, and ‘Ticket to Talk’. We frame these as artefacts and technologies which, in their design, create spaces for personalised lived experiences. We explore how the use of these artefacts in social engagements with people with dementia create the opportunity for expressions of personhood, which can help reaffirm the person with dementia’s social roles within the wider dementia care ecology. Both studies also use these design objects primarily within intergenerational interactions.

3.1 Case Study 1 – Designing ‘Life Story Boxes’ with People with Dementia as a Means of Supporting Meaningful Engagement

Life Story Boxes are part of a long-term ongoing ethnographic study that has been carried out over the past two years. The state-funded residential unit in Southern Ireland, Oakfield House, is home to approximately 85 long-term residents, the majority of whom have received a diagnosis of dementia or some form of cognitive impairment. Initially, the fieldwork involved observation and researcher-participation in the daily activities carried out in the care home as a means of developing an understanding of the ways in which residents engaged with the activities that are organised within the home. These include music sessions, arts and crafts, religious ceremonies, family events and day trips. While these activities are accessible to all residents, initial observations noted that residents
with more advanced dementia were less likely to engage in the activities and tended to remain in their bedrooms for longer periods of time.

As the ethnographic work progressed, the focus of project moved towards ways in which to engage in ‘meaningful moments’ of communication with people with advanced dementia. Capturing ‘meaningful moments’ as part of the project involved the researcher spending time with residents, engaging in conversations and activities, responding, and later reflecting on the communicative behaviours that were expressed. People living with advanced dementia often experience confusion and anxiety, and can communicate this through verbal and non-verbal actions. However, these communicative actions can sometimes be interpreted as symptoms of the dementia and therefore void of meaning (Twigg, 2004). The approach of the researcher was to view the communicative action of the residents as embodied and meaningful, and attempted to respond in a way that legitimised their communicative action (Kontos & Martin, 2013). The following account from the field notes describes an experience between the researcher and a resident that highlights the ways in which verbal and non-verbal cues are used as a way to express distress, but also as a means of connection and re-assurance:

She seems very anxious, gripping her pants with her hands, rocking back and forward. She kept saying ‘they won’t know where I am’ and I really didn’t want to leave her on her own so I said I’d wait with her until ‘they’ came. I tried to re-direct the conversation to her lovely scarf. She was dressed very well, in a co-ordinated outfit. There was an immediate change about her and she visibly calmed down. She started to run her hands over her scarf, explaining her daughter had got it for her - like all her clothes. I said her daughter must be very stylish and she agreed with me that she was. The nurse came in then and I took her hand to say goodbye, she gave me such a big smile and gripped my hand for a long time. It felt like she was clinging to me for reassurance that we were both here.

This experience highlighted the importance of not only embodied responses as a means of connecting with residents, but also the way in which significant personal objects (in this case a scarf) can be important communicative tools. For this resident, the scarf was physically comforting and aesthetically pleasing, but was also a reminder of her daughter, and so held more personal meaning. Through reflections on this experience, the researcher began collecting mediums that may hold personal meaning for residents (such as photos, vintage household tools) and could be used in conversations as a ‘way in’ to their experience. The following extract describes the use of historical
photographs of Cork City to re-focus a potentially distressing conversation with a resident who wishes to return to her previous home:

She’s awake and is eating biscuits, drinking tea while lying in her bed. I ask her how she is. She looks at me with a wry expression, as if she doesn’t recognise me, but smiles. ‘Good’ she says. She looks me directly in the eye then and says ‘Any chance of getting home?’ ‘Where’s home Cathy?’ I ask as light hearted as I can. She rattles off her address, as if she has it ready for anyone who might listen to her. She says it so fast I don’t catch the beginning, but I hear North Cork City. I have pictures of Shandon (Local Church) on my iPad and I take it out and ask her does she know it. ‘That’s beautiful’ she says, gazing at it for several moments, reaching her hand out to touch it. I then show her a photo of the high street, taken in 1945. ‘That’s beautiful’ she says again. Maybe she’s forgotten, but she doesn’t ask again about going home, we just chat about what’s on the television. It’s a soap opera or something-. I ask her if she likes it. ‘It’s very dramatic’, she looks at me and we both laugh. ‘Will I change it?’ I ask. She nods in approval. The next channel has an old re-run on, it looks to be a period drama. ‘That’s much better’ she remarks. Maybe it looks more familiar to her. We watch it together, making remarks every now and again about the characters.

This moment demonstrates how meaningful and familiar media can be used as communicative tools that is both responsive to the reality that is being constructed by the person and draws on their personhood and life experience. During moments of agitation or distress, the primary reaction is to try to reassure and alleviate suffering for the person. It must be acknowledged that for people with advancing dementia, communicating this sentiment is not also easy or possible. However, as the above excerpt demonstrates, attempts to communicate and respond with compassion can create moments of connection. The time spent on a one-on-one basis with the residents was invaluable in terms of understanding the importance of individual engagement and effective means of communication. This understanding has led to the design and implementation of customised conversation probes that speak to the personhood of the individual, and support meaningful engagement with student volunteers.
3.1 Case Study 1 – Designing ‘Life Story Boxes’ with People with Dementia as a Means of Supporting Meaningful Engagement

In response to the need for supporting and encouraging meaningful engagement with people with dementia, we adopted methods of participatory design with residents and student volunteers to design ‘Life Story Boxes’. This project draws on the Life Story Work literature (McKeown et al., 2006) with a focus on designing physical objects to support and encourage reminiscence during the more advanced stages of dementia. Recruiting student volunteers to take part in the design phase of the study had two functions; we could support more residents to be involved in the process, while also providing the opportunity for intergenerational engagement. We wanted the experience to be mutually beneficial, and support both the students and residents in communicating with each other in a meaningful way. Finding media that connected residents and students, such as the city that they live in, allowed for all participants to draw on their lived experience, and create common understanding. The following excerpt demonstrates the ways in which photographs were used to support communication:

There’s a picture of a famous old dance hall in Cork and I ask the residents if they ever went dancing there. Anne recognises it immediately as where they used to go when they were dating and shows the picture to her husband and daughter. They all lean into the photography, remarking on the people and the hall. Eoin pulls out another photo then of couples dancing, and asks if this is similar to dances they would have gone to. They talk about jiving and the foxtrot and we joke that we can’t dance at all these days and how different night clubs and going out seem to be compared to the dance halls.

While photographs as a medium were useful communicative tools as an initial talking point, we wanted to curate information and design probes that held personal significance for the residents that we engaged with (Wallace et al., 2013). This involved the students working with residents over a number of weeks, initially accumulating information about the resident’s lives during informal visits. This gave the residents and students the opportunity to build up a rapport, which became central to the design process. After each visit, we would reflect on the topics that came up and discuss ways to design communicative tools that represented the interests and character of the resident. If residents engaged with and responded to the probes, they would be added to the ‘Life Story Box’ (see images for examples).

The intergenerational communication that resulted throughout the design process supported both the students and residents to draw on their own experiences and curate mediums that spoke to the rapport that had been developed. The understanding established between the students and the residents resulted in an empathetic response to the lived experience of the residents, which was reflected in the design of the Life Story Box. In the following excerpt, one volunteer discusses how the meaningful communication between herself and the resident she worked with resulted in a more empathetic understanding of what was important to her specifically and more generally, what it means to live with dementia.
‘And that, that’s her thing, how she looks is important to her so like, you know, as you said, prioritising those things and the other point...them kind of being stuck,...being stuck here. You know, Rita talked about like, not being able to clean, or cook and boil the kettle or whatever. And even for people outside having dementia, not having that freedom is kind of...even talking about the weather is difficult to talk about that when they haven’t been outside.’

Not only did the communication between residents and volunteers result in more effective content generation for the design of the probes, but the experience of getting to know the residents created a new role for the students that they described as mutually beneficial:

‘Yeah... any time I’ve ever, after we chat with Christine, I always go...'Oh that was so good,' and like..... It’s always a positive feeling you get out of it. Um, yeah. No matter what, and I feel like it goes both ways. When we leave Christine I feel like she has enjoyed talking to us as much as we’ve enjoyed talking to her you know? And it’s just a good feeling.’

Supporting students in their role as volunteers, researchers and designers creates an opportunity for them to gain both experience of how participatory design is implemented in community settings, but also engage in meaningful communication with individuals who risk being socially isolated from the communities they live in. Carrying out participatory design in care homes with younger people can result in the formation of social connections across generations, supporting those involved to step into new social roles that are mutually beneficial.

3.3 Case Study 2 – Ticket to Talk

Ticket to Talk is a mobile application developed in partnership between youths (aged 15–24 as defined by WHO (World Health Organisation, 2014)) from Youth Focus North East, a charity which supports youths in the north east of England, and Open Lab at Newcastle University. The application originates directly from the workshops discussed by McNaney et al., already visited earlier in this paper (McNaney et al., 2017). There has not been an evaluation of Ticket to Talk at this stage, instead this case study focuses on the fieldwork from McNaney et al.’s research which directly inspired this application. This section outlines the concept of Ticket to Talk and how findings from these workshops have directly shaped the design of the application.
Ticket to Talk aims to promote positive social interactions between younger people and older relatives with dementia through scaffolding conversation with the use of carefully curated digital media. This is in direct response to the youths’ expressions of difficulties in starting and maintaining conversation with older relatives living with dementia:

“I find it quite heart-breaking to visit him [her grandfather] because I just feel so bad for how confused he is. So it makes it a lot harder because there are very few ways in which we can connect anymore”. (McNaney et al., 2017, p. 1317)

“They never really know what to say anymore [...] they go because they feel like they should go and see my Nana but they don’t really know what to do [...] It’s quite hard”. (McNaney et al., 2017, p. 1317)
These quotes from the workshops outline a felt loss of closeness and difficulty in connecting. Ticket to Talk aims to create talking points for younger people to help conversations with their older relatives who have dementia. To achieve this the application effectively acts as a repository to hold photos, sounds, and YouTube videos, created by the younger person, to use as topics of interest to support conversation between themselves and an older relative with dementia. When using the application the younger people are encouraged to create a library of ‘Tickets’ using the camera and microphone on their mobile phone to capture old family photos and record sounds such as songs from different periods of their older relative’s life. The application is centred around a profile of an older relative or friend with dementia, which a younger person has either created themselves or been invited to contribute towards. Tickets are then attached to the profile of the older relative or friend, allowing them to be shared between all contributors, which would typically be family members, friends, and professional carers. On invitation to contribute to a person, users are assigned an access level, as are tickets, meaning sensitive information can remain between families, and bleed into wider circles of friends and professional carers if appropriate.

As a supplement to conversation rather than a mediator, Ticket to Talk encourages users to compile tickets into ‘Conversations’ prior to interactions with their older relative. A ‘Conversation’ within the context of Ticket to Talk is essentially a metaphor for a music playlist, but has attached notes where the younger person can record and share their observations on the future interaction. The younger person would then use this in conversation with their older relative where they can present this list of tickets as potential topics of conversation. The younger people are then prompted to reflect on and record their thoughts of the conversation to support collecting new tickets and further interactions. These observations are then shared between all family members and friends who contribute to the collection of tickets.

“if you start prompting too much about Fred, if he isn’t around any longer how do you handle that if she isn’t aware that he’s not there” (Nicole); “or if she suddenly remembered that he’d died and it affected her” (Shelley) (McNaney et al., 2017, p. 1321)

The quote above from McNaney et al.’s workshop touches on some of the difficulties in working with personalised media. Participants here have highlighted the potential for resurfacing negative memories along with the negative emotions they carry. Curating a collection of media is then a creative but often an difficult process, requiring the curator to have some awareness of the person with dementias’ background to avoid situations described in the quote above. The application tries to support the younger people by using a small amount of biographical information about
who the younger person wants to talk to generate personalised prompts such as: “John was born in London. Can you find a picture of London in 1950 when John was 5 years old?”.

The generated inspirations are designed to be deliberately generic to minimise the resurfacing of negative memories during conversations but focus on likely aesthetic experiences occurring during later adolescence and early adulthood in order to utilise the effect of the reminiscence bump (Jansari & Parkin, 1996) on the older relative. However, the application is deliberately ambiguous in its guidance. For instance the application will ask the user to collect ‘Sounds’ rather than songs.

“The prompts leave space for the user to be creative in creating tickets without prescribing for the younger people to use. This draws from Wallace et al. (2013)’s method employed in her inquiry into personhood in dementia, of undertaking a thoughtful and reflective approach to design which aims to encourage meaningful conversation based on feelings of nostalgia and reminiscence. In the case of Ticket to Talk the technology itself does not aim to be creative, but instead encourages the younger people to be reflective and thoughtful in their curation of media to achieve the same desired effect of the jewellery. There is a question however surrounding how working with a platform such as Ticket to Talk differs from working with a rich, embodied method. This is discussed further in the final section of this paper.

The interaction prompted by Ticket to Talk encourages the younger person to enquire into a person with dementia life, engage with their interests, and explore their past experiences, in order to curate this collection of digital media. As stated by Wallace et al. (2012), such interactions have the potential to preserve a version of the older relative’s ‘self’. Furthermore, social roles often change in families with people with dementia experience a change of roles from family member to care receiver, reporting negative effects on their perceived social identity (Ryan et al., 2009). Whilst the use of a curated set of digital media might be a small change in the method of interaction for the younger relative, it has the potential to shift conversations from that of a carer to care receiver, to that of grandparent and grandchild. While mentioned previously that at this stage there is no fieldwork evaluating the effect of Ticket to Talk on intergenerational interactions in dementia, it is our hope that it will support younger people to re-conceptualise relationships with older relatives who have been diagnosed with dementia (Hall & Sykes, 2016) in re-affirming the previous family roles.

“if the app had somewhere where you could tap for inspiration […] if you’re at a loss then you’ve got something like, “Write them a letter about something you’ve done in the past” or, “Ask them about Uni”, or something like that.” (McNaney et al., 2017, p. 1317)
4. Opportunities and Designing Media

Our work shows how creating and using curated personalised media has the ability to support and enrich positive engagements with people with dementia, and through this reaffirm social roles within the wider dementia care ecology. Through encouraging families, friends, and carers to invest time in collecting media such as songs, pictures, and other artefacts, social interactions can shift from formal visits with care home residents to memorable moments with friends, parents, and grandparents. While there is a rich body of research in this area, through our own work we have found many opportunities for design in the use and creation of curated media.

4.1 Finding Similarity Through Difference

Working with people with dementia can be a personally challenging task for researchers and volunteers new to the area, wherein they may have misguided perceptions of dementia, or may find people with dementia challenging to engage with because of the generational gap. As younger people, (the primary researchers aged 23) this generational gap can often provide more opportunities to work with people with dementia, where people with dementia can be sometimes happier to talk to us as we are often the same age as their grandchildren. Furthermore, working within the space of dementia as younger people helps to inform and change some of the previous misperceptions and anxieties of the area. For example, the student volunteers engaged in the Life Story Box project spoke of the contrast between their previous understandings of dementia solely in terms of cognitive decline, and how the capabilities of the residents they worked with has altered this understanding.

4.2 Good Design is Design for All

When using media, we must also consider the physical and medical conditions that are associated with old age, such as visual impairment, motor-neuron disease, and frailty, which can often make it difficult to interact with conventional technologies. Establishing the appropriate form of technology and media will depend on the cognitive and physical capabilities of the individual, requiring us as researchers to work closely and attentively with participants. However, we believe an example of good design not only accounts for these complexities, but is universally accessible for all users, regardless of their conditions. The case studies discussed can be applicable to any interaction, as they are not designed for a specific relationship or condition, but rather create a space for expression and sharing of experience.
4.3 Take Inspiration from Other Mediums

The literature and case studies outlined above explore only a small range of available media that can support expressions of personhood and creativity for people with dementia. Exploring senses other than sight and sound could mirror particular familial rituals, e.g. preparing meals, creating a space for “small c creativity” (Killick & Craig, 2011) and further expressions of personhood. As highlighted in the first case study, personal objects – such as the resident’s scarf – can be used as a focal point in the conversation, while also drawing on the sense of touch to support conversation.

4.4 Widening the Ecology of Care

Previous literature has traditionally focused on the relationship between the primary care-giver and the individual with dementia (Beard, 2004). Both Ticket to Talk and Life Story Boxes highlight other important relationships within the lives of people with dementia, such as those with younger family members and volunteers. Curating media with a view to support intergenerational engagement can widen the dementia care ecology by supporting younger people to take a more active role in the lives of people with dementia. These case studies also highlight the positive social impact people with dementia can have on younger people, placing them in a more active role in the lives of others (Black & Dobbs, 2015).

4.5 Making Space for Experience

The benefits of using media in interactions within dementia has been discussed across a large body of literature, each taking slightly different approaches. Some technologies in this space have designed for scale and taken a generalised approach to the media they are centred on, i.e. Photostroller (Gaver et al., 2011) and CIRCA (Gowans et al., 2004). Ticket to Talk and the Life Story Boxes take a different approach and show how experience can be designed for at scale, but still be personal to all users, instead of anchoring on a common experience. We show how to approach this in the case studies by creating spaces within technologies and artefacts which users can populate with media that represent their own personal experiences. We believe the curation step populating these spaces helps strengthen positive social roles of people with dementia within dementia care, by encouraging the wider dementia care ecology to actively engage with the person with dementias’ life and lived experiences.
5. Conclusion

The literature and case studies discussed above show the value of using curated and personalised media in supporting conversation with people with dementia. We propose that using such media can have a positive effect on the social roles of people with dementia in the wider dementia ecology. We believe that through such social interactions, perceptions of people with dementia can shift from being seen as someone living with dementia, to that of a friend, family member, or loved one. Designing to support the curation of media for people with dementia can result in it being an enjoyable experience requiring minimal effort for people within their care ecology. In designing to support this experience we hope to encourage more positive social engagements, turning visits into meaningful moments, and patients into people.

Acknowledgement

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Author Bios

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Kellie Morrissey completed her PhD in University College Cork’s School of Applied Psychology in 2016. She now works at Open Lab, Newcastle University, where she is primarily involved in exploring the role of technology and service design for dementia-friendly community initiatives.

References


Exploring the experience of social touch in old age and in dementia: Opportunities for design?

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Abstract

The sense of touch is the most basic and profound in our lives. It is the first sense to develop in the womb, and remains important throughout the lifespan. Affiliative interpersonal touch has significant health effects, and is critical for healthy development. In old age, even as the touch modality suffers from age-related decline in sensitivity, the importance of social touch for a person’s mental health and wellbeing remains undiminished. In our work, we are exploring the touch needs and preferences of seniors and people with dementia, and hope to identify opportunities and requirements for the design of social touch artefacts that will support seniors, both with and without dementia, in fulfilling their touch needs.

Over recent decades, social touch devices have been explored that support informal, personal, intimate, and emotional forms of touch between geographically separated individuals. Design explorations in this emerging field of mediated social touch have focused, for example, on the transfer of relational messages (e.g., intimacy) or the communication of emotions (e.g., sadness). At the same time, social touch technology to date has not been developed with an explicit aim to meet the needs of seniors, let alone seniors who suffer from dementia.

We feel that a focus on these groups will inspire a different set of design approaches and considerations that may offer a refreshing and perhaps also a sobering perspective on the design of artefacts aimed to support mediated social touch.

Keywords: dementia, social touch, well-being
Background & context

Dementia is a general term for a class of diseases that affect the brain, usually at an advanced age, resulting in a persistent disorder of mental processes, including memory, reasoning abilities, and personality. Dementia is gradual and progressive, eventually severely affecting a person’s abilities to function independently, and greatly diminishing quality of life.

Dementia is, at the time of this writing, without a known cure. Between the ages of 65–74 approximately 3% of individuals suffer from dementia, increasing to 19% between the ages of 75 and 84, and affecting nearly half of those over 85 years of age. In almost 70% of the people who suffer from dementia, the dementia is caused by Alzheimer’s disease. Other common types include vascular dementia, Lewy body dementia, and frontotemporal dementia.

Despite significant efforts invested in fundamental research over the past 30 years, no reliable medication for Alzheimer’s disease has been found that may cure or significantly ameliorate the condition. This remains a major focus area of research, with new global initiatives such as the G8 Dementia Summit in 2014 that formulated an ambitious agenda for global action, and several national action plans, such as the ‘Deltaplan Dementie’ in the Netherlands, and the launch of the Dementia Discovery Fund in the UK in 2015. In addition to the search for a cure, there is an increased focus on prevention of dementia by maintaining a healthy lifestyle and a healthy living environment which can protect you from developing dementia. Moreover, we see an increasing sense of urgency to understand and improve quality of life of people currently affected with the disease.

Enhancing quality of life for people with dementia, as well as their social circles and informal caretakers, is the reason why Eindhoven University of Technology recently established the Centre of Expertise on “Dementia & Technology”, a collaboration between several departments within the university. Promoting wellbeing of people with dementia and stimulating graceful aging with dignity, is central to our current policy and a challenge to all.
Touch in old age: Sensory and social sensitivities

It is hard to overstate the psychological importance of touch. In some ways, touch can be regarded as the most basic and profound sensory modality in our lives. It is the first to develop in the womb, and the last to go when we die. As Sachs (1988) describes, people are able to adapt very well to a life without vision or hearing, but “an existence devoid of tactile sensation is another matter; sustained physical contact with other humans is a prerequisite for healthy relationships and successful engagement with the rest of one’s environment” (Sachs, 1988, p.28). Touch is a crucial element of healthy child development, and remains highly important throughout our adult lives.

While hearing loss and decreased eyesight are things we all expect with normal aging, a decline in touch sensations and perception is also known to occur but usually remains unnoticed (Tremblay & Master, 2016). The effects of ageing on touch are more difficult to study and measure, than those in other modalities, especially in a person suffering from dementia.

In touch research, much is known about the sensory-discriminative properties of touch, helping us to understand object shape through touch and identify the location and intensity of a stimulus on the skin surface. However, this does not yet address another essential property of touch, namely the fact that touch can be pleasant. This motivational-affective dimension is critical in understanding the positive effects of social touch, from a comforting touch, to a sensual caress, to a relaxing neck massage. Research on the affective aspects of touch has only recently received systematic attention in the neuroscientific literature (Morrison, 2016; Olausson, Wessberg, Morrison, McGlone & Vallbo, 2008), although in psychological literature the positive effects of touch have already been studied for several decades (Field, 2001).

Recent research on the affective aspects of touch has focused on specific dedicated neural pathways, including the so-called CT-afferents in the skin (McGlone & Reilly, 2010; May, Stewart, Tapert & Paulus, 2014; Morrison, 2016; Björnsdotter, 2016), responsible for feelings of pleasantness.

These are slow, unmyelinated nerve fibers, mainly found in hairy, not glabrous skin. CT-afferents are maximally activated by light, slowly moving stimuli at skin temperature. The central processing and activation is localized in brain areas that process emotion; the posterior insula, the region that deals with taste, pain and emotion. A location where integration of sensory with affective information takes place, important for homeostasis of the body (McGlone & Reilly, 2009; May et al., 2014; Morrison, 2016; Björnsdotter, 2016). Other research provides evidence that tactile stimulation, of sexual or non-sexual nature, induces the release of oxytocin, known as the “cuddle hormone” (Gallace & Spence, 2010).
Aging has a significant impact on tactile sensation, first on the tactile detection of the skin, the sensory conduction and processing, and also on the efferent response (Decorps, Saumet, Sommer, Sigaudo-Roussel & Berengere, 2014). Older people are significantly less sensitive to tactile stimulations and vibrations and less sensitive to warm stimuli (Guergova & Dufour, 2011) than younger people. Most decline is found in task-related situations, for example an increased threshold during touch detection, when determining the shape of a test-object (Wickremaratchi & Llewlyn, 2006; Tremblay & Master, 2016). Overall loss of touch performance is the most common effect of advancing age.

Despite this overall decline, the perception of light touch is comparatively preserved in healthy elderly subjects during normal aging. Subjective pleasantness ratings of slowly stroking touch even increase with age (Jönsson, 2017; Sehlstedt et al., 2016). Positive or negative perception of pleasantness of light touch and individual touching behavior also depends on the individual’s background, early social contact during infancy and childhood, gender differences and culture (Hielscher & Mahar, 2017).

**Touch needs in people with dementia**

As we grow older and move into late adulthood our “tactile circumstances” change. There are often fewer children to cuddle and we usually experience less sexual activity. Furthermore, if we lose an affectionate partner we lose the associated touch experiences and these are not easy to replace. In addition, physical mobility limitations may reduce the options seniors have at their disposal to engage in social interaction, adding to a sense of isolation. Whereas loneliness is not simply a consequence of being alone, social isolation has a number of significant cognitive and health risks associated to it, including stress and depression (Hawkley & Cacioppo, 2010). This is already a significant issue for healthy seniors, but increases in importance for seniors who are suffering from memory disorders, personality changes, and impaired reasoning skills as a consequence of dementia. We know that in different stages of the disease the person’s inability to communicate with language increases. Utilizing touch as a form of non-verbal communication, as during a therapeutic massage to relax, can certainly be useful (Nelson, 2004) and may, during the severe stages of dementia, become one of the most important ways of communicating with a person with dementia. At some point, affiliative touch may become the only way to reach a person.

Wellbeing and quality of life of people suffering from dementia starts with
a feeling of comfort, trust and safety. However, people with dementia often feel anxiety, show agitated behavior and depression (Hansen, Jorgenson & Ortenblad, 2006). Research (outside the realm of people with dementia) has shown that social touch can have a powerful effect in reducing stress and anxiety. For example, when people were exposed to an artificial social stressor (e.g., having to prepare for and give a public presentation in front of a critical audience), participants in the group that received comforting touches (e.g., a neck massage) felt more relaxed than those who received no such treatment (Ditzen et al., 2007).

Several nursing studies involving people with dementia (Bush, 2001; Field, Diego & Hernandez-Reif, 2007; Kolcaba et al., 2006) demonstrate decreased anxiety and stress after massage therapy, therefore indirectly having a positive impact on dysfunctional behavior. Although important for the wellbeing of the patient, this is originally a task-oriented procedural touch (also known as instrumental or technical touch) that can provide feelings of comfort as an unintended, albeit positive, consequence. We think that (in the right way) integrating intentional comfort touch, the so called ‘affective touch’, may be a vital and indispensable part of care and can obtain positive health effects. The experience of touch can move from unintended procedure-centered experiences of touch, to intended, affect-centered experiences (Connor & Howett, 2009).

Mediated social touch: Opportunities for design?

One avenue that we would like to explore in this context is the extent to which communication technology can play a positive role in alleviating loneliness, stress and anxiety, especially for senior citizens and people suffering from dementia. We are particularly inspired by the positive results of affiliative touch on enhancing people’s wellbeing and decreasing levels of anxiety and stress. We feel that the area of mediated social touch (Haans & IJsselsteijn, 2006) may offer interesting opportunities for research and design in this respect.

When looking at touch devices, the state-of-the-art in haptic technology over the past 50 years has been dominated by tactile communication systems that attempted to convey – often in high-fidelity – a credible kinesthetic sensation of a tangible virtual object, including properties such as object shape, rigidity, and surface texture (e.g., PHANToM and ReachIn Desktop). Other systems used cutaneous sensations (via innervation of mechanoreceptors in the skin) to convey formal features of communications (e.g., braille reading aids) and environmental information (e.g., sensory substitution systems, tactile vest display).
Over the past two decades, however, we can observe a slow but gradual shift towards tactile systems that support informal, personal, intimate, and emotional forms of social touch between geographically separated individuals. Design explorations in this emerging field of mediated social touch have focused, for example, on the transfer of relational messages (e.g., intimacy) or the communication of emotions (e.g., sadness). This is a major change in direction as such a design orientation is grounded, not so much in the psychophysics of the somatosensory system, but in the psychology of touching behavior and (mediated) interpersonal communication.

Example prototypes include Hug-over-a-Distance (Mueller, 2005), where the sender can convey a “hug” by having an inflatable vest worn by the receiver fill up quickly. Another example prototype is the tactile vest, used by Haans, De Bruijn & Ijsselsteijn (2014), which consists of a flexible vibrotactile motor array attached within a remodeled surfing suit that can be applied to larger (abdomen, back) or smaller (e.g., upper arm) areas of the body and remotely actuated.

However, these devices can be best described as advanced prototypes for research, and still need adjustment and improvement to capture the fundamental aspects of social affective touch. It seems almost impossible to offer a multisensory context so important to our social interactions (Gallace & Spence, 2010).

More importantly, perhaps, social touch technology to date has not been developed with an explicit aim to meet the needs of seniors, let alone seniors who suffer from dementia. It is still a significant challenge to determine what kind of touch experiences older people, with varying social and cultural backgrounds, age, gender, and varying levels of sensory and cognitive impairment, actually need. It is entirely possible that technological mediation of social touch may be a confusing or unnerving experience, perhaps even alienating or frightening. So, despite all the experimental mediated touch devices developed and good intentions of researchers, we want to focus on the actual touch needs and experiences of the elderly within their own environment first and foremost. At a later stage, we want to discover a proper way to introduce haptic technology, if necessary.

Our focus on improving the quality of life for seniors with and without dementia has the potential to inspire a challenging set of design constraints and considerations that need to be met. Working with groups of vulnerable people poses stringent requirements on both the process and products of research and design. We expect that this work will offer both refreshing as well as sobering perspectives on the design of artefacts aimed to support mediated social touch.

At the same time, elderly (also the cognitively impaired) might come to the realization that efforts to increase quality of life by providing touching experiences is also a way to fight decline. Their positive attitude is essential for the chance of aging successfully by embracing life, accepting new forms of communication when verbal communication is a challenge and cooperate while looking for ways to enhance resilience in life (Cabeza, Anderson, Locantore & McIntosh, 2002).
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Author Bios

Ir. Ans Tummers-Heemels holds a master degree in Industrial Engineering. She spent the last 10 years in the Supervisory Board of the Alzheimer Foundation and is currently a member of the German Board of the Alzheimer Forschung Initiative. Additionally, she is a coordinator network and PR of Technical University of Eindhoven Expertise Centre Dementia & Technology. Last year, she started PhD at Human Technology Interaction at the University of Eindhoven. She is dedicated to increasing the quality of life and feelings of well-being of people with dementia and their caregivers by exploring the field of touch and dementia.

Prof. Dr. Wijnand IJsselsteijn has a background in artificial intelligence and cognitive neuropsychology. Since 2012, he is full professor of Cognition and Affect in Human–Technology Interaction at Eindhoven University of Technology (TU/e). He has an active research program on the impact of media technology on human psychology, and the use of psychology to improve technology design. He is scientific director of the interdisciplinary Center for Humans and Technology at TU/e.

Dr. Ir. Antal Haans is an environmental psychologist who is fortunate to work in the midst of technology development. These developments are rapidly transforming our discipline by offering new technologies and tools in aid of psychological research. Also interested, not so much in the environment and its preservation, but in the discipline’s original aim of understanding the interplay between people and their surroundings in explaining human behavior and experience. My research interests include smart urban lighting and advanced media technologies.

References


Music Memory Box

Chloe. A. Meineck
Director and Founder of Studio Meineck, Bristol, UK

Overview of Demo

The Music Memory Box is a physical box that contains people’s most important objects, music and photographs in. The product uses RFID technology to allow music to be triggered through an object when it is put in the centre of the box. The box and its guide helps people living with dementia, their families and care staff through the process of linking music with objects to create a personalised tool that can be used to reminisce, reawaken and reconnect.

Adrian Clarke, one of the first owners of a Music Memory Box, and his two sons linked a cassette tape, with James Taylors ‘You’ve got a friend.’ It was Adrian and his late wife’s love song. When they lived apart they sent cassette tapes to each other and the start of the tape would always play this song. Before placing the cassette tape in the centre of the box – Adrian struggles to recognise who anyone is in his photo collage in the lid of the Music Memory Box, but as James Taylor starts – Adrian sings along. Reminiscing about his late wife and the times they spent together – pointing at himself in the photos.

Music Memory Box was inspired out of a personal unmet need for products designed for people living with dementia that used music as the key component, could be personalised – not based on generational or thematic reminiscence and were tactile and easy to use for the person living with dementia. The product has been co-designed with hundreds of people living with dementia in the UK, US, Japan, their families and care staff to fine tune the design over a number of years.

A 30 Music Memory Box pilot is currently being run around Bristol with three care homes Brunelcare, Bupa, St. Monica Trust, independent families and Bristol Black Carers a community group that supports Black and Minority Ethnic Carers in Bristol. The pilot is being evaluated by an academic from University of West England around the impact Music Memory Box has. We’ve found so far that key measures around increasing communication, increasing independence, improving sense of identity, reducing anxiety and increasing enjoyment can be met and culminate in improving quality of life for those living with dementia through using the Music Memory Box.

Studio Meineck will be launching the product for sale to care homes and families across the world in 2018.

www.musicmemorybox.com
Figure 1. Adrian pointing at himself and his late wife whilst singing along to James Taylor ‘You’ve got a friend.

Figure 2. Vera, a resident from Brunelcare singing along to her Music Memory Box with care staff as part of Music Memory Box care home pilot October 2017.

Figure 3. John, a resident from Brunelcare reminiscing about the many dogs he used to walk with Jane the senior activity organiser as part of Music Memory Box care home pilot October 2017.

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Author Bios
Chloe Meineck is Director of Studio Meineck an award winning social design studio dedicated to creating beautiful products that benefit people’s lives. Chloe has been on many national & international design, art + business residencies including ‘Designer in Residence’ at the Design Museum in London.
MobiAssist: An ICT-based training system for people with dementia and their caregivers

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Abstract

Dementia not only afflicts the cognitive capabilities (especially memory and orientation) but also the physical capabilities and therefore, the activities in daily life. Information and Communication Technology (ICT) can play a major role to have positive effects on people with dementia, but also on other stakeholders such as relatives, professional and informal caregivers. The aim of the presented system is to increase the physical and cognitive capabilities to cope the activities of daily life of people with dementia and their caregivers, and relieve the caregivers.
ICT-based training system for people with dementia

To this end, the MobiAssist System is being developed with and for people with dementia and their relatives. The aim is to provide training exercises (physically, cognitive and creative) to enhance mental and physical resources for the activities of daily living. The system consists of several technical components that are centralised around the TV, having in mind, that older adults watch more television and use less ICT compared to the younger generation. The MobiAssist system is running on a space-saving and quiet mini-computer to reduce the disturbances of using too much technology. Currently, a MS Kinect is used to detect the motions of the participant while interacting with the system, but the open implementation will allow other cameras to be used as well. To simplify the interaction with the overall system, a tablet and a PlayStation 3 Buzzer were used. The tablet shows the current exercise plan, the results of the different games and education material about the disease, while the Buzzer with its big colourful buttons is used as input device during the games.

Figure 1. System Overview
Training Aspects

In order to counteract the progression of the disease and to support people with dementia to be autonomous and thereby disburden the caring relatives, exercises and games as well as tests to examine the performance for people with dementia has been developed. The program includes exercises that are necessary for the autonomous execution of activities of daily living (e.g. climbing stairs, carrying bags, washing or transfers like lie-sit-stand).

To strengthen the upper and lower limps and muscles, established exercise programs, like the Otago–program or the Ulmer–model, has been incorporated into the MobiAssist system. The training is connected with a progressive level structure and additional assessment to test balance, reaction time and strength. The focus of the balance and coordination games is to train perception-, balance, reaction- and aiming-tasks in a playful way. The exergames are primarily about maintaining coordination and agility, in higher levels coupled with smaller additional cognitive tasks to promote concentration.

The creativity and cognition aspect was developed together with professional caregivers and therapists who are working with people with dementia on a daily basis. The ICT–based system itself was designed and tested together with people with dementia and their caregivers. The system and the related exergames were developed and selected from the fields of sport science, sport gerontology and nursing science and integrates for the first time different ideas (activity, cognition, creativity) based on established interventions.
Demo: MobiAssist: An ICT-based training system for people with dementia and their caregivers

Figure 3. Creativity and Cognition games

Author Bios

David Unbehaun is research associate and PhD student at the University of Siegen. His current research is about usage behavior of older adults and designing ICT based solutions in the field of active and healthy aging, cognitive and physical frailty, age related diseases and especially in the field of dementia.

Konstantin Aal is a PhD student and a research assistant at the University of Siegen. He is part of come_IN2, a research project which founded several computer clubs for children and their relatives including refugees. Currently he is one of the project leader of the Nett.Werkzeug.

Daryoush Vaziri is an information systems researcher and PhD student at the University of Siegen with an interest in the design and development of technologies that support active and healthy (AHA) ageing and works in the European funded project My-AHA and the national funded project MobiAssist.
Chrono-App: Supporting care assistants’ daily work by providing a management and presentation platform for biographic multi-media content

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1. Abstract

The increasing use of digital media in health care offers opportunities, but at the same time also challenges for residents and staff working in care homes. In this project we developed an easy-to-use tool for caregivers to access, structure, share and present media to people with dementia in single or group sessions. The development was done in cooperation with the dementia care service center of Bielefeld in a user-centred design process grounded in focus groups and field studies.

The final result is an Android Application that is capable of viewing four different media types: Music plus lyrics, texts, videos and pictures plus additional information (Fig. 1). Media is arranged in topics and can be either generic and accessible for the public or personalized and restricted to individuals (Fig. 2). The design included a dementia-friendly presentation platform and an easy-to-access platform for the caregivers to manage the different media types. The media itself is stored on a tiny local server in the care home, syncing the content between multiple tablet devices and enabling the management of the media via a web-interface (Fig. 3).
2. Outcomes

We experienced several insights through field studies and focus groups. First of all, it was difficult dealing with the local IT-services and data protection commissioners to setup the system at the resident’s homes, we had to limit the primary field studies to an offline version and span up a local network without internet access. We did add the internet access again in the recent version, mostly because we needed to access YouTube-videos (Fig. 4) to fulfill the regulations on usage rights (gema.de). Additionally, the little provided media content in the field studies discouraged the care-givers as they had to gather material on their own for the initial setup and their daily work.

We also gained insights on prohibiting touch gestures as we assumed that people with dementia will get distracted if they point onto pictures or movies and trigger interactions, but on the other hand the caregiver’s response was the opposite – they felt limited in the usage. One solution for this might be an engaging-button in one of the corners to activate touch gestures while being pressed. Summing it up we received positive feedback from the caregivers pointing out the necessity of the system in their daily work. They especially honored the opportunity to share the collected media with each other via the connected devices.
Figure 1. App: Choose one of the four media types to proceed to the presentation view.

Figure 2. App: Choose between personal or public topics.

Figure 4. App: Video content presentation with YouTube embedded.
Figure 3. Web: Picture management for public subjects

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The d-ball project is a design study by Antje Obreiter and Franziska Gabriel at the University of Vechta and its faculty Design Pedagogy.

‘d-ball’ is an intelligent toy, which stimulates the activity of persons with dementia. Through active gaming, the players are encouraged and challenged.

The design concept consists of a very robust rolling object which is used on a table. d-ball can be actively rolled forward and backward between various players. It stimulates reflex actions by a person to which the sphere is travelling. This object, however, is able to recognize the table’s edge by its intelligent digital inner parts, which prevents it from dropping of the table top. Vibration sensors detect the movement created by a person pushing it as well as motionlessness while standing still. In case a player is inattentive the ball can return autonomously to the place it was pushed from. The active member of the group can now send it to someone else at the table.

The program steering this ball enables a group of people with dementia to play a game continuously without the active help of a caregiver, which means they can play relatively independently. Even for a group of people in different stages of dementia, a game without the direct interaction of a caregiver is possible.

The aim is to strengthen the self-confidence of people with dementia who can still concentrate well as well as to integrate the those who only have fewer lucid moments. Caretakers can survey the situation from further away and preserve the dignity of their patients as long as possible.

Within the exhibition space of Dementia Lab event, the design concept ‘d-ball’ was showcased on a table. The handling of ‘d-ball’ was shown on a display on a different pedestal running throughout the day. A poster stated the main features of the design process.
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1. Abstract

Most tools to measure User Experience (UX) rely on self-reflection and self-report. Users are required to operate those tools next to the system currently being evaluated and have to deal with the additional workload. Progressing cognitive decline and aphasia make those UX tools unusable for people with dementia who lack the ability to communicate how they feel about an object, content or interaction. To still capture emotions in people with dementia there are so called Quality-of-Life (QoL) methods, which are characterized by proxy ratings. QoL methods provide a varying range of observed emotions and actions as labels for observation periods of several minutes. The length of the observed timeframes, however, makes QoL tools unsuitable for linking emotions to specific triggers. Mapping content or interactions to the resulting emotions is indispensable for informed iterations of a user interface design. Thus, new tools for systematically evaluating interaction triggered emotions in people with dementia are required.

As one possible solution we present Proxemo (Huber, Preßler, Tung, & Hurtienne, 2017) an approach to real time emotion classification by proxies. Its simple emoji interface based on a scale by Lawton, Van Haitsma, and Klapper (1999) enables proxies to log the person with dementia’s emotions when they occur (see Demo 1). Proxemo is running on a smartwatch (Gear S2, Samsung Electronics GmbH, Seoul, South Korea) that allows evaluators to move around and stay hands-free seconds before and after usage. A further advantage is the small size and similarity to an everyday object (see Demo 2) that makes it less prominent for data collection than a clipboard for notetaking which is common among evaluators in dementia care settings. Emotions documented with Proxemo are written to a log file next to a timestamp. The log files can later be synchronized with a video to communicate to designers which emotions were triggered by specific interactions.
Data quality depends on one critical precondition inherited from QoL methods: proxies (evaluators) need to be well trained or have a close relationship to the observee in order to reliably read their emotions. Our next steps are to implement emotion logging for multiple observees and conduct tests in dementia care settings. We strive to optimize Proxemo in close collaboration with experienced evaluators.

Figure 1. Wireframes of the prototype show a user profile (left) in which an emotion is logged (middle) by tapping the corresponding emoji-icon. Turning the bezel changes the user profile (right). Emojis represent the set of emotions used by Lawton et al. (Lawton et al., 1999), clockwise from top: pleasure, sadness, fear, anger, general alertness.
Figure 2. Picture of evaluator documenting the emotion general alertness on the latest version of Proxemo.
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References


Author Bios

Stephan Huber studied Human–Computer Interaction (M.Sc.) at the Julius–Maximilians–Universität Würzburg. Currently he works as a research associate at the chair of Psychological Ergonomics and contributes user centered design methods and evaluation techniques to the project Interactive Memories (www.intermem.org).

Jan Preßler studied at the University of Augsburg and at the Julius–Maximilians–Universität Würzburg. He gained experience in the Industry as a User Experience Engineer before becoming a research associate at the chair of Psychological Ergonomics. There he is currently working on the project Interactive Memories.

Jörn Hurtienne is professor of Psychological Ergonomics at Julius–Maximilians–Universität Würzburg (Germany). His research interests include design for intuitive use, design for older adults, and the psychology of knowledge work.
Designing interactive objects for people with dementia: An interdisciplinary course

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1. Background

Interactive digital media provide new opportunities for designing for people with dementia. Designing for this target group is a challenging endeavour with many sensitivities, obstacles, and emotions. In 2013, the university of applied sciences in Düsseldorf started a research program called ‘Nutzerwelten – designing socio-technical systems for people with dementia’ (www.nutzerwelten.de) in which teachers and researchers from four faculties collaborate. As part of the program we set up an interdisciplinary course on designing interactive digital media objects (see Fig.1) in this context. Motivated by the lack of medical treatment and caregiver resources, the focus of the course was on the design of artefacts that can act as psychosocial interventions, e.g. by supporting the reminiscence and communication of people with dementia. The course was offered as an elective for Media Informatics and Communication Design students and is novel in our program in two ways: (1) it integrates two disciplines and (2) students engage in a close relationship and have interactions with people in the care field.

Figure 1. Interactive objects created in the course.
2. Course Set-up

A lot of effort went into establishing the right conditions, e.g. agreements on teaching formats, and establishing a network of partaking care facilities. The latter was supported by the local dementia network in Düsseldorf. It was crucial to establish a trust relationship to people in the field, and define value for both the university and the care home (reciprocity). The role of people with dementia was to give students insights into their experiences early in the design process and feedback on designed prototypes throughout the process. Each student group had close contact to at least one person who suffered from dementia or a caring relative, and could spend time with that person outside course hours.

The course consisted of four steps: (1) getting acquainted with dementia through expert information (rational level) and films (emotional level) and breaking down misconceptions; (2) Understanding and empathizing with the target group to ensure design outcomes fit people's real needs. (3) Sharing experiences in class and creating a design vision to inform the ideation processes. Last, (4) iteratively, evaluating designs with experts (social scientists, dementia experts) and in field tests with people with dementia. For more information see (Huldtgren et al., 2017; Huldtgren et al., 2016; Huldtgren et al., 2015).

3. Experiences

Before the first student encounters with the care field, some felt uncomfortable and fear of contacting people with dementia. Especially computer science students were not used to go into the field and interact with vulnerable user groups. Several students reported, contrary to their assumptions, that field visits were positive, people with dementia were open and sometimes even cheerful and care homes far from depressing. Also, seeing residents enjoy the created designs was a major boost in motivation. Care workers ensured that the people with dementia were not overwhelmed by student visits.

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