Valuing implicit decision-making in participatory design: a relational approach in design with people with dementia
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Abstract

Sharing design decisions between designers and the people we design for and with, is a common aim in participatory design (PD). When working with people with dementia this rarely happens in explicit ways. Design decisions implicitly emerge from the relationships designers build with people with dementia. We argue that designers should value this relational approach and make transparent how it informs the design decisions. We were inspired by how person-centred care (PCC) is used by care practitioners to explain how they work in a relational way with people with dementia. In this paper, we explore how PCC can support PD researchers to acquire relational expertise, which we illustrate by means of a design project for and with people with dementia.

Keywords

This paper uses a case of involving people with advanced dementia in the design process as a way to show how implicit design decisions are of importance to the participatory design process. It explores how designers build relationships and how these inform their design decisions. It links shared decision making to the relational expertise of the designer and person-centred care, a care paradigm in dementia care.

1. A relational approach to participatory design with people with dementia

Design research engages strongly with societal challenges particular to the ageing population in our Western society (Lee & Moore, 2015). This paper deals with the challenge of designing for and with people with dementia. We position our work in the field of Participatory Design (PD), which has explored the benefits of deeply engaging with individuals from different societal groups in design processes (Smith, Bossen, & Kanstrup, 2017) even more so with groups that are perceived as challenging to engage with (e.g. Frauenberger, Good, & Keay-Bright, 2011; Lindsay et al., 2012; Moffatt, McGrenere, Purves, & Klawe, 2004).

Dementia is commonly defined from a biomedical perspective and can be seen as an umbrella term encompassing several psychological and cognitive symptoms. Problems with remembering is the most commonly known symptom, however, a disorientation in time and place, impaired reasoning, difficulties with language and performing motor tasks are also common. Although the way dementia affects a person's life is highly individual, in general, all symptoms will interfere severely with daily life (ALZ.org, 2012). Despite there being different ways of categorizing the dementia process, it can be split up into three phases: early, mild to moderate and late stage. In the later stage, a person with dementia will have severe trouble communicating and needs continuous help (ALZ.org, 2007).

Several strategies have been used by PD researchers to overcome the challenges of involvement (Crosskey, 2014; Mayer & Zach, 2013; Rodgers, 2017). Many focus on communication between the designer and the person with dementia and apply verbal or visual ways of communicating. Robinson et al. (2009), for instance, invited people with dementia to join focus groups and Van Steenwinkel et al. (2014) made use of poems and interviews. Mayer & Zach (2013) employed visual tools (photos, icons) to engage people with dementia. For people in advanced stages of dementia, however, interacting through speech or other verbal utterances becomes too complex as many suffer from aphasia or severe cognitive decline that inhibits their ability to converse. Visual ways of working can also become difficult due to impaired eyesight and limited abstraction ability. Therefore, many design researchers have explored other tools and techniques that intend to work better. Caris-Verhallen et al. (1999) and Cevasco (2010) experimented with proximity and touch; Branco et al. (2016) used openness (elements of the artefacts left open to be filled in); Wallace et al. (2013) took on artefacts as mediators in communication; Morrissey (2017) focussed on touch, movement, song and dance; Kenning (2017) used a variety of tools from surveys to like/dislike-tools to enable less direct ways of involving; Rodgers (2017) applied visual tools while facilitating an openness to failure.

Although these methods, tools and techniques were specifically made with and targeted at people with dementia, researchers like Branco, Morrissey, Wallace, Kenning and Rodgers describe that they could only be used meaningfully in the design process after they had built close relationships with the people with dementia, the environment in which they were embedded, and the subjective ways in which a person with dementia experiences and makes meaning of their surroundings.

Dindler & Iversen (2014) stress that building such relationships requires relational expertise. They indicate that every design process entails new practices and artefacts, but also the development of new networks and relations between people. These networks and relations can be considered as an object of design, which can support the development of new designs. However, as Dankl (2017) indicates, design researchers are mostly not trained, as many health care workers are, in taking the relational dimension (of dementia) into account. Dankl was inspired by Ingold (2013) to engage more with the relational knowledge of people and sees a design anthropological way of working, supplemented with the act of making, as a starting point to this.

The specific ways in which such relations are built and relational expertise is 'practiced', and how this in turn informs decisions in the design process, remain rather implicit. Bratteteig and Wagner (2012) point to a problem in connection with the implicit character of how relations inform design decisions. They state that many decisions are based on people who implicitly exercise power, because they have certain expertise or skills or because they built a relation of trust or influence. While it is characteristic to and inevitable in a PD process that many decisions are made implicitly, Bratteteig and Wagner make a plea for design researchers to be more transparent and conscious about them.

This paper specifically addresses the challenge of making these implicit decisions that emerge from the relationships that designers build with people with dementia more transparent. To do this, we provide more insights in how and when decisions are taken in PD while working with people with (advanced) dementia. Next, we refer to how the person-centred care (PCC) approach is used to train care workers in healthcare contexts to build relational expertise to care for people with dementia. We explore how PCC can support PD researchers to be transparent on how they build relationships and how these inform their design decisions. To illustrate this, this paper shows how these principles of PCC supported PD researchers in setting up and discussing their relational way of doing design research in a 2-year PD project set in a dementia ward (AtHome). The research question this paper thus deals with is twofold: 1) "How can we make implicit decisions that emerge from the relationships that designers build with people with dementia more transparent? 2) What are the consequences of making a relational approach and implicit decision-making more transparent in PD in dementia care and for the PD research process in general?"

2. Decision-making in participatory design with people with dementia

As mentioned before, PD is concerned with sharing the decision-making process in the design process with those who design is for. While most literature in PD deals with the ways in which design researchers share decisions, some authors focus more on the political and ethical aspects of decision-making.

Bratteteig and Wagner (2014) gained insight into the politics of the more explicit and implicit decision-making in the design process by evaluating the design process in relation to four aspects of Schön's 'design moves' (1995): creating choices, selecting among them, concretising choices, and evaluating the choices and the design results. The "move experiment includes the designer's evaluation of a situation, a move to change it, and an evaluation of the move" (Bratteteig & Wagner, 2014) in the relational interaction with the world.

The group of people we worked with in the research project described in this paper are people with advanced dementia who struggle with reduced abilities and capacity to explicit consent. While individuals with early stage dementia might still be capable to take the lead in a collaboration with a designer and participate in explicit decision-making, working with people with advanced dementia brings additional challenges as making abstractions is difficult, severe memory problems occur, communication gets even harder, frailty is strongly increasing, and, in general, the ability to collaborate and explicitly consent becomes more challenging. Therefore, Berghmans and Ter Meulen (1995) provide a rather negative view on involving people with dementia. They consider non-therapeutical research with people with dementia immoral as it does not provide any direct benefit to the person involved. Newer views on dementia (Craig & Killick, 2011) favour more inclusive forms of research, valuing the person with dementia as a subjective being, which demands discovering alternative ways of sharing decisions than in explicit situations of consent.

This inclusive vision is in line with the general opinion in PD, which is also the basis of the framework proposed by Bratteteig and Wagner. They foreground that it is the designer's moral duty to involve the stakeholders in the design process without however asking whether this participation can be traced back in a final design result, let alone be quantified ("how much participation"). Whether participation in a design project is in the person with dementia's own interest ("what do they gain from participating") can not only be assessed in relation to 'design results'. There is also value in having a pleasant encounter with the designer, enjoying the use of an artefact, or, as Kenning (2017) formulates it, 'in the moment pleasure'. In an inclusive vision, the opinion is thus that what people get out of the PD process is more diverse than only the result. In a similar vein, giving consent can take other

forms than giving explicit verbal consent. Dewing (2002) pleads for non-traditional consent giving that lets the researcher continuously asses -through the knowledge of previous encounters or observations- the well-being (and ill-being) during the involvement in the research and design process. Similarly, Bartlett & Martin (2001) refer to guidelines from the UK Royal College of Psychiatrists, that take 'common sense' as the leading principle.

In summary, even without explicit consent giving or explicit decision-making, clear benefit of participation or direct involvement in decision-making should and can happen. The reference to 'common sense' relates closely to what Dindler & Iversen call relational expertise, the sensibility of designers on when, how and in what way their design partner gives input for design decisions. By looking at person-centred care we want to further deepen our understanding of how this relational expertise can be enhanced.

3. Person-centred care as a way to enhance relational expertise

Person-centred care is the ruling care paradigm in Western dementia care. This paradigm focuses on enhancing care workers' expertise in building relationships and using this as a resource for improving daily life and care of their residents. PCC emphasises the relational aspect in the caretaking process in contrast to care working only on a functional level looking at (dis)abilities and focussing on the performance of tasks and control (Epp, 2003).

Despite the fact that there is no uniform description of what PCC entails (Lann-Wolcott, Medvene, & Williams, 2011), the set of characteristics of PCC can be divided into three categories. The first category deals with (1) the concept of personhood, which can be defined as "a standing or status that is bestowed on one human being by another, in the context of relationship and social being. It implies recognition, respect and trust." (Kitwood, 1997) Central is thus the relational way of working in which one respects the person with dementia as an individual with a sense of agency, embedded in the context of relationships. A second category deals with (2) who the person with dementia is and was (Surr, 2006). The way a person with dementia perceives reality, their lived experience of the here and now, should be valued. The final category deals with (3) the body as a communication tool. The body has embodied intentionality suggesting that even with severe cognitive decline, the body gives a sense of agency, can express awareness, etc. (Kontos & Naglie, 2007).

PCC proposes several actions that support care staff in gaining capabilities to work. There is quite some focus on (a) reflective actions, analysing one's own fears/challenges and

evaluating how one relates with, experiences and responds to a person with dementia (Passalacqua & Harwood, 2012). This (self-)reflection happens both individually as well as in a group of peers. To be critical towards one's own way of dealing with people with dementia and explore the relationship one has with a person with dementia, much effort is put in (b) acting (or role play) (Kontos, Mitchell, Mistry, & Ballon, 2010). Drama is effective to acquire a better patient understanding and to appreciate a potential power imbalance. Staff is also encouraged (c) to create the story of the person with dementia via reviewing biographical data and narrate their encounters with the person with dementia.

4. Four guiding principles to build relational expertise in PD

PCC is inherently a care paradigm, while PD is a specific design approach. Literature has shown that both can benefit from each other. Branco, Wallace, Morrissey all refer to Kitwood, the founding father of PCC in dementia, and regard the principle of personhood and the preservation of the self, as guiding principles or moral backbone in their design work. Wallace et al. (2013) see the preservation of the self as a leading principle in the contact with and the design work for a person with dementia and her husband; Branco (2016) adopts the concept of personalisation in PCC; while Morrissey (2017) sees PCC as a reminder for designers to find ways to 'listen' to people with dementia.

Concluding our brief review of the literature, we match the three actions that caretakers are trained in to acquire capabilities in PCC, with the typical moments in PD where design decisions are taken (sharing of power in creating, selecting, concretising and evaluating choices in the design process - Bratteteig & Wagner, 2014). This results in a set of four guiding principles that allows PD researchers to build relational expertise.

4.1. Creating choices through reflective actions

The first phase of a PD process generally involves designers who create choices together with the people they design for. Several techniques (design games, prototyping workshops, forum theatre, etc.) exist to postpone closing off a design path and support all participants to create potential design choices. This is thus the action where handles for the design process are generated. As indicated, creating choices together with people with dementia happens only to a lesser extent using explicit methods, tools and techniques. PCC takes an effort to make the

step of making implicit (care) choices transparent by taking reflective actions. When translated to a PD context, these reflective actions ask to look critically to the build-up of the relation between the person with dementia and the designer, how implicit design choices were derived therefrom and how they were shared with the person with dementia.

4.2. Making selections through storytelling

At some points in a PD process, power is shared in making selections in the design choices created: what paths will be followed or closed off. In PCC, storytelling is used by caregivers to make selections in all the data they receive when interacting with the person with dementia. PCC asks to create the story of the person with dementia using biographical data, to narrate the encounters with the person with dementia and the way the relationship between the carer and the person with dementia is built and interpreted. Combining insights from the PD and PCC ways of working, suggests that sharing design decisions in the selection phase in PD can be made transparent by placing the design decisions - explicitly made together with the person with dementia or implicitly derived from their encounters - in relation to the story of the person with dementia in the past and present. This is done via the action of making and sharing stories on the person with dementia and their network. In these stories designers make their selections transparent on which they will build for possible future designs.

4.3. Concretising design choices through role playing

In PCC, role playing is used by caregivers to explore alternative or new relationships with the person(s) they work with. Role playing can be used by PD researchers, in order to give form and explore the alternative or new relationships that emerge and how they support the concretising of the design with people with dementia. Roleplaying allows to pay careful attention for the possible power imbalances that emerge during the PD process.

4.4. Evaluating design decisions

In a PD process designers evaluate design decisions and results with the people they design for. This becomes difficult in cases where explicit evaluation is challenging. PCC pays little attention to evaluation of results. For PD researchers this is thus a category they should add to the PCC ways of working. As Bratteteig and Wagner (2014) indicate, the evaluation of the

design decisions can happen both explicitly as 'in use'. In the philosophy of PCC, designers can make transparent how they share decisions 'in use', by evaluating the new relationships that are built and the design results that are generated.

5. Field work: AtHome

We matched the relational expertise that caregivers build via PCC with the democratic aim of PD to share design decisions. The resulting 4 guiding principles allow for valuing the implicit design choices that are made in PD processes and for critical discussions on power imbalances and ethical concerns. We explore these via a case study, AtHome (2014-2016), in a residential care setting and aimed to ameliorate the feeling of home for people with dementia through design. Personalisation of the living environment is a central aspect of the feeling of home. This is however a challenge (Popham & Orrell, 2012) , since rooms in care facilities need to be furnished (or 'de-personalised') to be quickly re-used and to comply to medical and safety requirements.

5.1. Approach

The research project was led by two design researchers, both with more than five years of experience in designing for and with people with dementia. In the line of Ingold (2013), the research described in this paper explores a design anthropological engagement with the world (the physical context, the lived reality, etc.) combining both design and ethnography. Being reflective and prescriptive is what is taken from ethnography while the research and design process tries to be involved and active and creates knowledge in and through action (Gunn, Otto, & Smith, 2013). This approach encompassed a long-term (two years) embeddedness of the two researchers in a dementia ward, with one day a week presence in the dementia ward, working as design researchers. During twelve weeks of research residency each year, the two researchers were accompanied by visiting design researchers, being design students (master level) and professional designers.

Each designer was supported by the ward's clinical psychologist, the design researchers and a group of caregivers, the latter providing practical support in the contact with the person with dementia and facilitating contact with the family members. All participating designers attended an introduction in the topic of dementia, the basics of PCC as well as a presentation refreshing the essentials of PD.

Since the symptoms and the way dementia affects daily life are different for each resident, the project entailed a one-on-one design setup that coupled each designer with one person with dementia. During twelve weeks, the designers accompanied a person with dementia in everyday activities such as having lunch, singing along in the dementia choir, taking him/her out for a walk or just being together in the common room. This time spent on such non goal-oriented moments together with the person with dementia helped the designers to perceive them not as an older person stricken with dementia, but as a human being who enjoys their lunch, likes to sing etc. and supported the designers to build a relationship. Over the course of two years, a total of 28 persons with dementia and 21 visiting designers (students and professionals) were involved.

We briefed the designers to take into account the four principles to support the build-up of the relational expertise in designing with people with dementia during their stay. We evaluated how the relationships informed their design decisions through interviews, a round table conversation with the designers and weekly video reflections. The interviews were done in the last week of the residency to chronologically reconstruct the design research process. In the videos, the designers reflect on the participation of the person with dementia they collaborated with, what they learned, and how this was translated in different decisions. These video-reflections were recorded after each contact with a person with dementia. The round table conversations brought together small groups of participating designers to discuss, in a non-directive style, the past experience of a relational approach to designing with a person with dementia. We clustered quotes from the transcripts of the videos, interviews and round table conversations via the four guiding principles that were part of the conclusion of the literature. In the findings section we discuss particular opportunities and challenges of these principles that emerged from the data that were generated during the participatory process in the AtHome-project.

The findings we report will be enriched by stories and anecdotes, in which we focus on new insights in relation to our research question. The informative quality of such narrative elements as part of the design process has been experienced as inspirational by several authors who design for and with persons with (cognitive) impairments or about ageing (anonymised reference; Luck, 2018; Escalante, Tsekleves, Bingley, & Gradinar, 2017). Michael (2012) refers to the performative character of the anecdote as "the making and enacting of anecdotes is a means of interrogating the research process itself". Lindström and

Ståhl (2014) state that anecdotes have a double meaning of sharing and producing. They are used to share a challenge (with peers or caregivers) that came about during the research and design process. Through narrating these stories, meaning is produced as it helps the narrator to better understand what happened, come up with new arguments, details or ways of dealing with what is told. When reading the stories, one has to keep in mind that narratives placed under one category could also have served as exemplary to another. Just like Bratteteig and Wagner do not see creating, selecting, concretising and evaluating as discerned chronological phases, so the four categories might go for multiple anecdotes at once.

5.2. Findings

5.2.1. Creating choices through reflective actions

To engage as designers in a reflective relation with the person with dementia and her/his network, and to make transparent which design choices were generated when building this relation, we introduced two elements to support reflective actions. First, we briefed the designers to create a video reflection after every contact with the person with dementia, wherein they zoomed in on the events of that day, moments of joy or doubts (in interacting with people with dementia; on the artefact creation). The designers re-viewed these video-reflections after three weeks, in the middle of the project and right before the end of their residency. Second, each designer also was coupled with another designer. These design-couples supported each other (e.g. in documenting a moment with a person with dementia), but they also aided in the reflection on the relation that is developed with the person with dementia and how this related to the participatory design research process. This happened while giving feedback on each other's work or discussing documentaries, articles or graphic novels on dementia.

The designers confirmed that the confrontation with their own words supported them to be critical towards their ways of working and allowed them to be more transparent about the way certain design choices implicitly were created. The created design choices were as varied as an interest in going to the seaside (clear from the emotional response every time photos of a beach trip would be viewed), a loving relationship for a parent's farm (each walk the person with dementia would stop and 'explore' a series of pictures of her father's farm) or an interest in fashion: "We read glossy magazines together. I thought she read it for the showbiz, for the beautiful celebrities or the glamorous commercials." (designer Mira). Mira later indicates that it was only after: "looking back [at the different videos], I realised I knew what I was going to do after we scrolled through the magazines. She was so enthusiastic about some pictures

and, well, others, she didn't care." While the design choices that were created were generally not spectacular and difficult for the designers to work with, the length of the design process and the debates with the design partners helped the designers to see the design value of seemingly little interesting 'discoveries' and made transparent the value of small interactions with the person with dementia.

5.2.2. Making selections through storytelling

Based on the encounters with the person with dementia and his/her environment, the designers were asked to build the 'story' of the person with dementia they worked with. This supported them in articulating their process of making selections. In these stories, the designer expressed what they experienced when being in contact with the person with dementia as to construct the image of the person with dementia not from a medical perspective (focussing on abilities and frailty), but in relation to her/himself, the designer. In the first two weeks of the design process, stories were generated from the premature phases in building a relation with people with dementia. Stories were told through sketches, photo-stories and more poetic materialisations: from soundscapes to small clay statues. The materialisations were an attempt to reflect the vision on and the designer's relationship with this person in a self-chosen way. The designerly response stayed with the designer throughout the process and confronted the designer with their (changed) vision on and relationship with the person with dementia. In a clay statue, designer Bea expressed the sadness she experienced in the person with dementia who cried very often. Later, she understood that this crying was not (only) an expression of him feeling unhappy, but a way to express negative as well as positive emotions. In this way, Bea gradually understood that Jean crying during their interactions wasn't to be interpreted as a negative thing. In the course of the weeks, she learned to decipher his responses (crying, holding hands, etc.) in their encounters.

The designers constructed and told the story of their encounters and information gathered to their peers, family and the caregivers. The build-up of this story (rich in detail and emotion) became an elaborate account of the historical and present self of the person with dementia as perceived by the designer. The designers used these stories as a leverage for the design selections they were going to make and left openness to grasp the story and intervene in it. The subjective views on the person with dementia of family/friends and the caregivers helped to establish the biographical self, informed the design process and supported the designer in making or altering the already made selections. Designer Jana, for instance, hinted at

pursuing a potential design path focussing on volleyball or "something creative". The family supported her in making the step towards the creative path: "I had the feeling I should do something with pictures or volleyball. She had quite some pictures and drawings (...) I read she used to play volleyball, just like me. (...) She (daughter of person with dementia) told me, she (the person with dementia) liked drawing on silk. A lot. (…) That helped."

Making selections in design choices does not function in a unidirectional way, which again stresses the relational in the PCC approach. Designer Jana made the choice to focus on drawings, not only due to what the daughter indicated, but also because it made her feel more comfortable: "I am not a talker. When I'm drawing, I'm feeling at ease". Mira too was happy to cut-up, alter magazines and fashion books in her process as "a book feels self-evident to me, to my abilities, competencies and what I want".

5.2.3. Concretising design choices through role playing

During the design research period all designers were stimulated to enact a specific care or daily living situation without and with (elements of the) designs created, reminiscent to the way of working as proposed by Brandt and Grunnet (2000). This supported them to bring to the surface how they saw the designs work in relation to the design handles and stories that were generated. In one acting workshop, with the aid of the psychologist, several scenarios that are characteristic to the dementia ward and the residents the designers worked with, were provided ("It is almost lunchtime. Rene is sitting at the table, waiting and getting slightly frustrated. It will still take half an hour for the food to arrive."). The supposed designs (prototypes, sketches or even just the concept) were used as a prop in the role-play. In the evaluation of each short play, the whole group of designers and caregivers joined in to reflect on the proposed design choice focussing on meaning (how will this design impact the daily life and care ?), functionality (will it 'work'?), aesthetics and material choices (durability; non-stigmatizing design), on power imbalances and ethical challenges (do we correctly interpret the emotions?).

Figure 1: design studios in the dementia ward

We also stimulated the designers to account for less explicit ways of 'acting' that happen outside a workshop-setting. All designers set up their design studios in the dementia ward (see figure 1). This became the space where they got feedback, tinkered, etc. and the common living room of the people with dementia was only separated by a hallway. This created a low barrier to step into the daily space for living and caring and, reversely, made it normal for a person with dementia to step in the designers' space. This embeddedness redefines the role of the designer from an objective observer to an involved actor. As the designers integrate in the way of acting in the everyday life in the dementia ward they get confronted with how caregivers talk to a resident who wonders when her mother is going to pick her up or how they try to stimulate a resident in eating by making jokes about the mashed potatoes on the plate. Moreover, while being embedded, the designers naturally exercised through role-playing how they could involve the person with dementia more in evaluating the concretising of choices.

Designer Karen designed together with Ann, who is confined to her comfortable chair without the possibility to converse. She sought for ways to naturally involve her in concretising design choices while creating a piece of clothing that would allow for fidgeting. She tried to understand what type of textures and material elements would give Ann the most

pleasant experience. She sought for a way to have Ann evaluate the set of materials she had, without it feeling unnatural: " (...) holding something wasn't awkward at all. It is something you dare to say: could you hold this while I go to the toilet? That is a natural thing. If I would just say: hold this, then she might think: who are you, why are you doing this?". Designer Xavier had a similar strategy when collaborating with a resident: "He smokes, just like I do. I waited for moments when he was allowed to go for a smoke and would join him. Then I would 'randomly' show him my designs and have him … well, respond to it. In the meantime, we talked about women, dancing and going out. Otherwise he wasn't interested." . Designers Karen and Xavier thus searched for ways to act/perform as friends (smoking buddies, acquaintance), as equals, seeing the person with dementia not as the ill, aged resident. In not choosing to be the 'design researcher', both tried to close the potential power imbalance between them.

5.2.4. Evaluating design decisions

As Bratteteig and Wagner (2014) indicate, the evaluation of the design decisions can happen both explicitly as 'in use'. The involved designers in AtHome evaluated the design through observation, but mostly by being part of the context of use.

Designer Karen evaluated her designs through the bodily expressions of Ann. She spent hours and days in the company of Ann. Karen understood that Ann would not respond verbally, but through looking at her face noticing small twitches (when a nurse passed by, talking loudly), seeing the muscles in her neck relax when a melancholic song is sung and observing the way she places her feet (re-shuffling constantly) provided hints on how Ann was feeling (disliking or liking; feeling at ease or agitated, etc.). When the actual design was in use, Karen tried to understand Ann's interaction via a translation of these facial and muscular movements and expressions of the feet while fidgeting with the created artefact.

As part of the overall evaluation, the designers created two posters, one focussing on the encounters and collaboration with the person with dementia and how every decision took form, the other focussing on the actual finished design. These story posters were aimed at caregivers and family and provided openness to not only look at integration of the design in daily life and care practice. They were designed to be transparent on how the explicit and implicit design choices and the resulting design came about based on the relationship between the person with dementia and the designer.

6. Discussion

This paper proposes four guidelines to enhance the potential relationship building by designers when working with people in advanced stages of dementia. Using principles from PCC the designer gains relational expertise that can be applied in the PD setup to come to involve the person with dementia in the design decisions in explicit and implicit ways. The marrying of PC and PDC brings on an added value to both domains, but also questions more fundamental elements of PD.

6.1. A relational approach to PD with people with dementia
It is beneficial for the care context, that through combining insights from PD and PCC the designer structurally makes more visible how decisions are made and, in this way, pays explicit attention to sharing of power. With a focus on power and the way decisions are collaboratively taken, PD supports the work already done in care contexts to transform towards more participatory care environments. While PCC in care environments focuses mainly on building relationships, the PD decision sharing model also demonstrates the value of designed artefacts.

The other way around, PCC contributes to PD through its strong focus on the relational dimension, in our case, the build-up of the relationship between the designer and the person with dementia and her/his network. We have shown that in a participatory setup this relational build-up is of aid in the process of sharing of power in the creation, selection, concretisation and evaluation of design decisions. Such a build-up requires, as Dindler and Iversen (2014) indicate, relational expertise, which demands that designers can professionally enhance their agency in the establishment and scaffolding of relationships with participants. PCC has developed this relational agency in working together with people in health contexts. The insight that can be transferred from this study is that getting acquainted with the rich experience in the studied domains in building relationships with their core participants - in this case the health context -, supports PD research that deals with the complex task of understanding others. The prevailing paradigms of each domain can then be confronted with the principles of PD. For designing with and for people with dementia this entails putting into practice actions from person-centred care. In another context, being street work and outreach work, the 'longitudinal engagement activities'-approach is an important paradigm (Szeintuch, 2015) which could be coupled with PD. In other words, in order to gain relational expertise,

one should couple the principles of PD to the method of relationship building particular to the studied domain, be it person-centred care, longitudinal engagement activities or other paradigms.

6.2. A relational approach to PD

Valuing relationship building and implicit decision-making has consequences for PD in general. From the field analysis we learned four core lessons on how to build relational expertise in PD.

First, we learned that in the phase of sharing the creation process of decisions we need to give more attention to implicit decision-making, which asks to pay close attention to the small and at the first sight banal elements that can inform design decisions. This can include designers and participants who are being focussed together just a bit longer on fashion photos in a magazine and that this might turn out to be part of the shared decision-making. Such an approach, however, entails skills that designers might not have and asks us to reflect on the way to train designers.

Second, we learned how in a relational approach sharing decisions in selecting between design choices is supported by storytelling. This includes a process of designers and participants who are learning to read, interpret and integrate small elements in stories that can gain meaning in the PD process. This process requires exercising by designers. How can they effectively interpret the longer pause while browsing through the pages of a magazine? Moving away from people with dementia, will a designer be able to value and interpret the small rituals, habits and ways of communicating (and making decisions) when working with homeless people or the employees of a technology start-up?

Third, in a relational PD approach sharing decisions involves role playing to explore the role of the design in the studied environment, but also the new types of relationships that are produced during the design process. In AtHome designers experimented with different roles and relationships that their participants felt most comfortable with (e.g. personal and informal instead of professional relationships). To do this in line with common sense and to not violate ethical boundaries demands from designers to exercise this process of role playing and make it part of their relational expertise.

Fourth, learning to work with the own body and read other people's body language was of value in a relational PD approach. Designers took the time to learn to understand what holding hands or relaxing neck muscles meant and used these as a way to share decisions in evaluating their design.

7. Conclusion

To conclude, defining participation from the discussed relational perspective and valuing the implicit decision-making is closely connected with the political tradition of participatory design (Robertson & Wagner, 2012) and with a broader ethical reflex in (participatory) design practice (van der Velden & Mörtberg, 2014). The focus on relational expertise and the implicit decision-making is also in line with attention for designers' capabilities and orientations surrounding the PD process (as opposed to the tools and techniques the designers employ – see Robertson, Mansfield, & Loke (2006)). Defining participation in such a way deliberately does not intend to measure whether 'genuine participation' (Robertson & Simonsen, 2013) happened and how far the participation went, since the PD practitioner is not seen as a neutral actor researching and designing in an absolute reality and extracting information from their participants (Frauenberger, Good, Fitzpatrick, & Iversen, 2015). The goal of participatory design as proposed in this paper, is to build relational expertise in shaping the involvement of the participants through the different design decisions that characterise the PD process. In the context of this relational approach it is important to remain critical towards the pitfalls of implicit decision-making and especially the risk it holds in shifting the power imbalance to the advantage of the designer. Via coupling the sharing of power with relationship building and attention for implicit decision-making; we aimed to provide an opportunity to debate the ethical challenges and power imbalances that are part of the PD process.

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