Getting to know you the best we can; embedding design in a dementia ward

Andrea Wilkinson, Niels Hendriks

University of Leuven, BE

Abstract

T(e)Huis is a project which began in October 2014 in which a design team are embedded in a care facility dementia ward for two years. Over the course of these two years, the role of designer (usually associated with a defined role of making) and researcher (often restricted to observational bystander) meld into that of layman carer and friend.

T(e)Huis follows in the wake of previous dementia-related projects which each lead to a refining of their participatory methodology to suit not the disease, but the individual; his/her context, their network of caregivers and, central to the way in which they work, the person with dementia themselves. Instead of designing for generic symptoms or user groups, they work with individuals, designing without a predetermined technological restraint or aim. The resulting innovations range from colouring books to way-finding jewellery to baskets for zimmer frames.

For T(e)Huis, the goal is to create bespoke designs together with people with dementia that support their feeling of 'home'. This project asks several questions relevant to both design and health. For design practice it asks about the importance of individuals; how a designer can embed empathy into their practice and continually adjust their way of working so that it is open for participation. For the healthcare sector, it asks what this sort of initiative provides as return in relationship to their core purpose of care. This paper will present how this work is carried out, initial reflections as well as how this way of working is shared in design education.

Keywords: dementia, participatory design, design education, methodology, design process

Introduction

Design often refers to an end result, an interface in its broadest meaning; the connectedness of screens on a smartphone, the simplification of data into a clear informative graphic or a beautiful (and often functional) object. If design is a result, then designing is an action that leads to this result. For the past four years my colleague Niels Hendriks and I, have been rethinking this action of designing. Instead of designing for, we are designing with. Instead of designing for idealised user groups, we are designing for specific and authentic contexts. This paper will describe key events that led to our investigation into an alternative, individualised way of designing.

The background; trying to translate empathy

Since 2011, we have been working respectively as design(er) researchers within the subject area of dementia. Initially having little or no expertise in working with people with cognitive impairments or disability, it became apparent early on that experience and empathy were necessary when developing relevant and meaningful designs for people with this condition. With the term *empathy* we are referring to what Kouprie and Visser (2009) describe as the stepping into and out of the user's life, providing not a cursory connection to the user but a level of shared understanding which informs design decisions. In regards to the creation of *meaningful designs*, the Dutch designer and critic van Eekelen (2010) describes this as an awareness of what is happening in society, a designer finding his/her role within this society and then making a contribution to his/her surroundings placing a designer in a position (or burden) of responsibility.

Our first contact with dementia within a designing context was a funded research project dealing with the 'internet of things'; how a network of sensors could benefit a person with dementia living in a care facility. Work packages were assigned with a sliding scale of involvement; direct contact with people with dementia was dependent on roles and outcomes. In an initial research phase, relevant insights from early rounds of ethnographic research were analysed and translated into experience-based workshops and presentations of story-based scenarios linked to specific daily rituals and shared with the entire project team.

To support our research, we also educated ourselves in the array of symptoms and the impact that dementia could have on a person's sense of self and daily life. This meant not relying on our pre-held belief that dementia manifests itself only as forgetfulness, but learning about the variety of psychiatric and cognitive symptoms that affect the each person with dementia differently. Our experience working with individuals in our partner care centres supported this literature; they almost always suffered from a deterioration of memory, but also showed difficulties in language and communication, struggled to perform purposeful movements and had difficulty in orientation in time and place (American Psychiatric Association, 2000). In addition to these more quantitative symptoms, behavioural and cognitive problems such as irritation/frustration, short attention span, restlessness, an inability to learn new routines or adapt to changing situations,… also occurred.

(Hendriks, Frederik and Duval, 2013). What was drawn from this was that the impact dementia had on a person's life experience was palpable and the experience of these symptoms varied from person to person. The people we came into contact with were not a neat, homogenous user-group, they were instead what Kitwood (1997) reminds readers, unique individuals.

As with many large research projects, hindsight offers the opportunity to question our success in translating qualitative research; whether it gave sufficient voice to the person/context of care. Distilling the experience we had had as researchers, of being in a dementia ward, sitting with people with dementia, talking to care givers and family members, observing work-flow, etc. into a list of slides or snapshots, missed much of dementia's story. Having worked in both the initial and later work packages, it was clear to see that although a prototype (design) was created and showcased, it reflected little of what had been prioritised in our presentations/workshops, the person we had presented in our scenarios and her network of care. There was a clear disconnect between maker and user/secondary user. Translation and transference of empathy had somehow failed.

This disconnect between the result and the experience caused us to critically question how we were working; what if we placed 'makers' in direct contact with the care situation? What if designers began to design for people instead of designing for a description of symptoms? What if a design's purpose was not linked to economical viability? The central problem space we took from our experience of this initial project was the idea that to generate meaningful designs, designers had to have an awareness of the context of potential use and empathise with users.
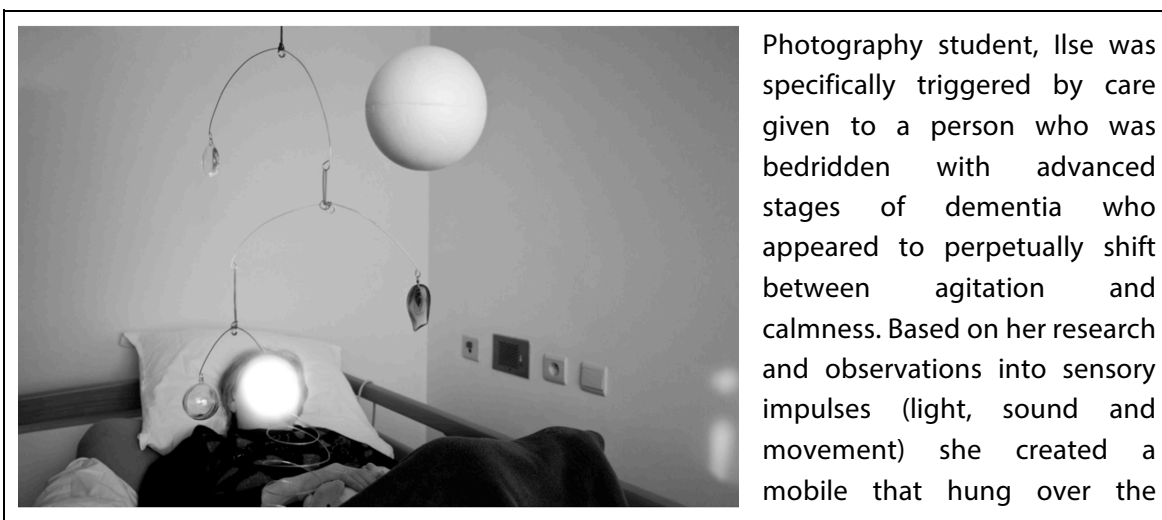
Minimizing the need for translation

Prioritising the person behind the title of user is not new. User/Human/People-Centred and Inclusive/Universal design are all processes or manifests that have humans at the core of their positions. Because we had found the contact with people with dementia to be crucial to the knowledge we gained, we saw this interaction as a form of implicit participation. Participatory design, often defined as an ideological approach in which all stakeholders within a design are involved in the design action, proposes that the end result (the thing designed) will be usable. We had already borrowed techniques of participatory design during the work packages of the previous project (co-designing, paper prototyping, mapping) that had delivered interesting insights in the research, but not led directly to any specific design results. For any new projects we knew we wanted to employ a design process that included working directly with people with dementia, their loved ones, care centers and care givers, where those impacted, in tune with participatory design's 'expert user' scenario, would be experts in their own experience instead of being research subjects (Sanders and Stappers, 2008).

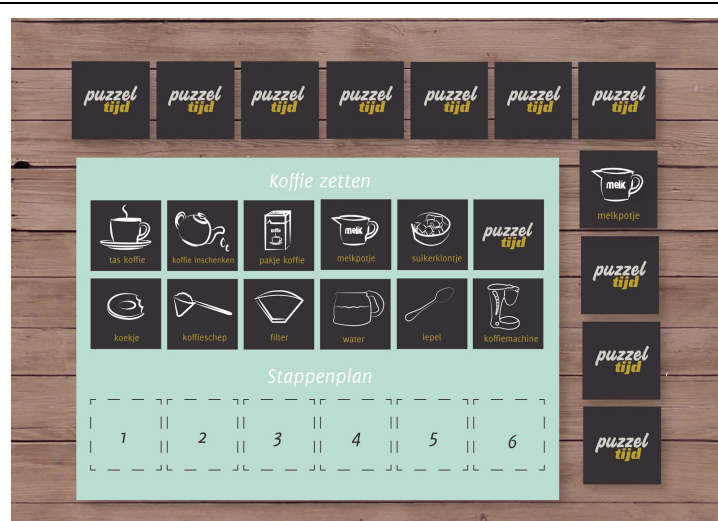## The crossover with design education

We first got the opportunity to explore some these issues when in late 2011 we were approached to develop a Masters module dedicated to the subject of dementia. Because of the good relationship we had developed with a care facility during the initial project, they provided us with a context to work within and opened up their dementia ward, their patients and staff to our Masters students. A six-week module, the goal of the course was not linked to a technology or limited to a particular domain; our students were to work with an open purpose in mind, to work towards a meaningful aim: *to make the life of someone with dementia more pleasant*. We started the students off with a deep-dive into dementia; from medical definitions to dos and don'ts to dramatised films. This knowledge immersion culminated in a 36 hours care facility experience where they spent time with people in the dementia ward, slept overnight in the facility and familiarised themselves with the rhythm of a care facility. Our design students continually shifted roles, from volunteer care support to observer, to hand-holder and listener (none of which are traditional maker-roles).

In the first edition of the module, we had few expectations of how this experience would impact the students. At the end of the module, however, it was clear that this initial 'deep-diving' (what Kouprie and Vissers refer to as 'immersion') played a dramatic role in generating empathy (concern, understanding, sense of responsibility, de-stigmatisation, etc) and set a common standard of understanding from which every student seemed to draw during their project development. Finally, what the students created were not generic dementia-related products, they were designs based on experiences with individuals, bespoke designs based on sometimes short, but meaningful moments of exchange.

Photography student, Ilse was specifically triggered by care given to a person who was bedridden with advanced stages of dementia who appeared to perpetually shift between agitation and calmness. Based on her research and observations into sensory impulses (light, sound and movement) she created a mobile that hung over the

person's bed. Each successive prototype refined the textures, size, colours, sound, imagery, etc. and tested the context in which it had to exist; also taking into consideration the amount of time that a carer had to give care.

Figure 1: Student Case 1

If students had a loved one with dementia, they were encouraged to work together with them. Graphic Design student Goele's grandmother had been diagnosed with dementia two years prior but still lived at home. No longer able to carry out regular tasks at home such as cooking, doing laundry, etc. she became angry when her husband did these tasks poorly. Triggered by her grandparents' frustration, and utilising her grandmother's love of playing cards, Goele developed a game that, when played with a second person, provided her grandmother enough support to carry out basic tasks such as making a cup of coffee. Her grandfather summed up the meaningful impact of this prototype by saying: It's the first cup of coffee my wife has made for me in two years.

Figure 2: Student Case 2

The projects the students made coupled with the enthusiasm of the care centre staff challenged us to continue exploring this theme. Continuing on an annual basis with the dementia module, we shared its story with a local care institution focused on providing care and support at home (OCMW Genk). They in turn partnered with us in a project called the Dementia Lab which focused on documenting and creating low-tech assistive tools for making the life of someone with

5

dementia who is still living at home, more enjoyable. Carrying on a process much the same as to that of our students, we invested in getting to know the individuals by carrying out design research through actions embedded in the day-to-day. Without a pre-determined concept as to what we should design, all concepts came out of the time spent (the participation) with the individuals themselves.

After a home-visit and a discussion with her son, we created prototypes of tools to guide Maria in preparing vegetables. On a Saturday afternoon we came to her house to have lunch, helping out with the preparation of the soup and using the tools that we had made; we were both friends stopping by for lunch and at the same time design researchers. Through this 'everyday action' it became obvious that any difficulties in food preparation she had were due to a difference of opinion between mother and her son about what parts of a vegetable was edible. Our design shifted direction. Through this action we noticed that Maria used her walker not only to aid in mobility, but as transport for actions in around the house which gave her a sense of contribution (setting and clearing the table, etc). Because the walker was not made for this type of use, she had broken many plates and cups and the son was threatening to no longer allow her this freedom. The resulting design included modifications to her walker/zimmerframe which helped her with these daily activities.

Figure 3: DementiaLab Case 1

Participation on location

The project we are currently working on, T(e)Huis, follows in the wake of the previous dementia-related projects. In T(e)Huis, the design-team (researcher/designer) is embedded in a care facility's dementia ward. This entails working on-site on a weekly basis and coming into regular contact with those who live and work in the care facility. Already 9 months into the first year, it is clear to

see that the role of designer (usually associated with a defined role of making) and researcher (often restricted to observational bystander) meld into that of layman carer and sort of friend (or trusted stranger), underpinning what Wright and McCarthy (2008) consider to be the foundation of empathic design.

The goal for T(e)Huis extends the theme of making life *aangenamer* (Dutch for 'more pleasant') with the goal to create bespoke designs together with people with dementia that support their feeling of 'home'. As we are embedding our practice into the care facility, so too are our students. In December 2014, the masters module ran exclusively on-location. After an intensive initial session, visiting the dementia wards, participating in the daily care, getting to know individual people with dementia and interacting with the care workers became part of the student's regular design practice.

Designing as actions

When working with people with dementia (or any other cognitive impairment) it can be difficult to achieve the sort of full-participation that advocates of PD espouse. Our way of working looks to be informed through participation, looking for clues (tacit knowledge) which we as designers can critically reflect upon and take on into a new iteration (Spinuzzi, 2005). Instead of working with explicit questions, issues that are important to the progression of the design are integrated into informal activities such as looking at magazines and photo albums, reminiscence exercises or daily rituals instead of being seen as an interview, test or medical research. If a person with dementia is unable to communicate, family members and care staff provide details to support the design direction. Finally all revised prototypes that are created are given to care center for use and improvement.

A care facility's view

None of the design research that we have carried out in the past four years would have been possible without the support and accessibility that care facilities and carers have afforded us. Being responsible for the care of vulnerable people, the benefits of stepping into a project such as this has to outweigh the potential issues. Sonja Dirckx, Director of Care (Christian Living and Care Centres) in Zonhoven, Belgium states that the partnership has to provide a mutual learning environment for both parties:

As a care centre we are a "learning organisation" which means that this learning is an interaction: we learn from the trainees, researchers, residents, their families, etc … and conversely, they also learn from us. We are both "better" through this. Designers see the elderly and care from a different angle, this helps us to expand our visions… and it brings surprising ideas. Sometimes designers hold up a mirror and force us to critically reflect on what we do.

In regards to opening up the facility to students, Nele Maeson, Clinical Psychologist, H. Katharina Living and Care Home, Zonhoven, Belgium remarked on the impact it had on the residents: *The residents were pleased with the additional opportunities for social contact and the caregivers saw that the students' interaction and visibility had a positive affect on the residents.*

Honesty about flaws and future-thinking; a conclusion

This highly personalised and customised way of designing together with people with dementia has its flaws or limitations that set it apart from other projects. First and foremost it remains safely within the comfort of funded research; it is exploratory in nature and works without some of the restraints that industry would impose (time, money, efficiencies,...). Secondly, because some of the work is based on tacit information, occasionally emphasis can be placed on elements which are not as important as they are perceived to be. Finally, because the project is working with people with dementia, the artefacts created are very momentary; designs are made according to participation as it was instead of for a certainty for how they might be tomorrow.

With such an ideological aim executed in very specific circumstances (working on an individual basis, in a time-consuming process, together with someone with cognitive impairments) the added value of working in this way might be overlooked. We propose that the work that is created, although bespoke in nature, can often be reworked to suit a larger user-group, including people without dementia. This means that the level of engagement, responsibility and social concern a designer can have by working together with an individual is not lost. Working backwards from a personalisation or hack of mass-market goods, the bespoke and the personal can become generalised.

In addition to this potential for innovation, this research is a clear example of how research and education can mutually support each other; a model for integrating social design into the design education curriculum. Although we have yet to know if this module will have an impact on young designers as they step into mainstream industry, the hope is that this way of working, developing a concrete understanding of the context and developing empathy with users will be embraced and that Participatory Design (or indeed, participation of users) will be regarded as a worthwhile approach as will the responsibility to create meaningful things.

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