Designing With Dementia: Guidelines For Participatory Design Together With Persons With Dementia

Niels Hendriks[1], Frederik Truyen[2], Erik Duval[3]

[1] Social Spaces | CUO - MAD-Fac - LUCA - KU Leuven
niels.hendriks@khlim.be
[2] Cultural Studies, KU Leuven, Belgium
fred.truyen@arts.kuleuven.be
3 Dep. Computerwetenschappen, KU Leuven, Celestijnenlaan 200A, 3001 Leuven, Belgium
erik.duval@cs.kuleuven.be

Abstract. Involving all stakeholders in the design process is often seen as a necessity from both a pragmatic and a moral point of view [1]. This is always a challenging task for designers and stakeholders and therefore many participatory design methods have been developed to facilitate such a design process. The traditional participatory design methods, however, are not fully appropriate to incorporate persons with dementia [2], [3]. They create issues as they assume that the participants are cognitively able; can make use of visual and hands-on techniques; or require a high level of abstraction ability of the person with dementia.

The aim of this paper is to present a number of guidelines which can be used as a starting point to set up participatory design projects with persons with dementia. This overarching set of guidelines provides for practical advice focusing on the role of the moderator, the preparation of a participatory session, the choice and adaptation of the method, the tools used, the role of each participant and the subsequent analysis. The basis for these guidelines stems from similar participatory projects with senior participants, persons with dementia and participants with aphasia or amnesia, two symptoms frequently co-occurring with dementia. All guidelines were evaluated and refined during four sessions with persons with dementia and a trusted family member. These participatory design sessions occurred in the course of the AToM project, a research and design project that tries to design an intelligent network of objects and people to ameliorate the life of persons with dementia.

Keywords: participatory design[1], persons with dementia, method, guidelines

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[1] We choose to use the term participatory design and not collective design or the Scandinavian tradition, being the predecessors of participatory design [4]. Neither did we use the term participative design which is set more in a UK tradition of participation and is thus less focused on co-creation [5].

1   Participatory Design: a necessity

Participatory Design [PD] is a set of rules, methods and theories that tries to work towards an enhanced participation of all stakeholders in the design process. Taking material from cultural studies Muller [2] describes that the use of PD practices happens in or leads to an in-between region, a so-called third space. This third space gives way for dialogues between the different stakeholders (a designer or developer, an end user, a policy maker,...) of a design process and in this way becomes a space where mutual learning and collaboration (designing together) can take place.

The reasons for doing PD are quite versatile but seem to come down to either pragmatic or moral reasons [1]. On a pragmatic ground, by working in close collaboration, the chance to end up with a successful design outcome reflecting the perspectives and preferences of the future users, seems to be much higher. In the pragmatic view, knowledge of the use context is needed by non-end users such as designers and developers; end-users, on the other hand, need knowledge of, for example, technological options. The moral proposition, on the other hand, is based on the belief that the knowledge of the end-users and the designers should be bridged [6] on political and ethical grounds.

In this paper we will lend on the work that has been done in the AToM project. AToM, short for A Touch of Memory, tries to create an intelligent network of objects and people to ameliorate the life of the person with dementia, their family and professional caregivers. From the start, the AToM project had the intention to have developers, designers, caregivers, the person with dementia and their family participate in the design process. This paper mainly focuses on the PD together with persons with dementia. The aim is to list guidelines to set up a PD process with the persons with dementia. This list of guidelines is based on a literature review of participatory projects together with older people and people with dementia and participants who suffer from amnesia and aphasia. These guidelines were used and refined throughout the AToM project. The novelty of this research lies in the attempt to present an overarching set of guidelines on doing participatory design together with people with dementia.

2   Dementia and Participatory Design

Dementia is a term used to describe a decline in mental ability that will interfere severely with daily life. The most common types of dementia are Alzheimer's disease, accounting for the majority of dementia (approximately 60 to 80%) and vascular dementia, the latter occurring after a stroke [7]. Working with persons with dementia asks for a specific approach taking into account the different cognitive and psychiatric symptoms (relative to the regression of their condition and the type of dementia they are in) a person with dementia can experience. Psychiatric symptoms may include personality changes, depression, hallucinations and delusions. On a cognitive level persons with dementia (from mild to moderate) mostly suffer from a deterioration of memory (such as amnesia), difficulties in language and communication (aphasia), the inability to perform purposeful movements (apraxia) and/or orientation in time and

place (agnosia) [8]. Furthermore, the large majority of the persons with dementia belongs to the group of older persons who might need to deal with the physical ailments like impaired eyesight, hearing or physical coordination [9], [10].

As indicated in the intro, doing Participator Design stems from the idea that a design will be better when a person with dementia is involved in the design process (the pragmatic motivation) and that it is an ethical or political belief to do so (the moral motivation). People with dementia have rarely been directly involved in the design process and most technology development has been done via proxies, such as the person with dementia's family, friends or the professional caregiver [11], [12]. An anecdotal example which shows that working with proxies might not always be the best choice has been described by Alm [13]. When developing a reminiscence system he notices that the vision of the professional caregiver contradicted with those of the person with dementia. The professional caregiver favoured a scrapbook metaphor while the person with dementia preferred a much simpler interface design.

To only rely on proxies stems from the vision on the person with dementia as the so-called 'uncollected corpse' [14] or as someone who no longer possesses a sense of self [15]. Kitwood [16], however, states that a person with dementia must be recognized as a person with thoughts, emotions, wishes and thus, a person who can and should actively be included in research. Letting these aged and impaired individuals participate, is thus a way to protect their previously ignored interests [17], [18]. Span et al [19] see different roles for a person with dementia in a research project: as object of study, informant or as an actual participant. Only a minority of the studies researched in their literature review has the person with dementia as an actual participant (co-creator). They stress the importance of giving the person with dementia such a role as they indicate that problems with the implementation of a design "may be due to the fact that persons with dementia were not adequately involved in the development process." Moreover they suggest that letting persons with dementia co-design can lead to better designs and may have "empowering effects on them".

Despite good reasons to do so, it seems however to be a challenge to include persons with (cognitive) impairments such as dementia, in PD processes. Muller [2] believes that the strong visual and hands-on nature of most PD methods create issues for these special needs groups. Dawe [20] states that "[t]raditional user-centered design and PD activities often ask users to describe previous usage scenarios or imagine future ones" and that this is a challenging activity for amongst others persons with cognitive impairments (such as dementia). In his work with persons with dementia, Lindsay [3] sees that traditional participatory design techniques focus on productivity and work and assume that each participant[2] is cognitively able.

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[2] Throughout this paper we will use the term participants to denote all stakeholders in the design process, meaning the person with dementia, their family, the professional caregiver, the designer, the developer and the design researcher. By placing all stakeholders under one umbrella term we want to stress the equality of all present in the design process and stress the mutual and collaborative nature of a participatory design process.

3   Learning From Other Participatory Design Practices

As already explained above, our working method for this paper is to investigate other collaborative and/or participatory projects designing a tool, a method, an application, a process, an environment: how did these projects set up their participatory process?; What are the lessons learned when working with their target group?; Which tools do they use?;… We will look at participatory projects together with people with dementia and participants who suffer from amnesia and aphasia. We will also try to shed a light on participatory projects which have older people as a target group. By looking at projects that zoom in at people suffering from symptoms such as aphasia, amnesia or ageing seems to be fit as dementia must not be seen as a single disease, but as a set of signs and symptoms including memory loss, decreased communication ability,... .

We did not focus on psychiatric symptoms of dementia (such as personality changes or depression) as the cognitive symptoms seem to be more crucial to the participatory process as they have a larger effect on the sensory level, an important element for participatory design. Furthermore, we were unable to find PD projects dealing with the cognitive symptoms of apraxia or agnosia.

Out of each project we will try to abstract guidelines which form practical reflections on or a concrete help to set up participatory practices for people with dementia. Most of the time, these guidelines were not literally denominated as such, but were interpreted and abstracted from the papers. The guidelines resulting from this were used, evaluated and refined during and after the AToM project.

We are aware of three potential points of critique to our approach: most of the times we were not able to determine at which level of severity the participants were suffering from dementia, amnesia or aphasia. This was possible nor for our own work in the AToM project, nor for some of the similar participatory projects we looked at. A quantifiable comparison is thus lacking. Besides this, some of the guidelines presented can be seen as too general and not typical to working with persons with dementia. In our opinion, each individual guideline should not be treated as a single item, but only in relation to the whole set of guidelines. A single guideline can thus be seen as generic, the set of guidelines is not. A last point of critique lies in the fact that it can also be felt as being too ambitious, if not audacious to try to find an overarching set of guidelines. We must stress however that we do not see this research result -the set of guidelines- as a passe-partout for each participatory project with persons with dementia, but more as a starting point and a first toolkit for researchers and designers who work with persons with dementia. Consequently, this is only our first attempt to come to these guidelines and more case studies should lead to more refinements and thus a higher level of accuracy.

In what follows, we identified the interesting lessons learned with a de# for dementia, am# for amnesia, ap# for aphasia and el# for projects with the elderly.

3.1   Dementia

Though not working in the field of design, Allan [21] has done an intense study on how persons with dementia can participate in the evaluation of their own care. She

stresses the importance of non-verbal stimuli like photos of objects (de1). To consult a person with dementia in an indirect way, using a fictive third person, turned out to be successful (de2). In general, Allan states, each chosen (set of) method(s) should be tuned towards the person's background and interest (de3). Overall, she indicates that a passe-partout method is likely not to work and promotes flexibility in the used methods. This flexibility does also mean to take into account that over the duration of your research participants might lose the capacity to take part (de4).

Hanson [22] performed a study on collaboratively designing a life book tool together with persons with early stage dementia. Hanson focuses on having small groups of persons with dementia (a maximum of 8, ideally 6) in design sessions (de5) and suggests to foresee enough time for getting to know each other, being able to be flexible and repeat the content at hand during sessions (de6). In her research Hanson also relies on the partner or care staff to play an important role (de7) and gives quite some attention to the location as she not only states that the location of the sessions should be within easy reach and accessible, but also hold the correct social status. The latter is based upon the enthusiasm of her participants caused by the fact that the sessions took place in a university building (de8). Dewing [23] adds the complexity of getting the consent to participate of people with dementia and sees getting consent as a process that runs through the whole research trajectory (de9).

3.2 Amnesia

Amnesia is a neurologic syndrome that halts the ability to create new memories. In general, there are two types of amnesia. Anterograde amnesia is the inability to process and 'store' new information; retrograde amnesia is the inability to recall old memories from long-term memory. For persons with dementia anterograde amnesia is usually the first type of amnesia they are confronted with. However, people with dementia tend to have amnesia but it does not occur in all forms of dementia [24].

Wu [25] has done extensive research on the participatory design of a memory aid with people with anterograde amnesia. Besides some general guidelines like assessing each participant (am1), understanding the cognitive deficit (am2) and adapting a chosen technique to the specificities of this deficit (am3), he sees 6 major elements to take into account when working with persons with amnesia. Wu stresses the importance of holding group sessions as a way to make key decisions with multiple persons with amnesia, instead of a designer deriving design decisions from several sessions with individuals (am4). Repetition and constant reviewing turned out to be a self-evident but necessary thing to do (am5). Planned and structured meetings help to remember specific details (am6). By creating environmental support such as name tags and the same room for different sessions one create distinctive contextual cues (am7). The use of physical artifacts like use case scenarios, option listings or a storyboard can work as a physical memory aid (am8). Wu [26] also indicates the importance of incorporating a partner, a family member or a caretaker (am8).

3.3 Aphasia

Aphasia is a cognitive disorder that besides with persons with dementia also may develop after other types of acquired brain injury such as a tumor, a stroke, brain damage or an infection. Aphasia is a language disorder that affects the capacity to speak, read, write or that has an impact on the sense making of these language utterances. Almost all forms of dementia occur together with a form of aphasia [27].

Moffat [28] describes the development of the Enhanced with Sound and Images Planner, a daily planner that enables persons with aphasia to independently manage their schedules. Throughout her research Moffat used four methods: brainstorming, low-fidelity paper prototyping, medium-fidelity software prototyping, and high fidelity software prototyping. Moffat emphasises that traditional low-fi paper prototyping is not suitable as it requires to think aloud, thus to understand and to produce verbal and textual language, which is self-evidently a hard thing to do for people with aphasia (ap1). To overcome this and other burdens, she uses non-aphasic participants to correct general design flaws not typical to the condition of aphasia (ap2). Moffat also discusses the necessity of finding a large set of participants (ap3). She ends her research with the advice to connect to existing groups and organizations (ap4). This might help to gain practical experience with the target group and grow a sensitivity, necessary to work with this special user group (ap5). In order to formalize this insight into the target group, she advises to use standardised tests to assess people's abilities (ap6).

Galliers et al. [29] have set up a series of PD workshops when developing a gesture therapy tool for people with aphasia. The research challenges they experienced deal with the difficulties in the sense-making of (abstract) words and concepts (ap7). Participants turned out to have difficulties with chains of actions or reasoning (ap8) following for example pre-defined steps to take for making a gesture. The researchers tried to minimize stimuli like other conversations in the same room or too many graphics as the participants with aphasia tend to be easily distracted (ap9). The choice of room for the workshop and the distance from the elevator were chosen to cater for people's physical disabilities (ap10). Galliers et al. end their research with two more general remarks. General practicalities (for example, to find a suitable date for a next session taking into account holiday or illness) turned out to be hard and time consuming (ap11). Finally, they end with raising the question of the representativeness of the participants as each individual's aphasia is different (ap12).

3.4 The Elderly

A large majority of the persons with dementia belong to the group of older persons. Some observations suggest that senile dementia is even the normal end-point of the ageing process [30]. Besides suffering from dementia, these older persons need to deal with the physical ailments like impaired eyesight, hearing or physical coordination [9] and cognitive impairments like diminished attention, problems with memory and decision making [31]. Incorporating older persons in the design process has not been a self-evident task as many designers hold a homogeneous view on older people

or tend to fully neglect them in the design process [32]. Moreover, designers feel they lack the necessary skills and experience to work with older people [33].

Lindsay [34] sees four challenges related to participatory design with older users. Throughout his research he felt that it was hard keeping participants on focus (el1) and not let them wander onto unrelated matters (also noted by Bamford and Bruce [35]). There is also a risk in not fairly translating participants views in design (el2) by over-analysing participants utterances or giving them too much complexity. The difficulty in envisioning intangible concepts formed a next challenge (el3). Lindsay also questions the nature of traditional PD methods. As most of these methods were originally intended for work-related design they do not work well with the elderly. The methods used in participatory setups with the elderly should thus also focus on the experiential aspects of design (el4).

Massimi et. al. [36] did a study of the development of mobile phones for senior citizens. Their evaluation of doing PD with senior participants adds the importance of alternative activities taking into account the different impairments an older person is facing (el5); trying to overcome deficits by pairing persons with different deficits into one subgroup (el6); and the strict manner to control the pace and structure of a session (el7). Finally, from the UTOPIA project Eisma et al. [37] conclude that researchers should clearly explain the purpose of events and the role of the participants (el8) and this should be done in an easy to understand wording (el9).

4   Combined Guidelines

In what follows we will try to give an overview of the guidelines resulting from these previous studies in designing together with older persons, people with amnesia, aphasia and dementia. As some studies would not explicitly define guidelines or the lessons learned, we tried to abstract and interpret them from the studies found.

All guidelines in the list below are formulated in an active manner. We see a guideline as a practical reflection on or a concrete help to set up a participatory practice. If applicable, similar guidelines were merged into one and the various guidelines were grouped together in 6 subgroups: preparation, method, moderator, tools, participants and analysis. Whether a guideline stems from a study on participatory design together with a person with amnesia (am), aphasia (ap), dementia (de) or the elderly (el) is indicated between brackets behind each guideline.

4.1   Preparation

1. Search for and connect to existing groups and (patient) organisations (ap4)
2. Get to know your target group, try to understand their cognitive deficit and become sensitive to their needs and situation (ap5/am2)
3. Try to get the consent of the person with dementia on various moments throughout the research process (de9)
4. If possible, try to assess each participant in a formal way (am1/ap6)
5. Give yourself enough time for general practicalities (ap11)

4.2 Method

1. Participatory design methods should address experiential aspects (el4)
2. Each chosen (set of) method(s) should be tuned towards the persons' background, interest and specificities of the deficit (de3/am3)
3. If working in a group, modify your method taking into account the different impairments each member of the group is facing (el5)
4. Adapt your method so that it will take into account the difficulties in the comprehension and production of language, both verbal and textual (ap1)
5. Adapt your method so that it will take into account the difficulty in envisioning intangible concepts or abstract notions (el3/ap7)
6. Adapt your method so that it can overcome impairments of memory (am3)
7. Adapt your method so that it aids in following a chain of action/reasoning (ap8)

4.3 Moderator

1. Researchers should clearly explain the purpose of events and the role of the participants (el8)
2. It helps the participants to hold well planned and structured meetings (am6, el7)
3. Foresee enough time for getting to know each other, for repetition and constant reviewing of the different research/design phases (de6/am5)
4. During a participatory design session try to minimize distraction and keep participants on focus (el1/ap9)

4.4 Tools

1. The location should hold an appropriate social status (de8)
2. The choice of location should take into account the deficits of the participants and ensure easy access to the meeting room (ap10)
3. As the verbal might be a problem, make use of non-verbal elements such as visual stimuli like photos of objects or physical artifacts (notes etc.) (de1)
4. Use distinctive contextual cues (like nametags) (am7)
5. Use fictive 3rd person stories to consult a person in an indirect way (de2)
6. Use easy to understand wording (el9)

4.5 Participants

1. Give the family member or trusted caregiver an important role during each session in aiding the person with dementia in his/her participation (de7/am8)
2. Work in small groups of persons with dementia (6-8) (de5/am4)
3. Try to overcome deficits by pairing persons with different deficits into one subgroup (el6)
4. Use persons who do not suffer from a deficit to get rid of general design problems (ap2)

5. Participants might fail to stay in the research track. Make sure there is some flex-ibility in participants (de4/ap3)

4.6 Analysis

1. Try not to over-analyse the utterances of your participants (el2)
2. Be critical towards the representativeness of your participants (ap12)

5 Evaluation and refinement: putting the guidelines to the test

The guidelines presented here were tested during the participatory design sessions with persons with dementia within the AToM project. As already indicated this pro-ject tried to create an intelligent network of objects and persons to ameliorate the life of persons with dementia, their family and caregivers. The project has a strong par-ticipatory approach trying to involve all relevant stakeholders. During the AToM project three PD sessions were set up: one with persons with dementia and the design and technical development team and two sessions were held with the technical devel-opment team, the design team and the caregivers. As the latter two are not the focus of this paper, we will only zoom in on the PD with persons with dementia and the design team.

The evaluation of these guidelines is seen from the designer's point of view. We did not take the perspective of the person with dementia into consideration, as we did not organize a formal evaluation on how they perceived the PD sessions. This is a point of critique that can be met in future research.

The PD sessions held turned out to be useful to identify the focus of the project, to put the trusted other (a family member or care giver) in a more central position in the design and give an insight on the design requirements when creating an application for persons with dementia. These elements (the translation from the session into the actual project design) are however not the core of this paper,

5.1 The Participants Involved

All participants with dementia were recruited using the help of a memory clinic. The persons with dementia were selected on the fact whether they would have been will-ing to communicate about their illness and have a level of self-insight. All participants had undergone a formal diagnosis of dementia, but, legally, it was impossible to re-ceive more information on the stage of dementia the participants were in. All partici-pants with dementia were female, the youngest was in her 70s the oldest 95. Each person with dementia was accompanied by either a partner or one (or more) relatives, sons or daughters. The initial contact was not directly via the person with dementia, but went via a trusted person (most of the time the partner or a son/daughter). It is interesting to note that we received strict instructions not to use the terms dementia or Alzheimer in the contact with the persons with dementia (we used the more euphe-

mistic term 'memory problems'). In total we held 4 sessions with persons with dementia.

Besides the person with dementia and their family member, one designer, who assisted the person with dementia, and one design researcher who explained the different phases of each session and took care of time-keeping were also taking part. All sessions were held at the persons with dementia home and were preceded by a visit, explaining the goals of the research, introducing the researchers and going through the informed consent some weeks before the actual participatory session.

5.2   The Outline of Each Session

The designer and the person with dementia, with the aid of the family member, used icons and basic text to map out a problem definition and possible design suggestions. The chosen method is roughly based on the Map-It project. Map-It is a mapping method, a toolkit – or MAP-(k)it –, which tries to help to guide a conversation, discussion,.... While Map-it can be used in work contexts, it is based upon the idea to have an open method with a low threshold to participate and can be used for functional or experiential aims,... The MAP-(k)it typically consists of icon stickers, maps and a scenario [38]. The first map in the PD session was an abstract drawing of the person with dementia. The person with dementia was asked to place hand drawn icons (made in advance or on the spot) that represent persons, routines, places, objects,... which were of importance to her.

A selection of these important routines, places, objects, actions and persons was placed on a sketch of the layout of a 'typical' house. On the spot, the house was more or less personalised by adding elements of the garden or the interior design, or by creating a street name plate,.... The person with dementia was then asked to indicate in which way her condition affected her routines (eg. preparing dinner for the whole family), objects (eg. operating and selecting my favourite show on the television set), places (eg. walking to the weekly market and finding my way back) or contact with persons (eg. talking to my grandchildren). The reasons for linking this to a floor plan of a house was to make the abstract notion of a 'problem' more concrete.

We then used the idea of The SuperHero, a Mr Fixit who might help to overcome the issues the person with dementia is facing. The person with dementia was asked to paste The SuperHero on the five issues she found the most important to solve (eg. operating and selecting my favourite tv show on the television set). The next step was to indicate what different steps The SuperHero had to undertake to help the person with dementia (eg. provide a warning when my favourite show is about to start, set the television automatically on the correct channel,...). Finally, the designer with the aid of the person with dementia sketches a possible technological solution focussing on integration in the daily environment of the person with dementia and aesthetics.

6 Similarities and Differences with the Guidelines

In what follows we will focus on how the guidelines were put into practice in the sessions described above. We will use the same structure (from preparation to analysis) and will end each with our refinements or additions to the proposed guidelines.

6.1 Preparation

The participatory design sessions were preceded by a series of research activities (observations, interviews with family members and caregivers, empathy exercises, house visits together with caregivers,...) trying to get an insight in the life of a person with dementia and their family and caregivers, finding help in identifying possible participants and identifying domains which could be the topic of the PD sessions. We more or less focused our PD sessions on daily routines (such as eating, watching television, making coffee,...) as these are relevant activities to all ages and to all persons with dementia (4.1.1/4.1.2). One of our PD sessions needed to be re-arranged due to a surgical operation of the partner and one dropped out after the initial talk. Her partner indicated that she became too stressed some days before the first PD session was due (4.1.5).

As each PD session consisted of only one encounter with the person with dementia, we did not need to focus on getting consent on various moments throughout the process (4.1.3). We did not assess the participants in a formal way (4.1.4) as we were not aware of any tools to use which would fit this task, without placing too hard a cognitive load on our PD session.

As the recruitment of the participants was done through a memory clinic, the aim and specificity of our research was not always made clear. It once led to the confusing situation where several sons and daughters of one person with dementia turned up expecting the designer to indicate which elements of the interior design should be adapted to fit the changed condition of their mother, thus interpreting the word design as practical interior design (and not as a phase in a research project). On another occasion the design researcher and designer repeatedly needed to stress that they were not doing any medical research (after several questions on possible medication).

Proposed guideline: Communicate about your projects' goal of without intermediaries

6.2 Method

As indicated above we worked with a derivative of the Map-It toolkit using icon stickers and maps focusing on daily routines (4.2.1). The icon stickers (pre-made or hand drawn at the spot) helped to overcome the decreased verbal competences of some of our participants. The stickers were created as simple hand drawn icons with a clear text underneath, indicating what is on the icon. This serves as clarification and as a reminder for the depicted item to the person with dementia. When trembling prohibited active mapping (tearing of an icon, slightly adapting it, pasting the icons on the map, cluster different icons,...) more attention went to the telling of stories

(4.2.2/4.2.4/4.2.5). With one participant whose ability to express oneself verbally was severely decreased the family member 'guided' the words of the mother and stimulated her to reply. The different phases were hard to remember for each participant which made us cut them into smaller chunks (having the design researcher repeating what the aim of each phase was) (4.2.6/4.2.7).

Besides the difficulties in envisioning intangible concepts we see also a difficulty in making choices: making a choice, even on questions that -for the designer and design researcher- seem to be quite straightforward (eg. "What do you like to eat?") was a hard effort to do (eg. "I do not know what I like to eat?"). By using a pre-made set of icons, we tried to help the person with dementia to make a choice but it still was a heavy burden. It became even more complex when we introduced The SuperHero in our session. It was our aim to use this fictive persona so the person with dementia could imagine how technology could be integrated in their lives, without having to use the terminology related to technology. After our first session we soon found out that using this playful element didn't make the design exercise more transparent, but added a layer of complexity. The intangible technology became even more intangible by introducing a fictive element that contrasted the previous phases which all dealt with more real-life elements. In later sessions, we left out this fictive element and presented basic technology in an understandable way.

Proposed guideline: Try to avoid to make an appeal to the person with dementia's fantasy; avoid too much choice.

We didn't take 4.2.3 into consideration as we only worked in individual sessions. We will focus on the reasons for this in the 'Tools' section.

6.3 Moderator

Weeks before the actual PD sessions two design researchers thoroughly explained the goal of the research. A written version of this explanation together with an informed consent was given to each person with dementia. The roles of each of the researchers and of the person with dementia were clearly explained, focussing on why we found it important to do PD and in what way they contributed in participating (4.3.1). Before each session we communicated how long it on average would take, but foresaw enough time for repeating assignments or holding a break. Each participant knew in advance the duration of the session and they were aware that they could ask to pause or even stop the session (pausing occurred, quitting didn't). As already indicated each session was split up into small chunks and after each chunk the results were reviewed (4.3.2/4.3.3). It soon became clear that almost all participants easily drifted from the topic at hand. Conversations that occurred minutes ago became again the center of the conversation. As an example, one participant was triggered by a specific icon (a trailer) that reminded her of a warm and pleasant holiday she had with her family. Throughout the rest of the session she kept on referring to this holiday and the nicely drawn icon, causing the flow of the session to be interrupted constantly. Most of the times it was the family member who tried to keep the person with dementia on track

(the distraction caused more irritation with them than with the design research team) (4.3.4).

At the start of each of the 4 sessions we tried to make it personal. As we were planning on asking the person with dementia and the family member to disclose quite some personal information, we let the design researcher and designer start off by telling about their lives as well (where do they live, married or not,...). We eventually started to bring cake to some of the sessions. The first 20 minutes of each session were thus started with drinking coffee and eating cake, chit-chatting on a variety of topics. It definitely led to a relaxed atmosphere especially with those participants who suffered from some form of aphasia.

Proposed guideline: To enclose personal info will help the participants to feel at ease and be more open

6.4   Tools

We choose the person with dementia's home as it would lead to more flexibility in finding a good date for the session as well as to have the person with dementia feel at ease (4.4.1/4.4.2). The icons and the small text underneath each one of them helped to participate in the design process in a non-verbal way (4.4.3) and in understanding what was depicted (4.4.4). On the forehand all texts/icons were checked by several experts on their comprehensibility (4.4.6). We tried to introduce a derivative of the use of 3rd person stories by introducing The SuperHero (4.4.5). This has already been analysed in the Method section).

To use the own home gave the person with dementia a feeling of security, seemed to help them to overcome the feeling of anxiety (going to a 'new' location, searching for the correct room,...). It also helped to contrast with more medical related research some of our participants were also joining. The other helpful element was that open ended questions (such as what object they liked most or what routines were pleasant to them) were easier to answer using the objects they saw surrounding them. The choice for the home as the setting for our research is of course linked to the choice of working with individual persons with dementia.

Proposed guideline: Using the person with dementia's home might help to make the participant feel at ease

6.5   Participants

Four persons with dementia participated in our PD session. Quite a few potential participants didn't want to join the sessions after the first contact with the memory clinic (who helped with the recruitment). One person with dementia became too stressed and dropped out of the research and design process after we were in contact with her (4.5.5). Before actually doing the PD, we did a test run of our set up with a person without dementia, but with insight in the person with dementia's lives. This helped us in evaluating the feasibility of the setup we proposed (4.5.4). What we however were

unable to test, was the role of the partner/family member in this session. Each session the person with dementia was accompanied by a family member (partner, daughter,...). In our first session, the communication with the person with dementia turned out to be quite hard, though verbal communication was still possible. The partner of this person remained inactive, not wanting to interfere in the process and giving her all the space and freedom to participate. She seemed to be lost without his support, a support she relied on for most of her daily doings. As this trusted family member is so crucial in the lives of the person with dementia, we decided to incorporate them more into the following sessions together with persons with dementia (4.5.1). The family member could then stimulate the conversation, aid in pasting the icons, 'translating' the different goals, stimulating their loved ones to not wander off, etc. Needless to say their help turned out to be crucial. The major point of critique in using family members to help in participatory design is whether the results are still genuinely coming from the person with dementia: in what way is it not the family member who suggests a certain design choice?

The following conversation is indicative: After finding several ways to integrate technology in the activity of preparing food and eating, the conversation started to deal with the colour of an artefact. The question at hand was which colour the person with dementia would want the object to have or whether she subjected a certain colour.

Daughter: But Mum, do you remember the car daddy used to have? The one you said looked really ugly?
Person with Dementia (PwD): Uhuh.
Daughter: Now, what colour did dads ugly car have?
PwD: What car?
Daughter: The car you really said looked very, very ugly.
PwD: Uhm....(sighs).... What colour?
Daughter: That ugly black car!
PwD: Oh yes! Oh yes! Bah, black. That, I didn't like. No, I didn't like that black car. Ow, he... <stops>.
Daughter: So it shouldn't be black. No?
And, mum, that nice shirt you wear when we go out? The one with the flowers? The one you said looks really nice. What colour does that have?
PwD: The one with the flowers?
Daughter: Yes, the shirt.
PwD: Ehm. Ehm. <pauses> The shirt. Red?
Daughter: Yes, red! And you always say it's such a nice colour. So what colour should it be?
PwD: Ehm. Red.

Proposed guideline: Try to filter the research results and separate results which comes from the person with dementia and which comes from the family member

We choose to organise individual sessions and not to work in groups of people with dementia. In our contacts with a self-help group for people with dementia (as part of

the ethnographic study) it was suggested to hold individual sessions as these would help us to gain a quick level of intimacy. This was also noted by Bamford and Bruce [35] who found that people with dementia sometimes showed a lack of respect to one another when participating in group sessions. A conclusion we made as well after our observations during the ethnographic field study. In care facilities we experienced a strong harshness when residents were confronted with the deficiencies of other persons with dementia leading to irate whispering on the condition of the others.

Proposed guideline: add the possibility in organizing individual participatory design sessions (refinement of guideline 4.5.2 and 4.5.3)

6.6   Analysis

The results of the participatory design sessions (the maps created together with the persons, the proposed design solutions and the conversations during the sessions) were translated in several hand drawn scenarios depicting the different possible solutions raised during the sessions. The multitude of ideas gave inspiration to create prototypes in the next phases. To overcome the problem of over-analysing a single utterance by a participant and the non-representativeness of such a small sample (4.6.1/4.6.2), we went to the (formal) caregivers and asked them to check the feasibility and transferability of the scenarios. They evaluated each scenario, asked for clarification on some choices, suggested different solutions,... We did not include family members, nor went back to the persons with dementia for this stage. We believe that the caregivers are the best persons to think beyond a single unique case, while we are unsure about the ability to do so of a person with dementia or a family member.

Proposed guideline: use caregivers to help to go beyond the single cases

7   Conclusion and Further Questions

To collaboratively design with people with dementia seems to be quite a challenge. Previous studies indicated several guidelines for working with people with dementia or suffering from aphasia, amnesia and all ailments of 'normal' ageing. We tried to cluster these guidelines and nuance them or complement to this set using our experience of the AToM-project.

As a result we see a list of guidelines that might aid in the set-up of a participatory design approach with people with dementia. We are aware of the limitations of these guidelines (no quantifiable comparison, not all of them unique to working with dementia,...) but want to stress that the proposed set is not a passe-partout for each participatory project with persons with dementia but a starting point for researchers and designers who are setting up participatory projects with persons with dementia.

Consequently, this set of guidelines is only a first attempt and the guidelines should be tested in other research and design projects. At the closing of this first research

phase, we are in the midst of the second part of our research. Twelve designers (graphic designers, photographers, digital and product designers) are working together with persons with dementia to design simple objects that try to ameliorate the persons with dementia's lives. In this research and design project, the set of guidelines can be put to the test and thus evaluated and refined.

We see research necessary in four other domains. First, an attempt to link the applicability (or lack of it) to the different stages of the dementia condition is needed: what refinements are necessary when for example working with severe forms of dementia? Or, how does the way of working change within a home situation or within a day care centre? In general, we think a modular set of guidelines, taking into account the specificity of the group of persons with dementia one is working with, might be a challenge to investigate. Next, the set of guidelines is now evaluated from the perspective of the designer. Future research might look at the way the person with dementia perceives the PD session. A third step would be to deepen the methods used (4.2 in the list of guidelines): can a generalized way be found to, for example, overcome difficulties in speech or envision abstract notion? Lastly, further research is needed not on the content level of the guidelines, but on the format. We want this set of guidelines to become a toolkit that is used in the daily research and design practice. To attain this, the toolkit at hand should not be a number of lines of text, but a toolkit that integrates (more) in the way a designer and a researcher work.

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