

ICT-Design in a Complex Moral Universe – Ethnography-based Development of a GPS Monitoring System for Persons who Wander

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1. INTRODUCTION

Increasing life expectancy and reduced birth rates as results of the recent demographic changes is linked to drastic changes in respect to age structures. The amount of persons over 80 will double until 2025 and at the same time, the availability of care workers in the care sector will be reduced. That's why the ageing societies are facing enormous challenges which are linked to higher age, such as the increase of chronic conditions, reduced physical and mental capabilities and the risk of social isolation and reduced autonomy (EU Summit 2015).

Facing these challenges for the future, information technology (IT) is being attributed a major role in respect to the development of innovative solutions for preventive and curative measures which may contribute to quality of life and every-day support in informal as well as formal care settings and which may increase the agency of the elderly in their every-day life circumstances (EU Summit 2015).

A lot of projects and funding schemes in the fields of Active Ageing and Ambient Assisted Living thus focus on ICT-based innovations, which aim at developing innovative products as well as services and concepts. However, a sustainable implementation of these IT-based innovations fails, because they lack an embedding in every-day practices of elderly people and their surrounding social networks.

We see problematic issues in the following aspects: In many cases, IT projects for the ageing society are set up under the perspective of “technological innovations”. However, IT projects for the ageing society are in need for a strong focus on how the technological solutions could be embedded in the real life of the elderly people and the other relevant stakeholders respectively (e.g. children and spouses as informal caregivers, professional caregivers in homecare/ institutional care settings, etc.). Here we follow the path of practice-based ICT design and in terms of methodological thinking the Grounded Design approach by (Rohde et al. 2009 and 2016, Stevens et al, in this volume). However, we see the need for adaptation of the methodological and conceptual approaches of Grounded Design to be applicable for the field of IT for the ageing society, when it comes to research in every-day contexts of persons who are not IT affine. In addition, agency and autonomy of the persons we strive to design ICT for in this field are issues which need special attention and consideration.

In recent research funding calls, despite the increasing request for user participation in the design process, its realization often remains on a superficial level. Therefore, it is an important task to sharpen the conceptual and methodical design concepts for the field of IT

for an ageing society. By this, research may better recognize the subtle and - on the first glance - rather invisible specificities of the every-day life of the elderly and their surrounding and supporting social networks in order to come to IT designs which support sense-making processes and acceptance and appropriation by the target groups (Fitzpatrick & Ellingsen 2011).

The concept of Grounded Design (Rohde et al. 2016) is being developed as a framework with its instruments of “Design Case Studies” (Wulf et al. 2015, Müller et al. 2015a) and “PraxLabs” infrastructure (Ogonowski et al, in this volume) and it aims at the integration of relevant elements to anchor design projects more sustainable in the social practice contexts of the target groups. The approach comprises of an ethnography-based pre-study for a profound understanding of the envisioned field of practice, a cooperative prototyping phase as well as a long-term appropriation study which aims at an understanding of changes in the social practices through the usage of the technologies introduced and by this to be able to measure success criteria of the project. By this approach, design ideas may be grounded and carefully explored as well as designed in deep grounding in actual practices.

We would like to contribute to this conceptual framework of Grounded Design with a specific lens on design and research activities in a project aiming at the development of a locating system for persons who wander, which is a specific symptom in the field of dementia care. For the explication of Grounded Design Rohde et al. (2016) build upon case studies for illustration which are based on organizational use of information systems and/or encompassing actors who are younger, relatively tech-affine and with a research question which is from the beginning put very specifically in a relationship to a current and prospective usage of a ICT tool. We would like to open up discussion on the specificities of ethnography-based design for the field of IT for the ageing society and especially for the field of dementia care.

We have described elsewhere (Müller et al. 2012) the challenges of conducting ICT research projects with elderly persons who are not tech-affine and – this is in many cases coupled – with their caregivers (either elderly spouses at home or professional caregivers in institutional contexts) who often are not IT affine either. This poses a special challenge to the design team in terms of gaining access to persons who often are initially not very much interested in “our” technical subjective or do not feel comfortable to think about technological devices in their every-day circumstances. The build-up of trust, motivational aspects and a common notional frame of reference has proven to be essential. Amongst others, we have described activity-based research methods to aim these meets (Müller et al. 2012, Ogonowski et al. in this book).

ICT research in the field of dementia care, however, illuminates further design challenges beyond an initially lacking common notional frame of reference. In IS research, for example, a common theme or a vision for participatory design projects between a design team and prospective users in a work organization is more easily set-up because people already use current technology for their work. Gaver et al. (1999) pinpoint at difficulties when ICT development projects move from the work to the home domain, where every-day settings are less routinized and less “task-oriented” as well as less technology-centered than in work settings.

The field of dementia care poses, on top of this, challenges in the intermingling of autonomy- and agency-related questions of the target groups as well as in respect to technology-related attitudes and acceptance (Fitzpatrick et al. 2010; Müller et al. 2010). Our

research is inherently contoured by discourses in the field of professional care-giving which discuss the “right” way to understand and deal with persons suffering from dementia. ICT design projects in this field are inherently interwoven in these discourses, more or less specifically discussed by the design teams in the presentation of their research results.

We would like to present our reflections on IT design in this sensitive setting in respect to practice-based design or Grounded Design, respectively, and especially emphasize the usage of ethnographic and action research-based methods to gain a deeper understanding of some specificities of the field of dementia care in Germany.

Therefore, we present a case study aiming at the development of a location system for persons with dementia who wander. After having presented the three steps of the case study (a. pre-study, b. prototyping phase, and c. evaluation phase) we will enclose some methodological reflections. We are especially interested in opening up discussion of the tension between the actual practices of the caregivers in the field and their corresponding lines to societal, medial, and medical discourses.

2. RELATED WORK

Recent research work on Information Technology (IT) for dementia care has demonstrated the need of a deep embedding of technology in every-day practices which implicate the value judgments and attitudes when having to care for and take decisions for another person (Dahl and Holbø 2012a, Dahl and Holbø 2012b, Robinson 2009). The literature demonstrates a picture of the dual nature of surveillance (Essén 2008), which in the field of dementia care produces value conflicts of *awareness vs privacy* and *safety vs autonomy* (Landau 2010, Landau 2009). Other authors provide a more nuanced picture on the basis of qualitative research results, such as (Dahl and Holbø 2012a), who point at the multi-faceted nature of stakeholders’ views on the dilemmas of GPS tracking of patients in professional dementia care. In the same vein, we demonstrate that different aspects of a GPS-based monitoring measure are linked to distinctive and heterogeneous values that range across settings and roles.

For late-phase dementia sufferers, a tracking system could provide a balance between preserving the autonomy and protecting the safety for them. However, in a first trial of GPS technology to locate missing persons, Miskelly (though validating the accuracy and performance of the system was the focus of this work) found that 5 out of the 11 respondents dropped out of the test (Miskelly 2005). This is a starting point of our study – a detailed investigation of the sociotechnical factors which make GPS deployment so problematic. As of today, even though there are commercial GPS tracking devices, they are seldom bought and used (Robinson 2009). Our study shows that the take-up of such technologies in this complicated context has been underwhelming by both the familial caregivers and the care institutions.

Brodaty et al. (2005) show low take-up of available services by caregivers in general. Reasons, they suggested, were perceived lack of need and lack of knowledge of related services. Stigmatization was given as another reason for the caregivers’ reluctance to use services. The low uptake of technological aids in dementia care points at the need to a better understanding of the social/socio-technical issues in technology usage in dementia

care. The social, ethical and legal universe in which caregivers operate problematizes the deployment of such technologies in a variety of ways and this paper aims to detail this.

Here, we present a Grounded design study delivering a holistic documentation covering the full life span of a design case study. This includes:

1.) a qualitative pre-study on the practices of professional and familial caregiving for dementia patients who wander, 2.) design and prototyping of the technology and 3.) an evaluation phase in which the appropriation and usage of the developed technologies in real environment is being observed over a long-term period. As such, it is broadly consistent with the Grounded Design and Design Case Study approach advocated by Wulf et al. (Wulf et al. 2011, Wulf et al. 2015, Rohde et al. 2016). However, the very field offers some specificities which need more reflection, especially in respect to gaining a thorough understanding of the different discourses in the “application field” and the reflective work needed for ICT designers.

Practice-based design in HCI appears in methodological framings such as Participatory Design (PD) and Living Lab in real life contexts (Carroll and Rosson, 2007; Følstad, 2008; Ogonowski et al., 2013). These approaches aim at a better understanding of the social fabrics in which future technologies are to be used and how current end-user practices and attitudes may influence the design and appropriation processes of the final product to be developed. In regard to PD with/for the elderly research has demonstrated the importance of taking elderly persons’ attitudes and (self-) images into account. These are often based on a low familiarity with new media resulting in anxieties and reluctance to get in touch with and hence affords certain measures to develop technology which is meaningful and useful to the elderly (Brandt et al., 2010; Lindsay et al. 2012; Wan et al., 2014). Participatory design work with persons with dementia brings specific challenges with it, as e.g. discussed by Dahl and Holbø (2012a) who worked with persons with early-onset dementia and their relatives/familial carers. They reflect potential problems that the voice of the persons with dementia might be suppressed by the carers. When working in settings with persons in later stages of dementia, it may become necessary to rely more to the estimations of the familial or institutional caregivers, and the researcher needs to evaluate work with this substitutional interpretation. Then, the target group encloses the caring networks in a very dense way.

In the literature of ICT support for healthcare, there is a general move towards approaching the design problem from a sociotechnical perspective (Ballegaard et al. 2008, Fitzpatrick and Ellingsen 2012, Kaplan and Harris-Salamone 2009). Themes in the area of home-based healthcare, for instance, evolve around the communication & cooperation needs of various stakeholders in chronic illness treatment (Mamykina et al. 2008, Palen and Aaløkke 2006, Pang et al. 2013, Pratt et al. 2006, Schorch et al 2016). Research has demonstrated that values and attitudes of each stakeholder play an important role in appropriation and usage of ICT (Christensen and Grönvall 2011).

Other research stresses the social side of healthcare, e.g. research into support for social interaction and the sense of belonging for the elderly (Gaver et al. 2011, Judge et al. 2010, Uzor and Baillie 2013, Vines et al. 2012). Such work increasingly focuses on maintaining and boosting the participation and autonomy of older adults so that they can continue living, as much as possible, independently even in circumstances where older people are experiencing cognitive and/or physical decline. Research work in the context of cognitive issues has aimed at key problems such as the role of various stakeholders in the care process and has dealt

with such issues as ‘whereabouts’ or ‘biographical’ awareness (Abowd et al. 2006, Consolvo et al. 2004, Mynatt et al. 2001, Wittenberg-Lyles et al. 2010] and monitoring (Demiris 2009, Morris et al. 2003, Petrakou 2007).

This sociotechnical stance is all the more significant in the field of ICT for dementia care. Assistive GPS technology for healthcare, work on the living conditions of older adults with chronic diseases (e.g. dementia), and ICT support options point to the high degree of social embedding of e.g. location-based systems and how different strategies have been applied to minimize the tension between *privacy and awareness* and *safety and autonomy*, respectively (Crabtree et al. 2003, Gowans et al. 2004, Landau et al. 2010, Landau et al. 2009, Müller et al. 2010, Müller et al. 2013, Robinson et al. 2009, Tsai et al. 2009, Wan et al. 2014). This in turn has led some researchers to reflect on appropriate research methods, such as the testing of off-the-shelf technologies in real circumstances (Dahl and Holbø 2012b] and to a claim for more long-term evaluations of developed prototypes in general (Fitzpatrick and Ellingsen 2012).

While some research alludes to the insufficient acceptance of tracking devices in dementia care (Astell 2009), we do not fully understand why the take-up of such technology has been underwhelming. Our review of the literature found no example of previous work which compared different care settings and the moral and ideological world they inhabit. This study, instead, shows that the differences to be found in different contexts are sometimes striking, and have a direct impact on willingness to deploy technology.

Because of the richly situated, continuously evolving, and collaborative nature of healthcare, studies in the field of HCI or CSCW often are carried out with qualitative methods. In the case of dementia care – an example of the ‘sensitive setting’ that Crabtree et al. refer to – research into the problems of dementia sufferers and their families is particularly challenging. Crabtree et al. reported on their experience of adapting cultural probes when developing computer support for former psychiatric patients living in residential care settings, for older members of the community, and for disabled people living at home (Crabtree et al. 2003). Underpinning such work is a concern for ‘responsibility’- who is responsible for care and in what circumstances? Can sufferers be relied on to act responsibly in their own interests?

Some authors noted that when conducting Participatory Design workshops with both dementia patients and caregivers, it is important to prevent caregivers from becoming the dominant or only voice. Patients may be otherwise unheard (Dahl and Holbø 2012b). Value sensitive design (Friedman 1996), as an information system design methodology, emphasizes how values play out in design, and how balancing competing values in various situations plays an important role. Robinson et al. aim at supporting independent living and involving early-onset dementia patients in the design process (Robinson et al. 2009). We, however, are dealing with late-stage dementia. In fact, we tried to involve the patients in our work but the methodological challenges proved to be insurmountable.

The issue of how to analyze the complex, detailed qualitative data from in-situ studies in healthcare is a further challenge. We align our methodological approach with the practice-based computing research framework of Wulf et al. (Wulf et al. 2011 and 2015). Under this framework we approach our research in three phases: 1. Empirical pre-study: empirically analyzing actual practice in specific application context; 2. Participatory design: designing ICT artifacts based on the findings of phase one with inclusion of the stakeholders; 3. Evaluation:

examining the appropriation of the technical artifact over a significant period of time. Our work, then, focuses on presenting the whole design process that includes building, deploying and evaluating a system over a long period of time.

3. OVERVIEW OF THE CONTEXT STUDY

The aim of the pre-study was to gather data on how conflicting demands and values in dementia care are being dealt with in practice. To do this, we examined practices in domestic as well as in three different institutional care environments, relying mainly on interviews and participant observation for our data. Interviews were only loosely structured, reflecting our general, but initially unfocused, interest in attitudes to, and practices with, dementia care tools and resources.

The three different care environments in which we found interview partners were representative of: care homes, special dementia living groups, and institutional care facilities. In general, it should be pointed out, accessing 'users' in these circumstances is difficult. Our first attempts at user contact showed that many dementia-affected families feel reluctant to discuss this sensitive topic with unfamiliar people. It required, as is always the case in such sensitive settings, the development over time of trust in our motives and our ability to behave responsibly over time. To do so, we looked for 'gatekeepers' or 'door openers' who could help. They were available in the form of organizers of a local self-help organization. These persons had widespread contacts with families as well as institutions and the willingness of people to be interviewed by us largely depended on their vouchsafing of our good intentions.

We conducted 21 semi-structured interviews, with 6 family caregivers (2 wives, 1 husband, 2 adult daughters, and 1 adult son of a dementia sufferer) and 15 professional caregivers (6 ward nurses and 9 managers) from stationary care facilities. Each interview lasted about 2 hours. All the interviews were audio recorded with approval, and were transcribed and anonymized for data analysis. Besides interviews, we have held several meetings with an Alzheimer self-help organization. These meetings have been documented in field notes. Furthermore, we spent some days on participant observation in institutions and families (10 hours in care home and 10 hours in a dementia flat share). They were also documented in the form of field notes.

After we readied all the empirical data (interview transcripts, field notes), we started a collective and systematic coding process. As a team, we held data analysis workshops regularly to update the code system, cross-code each other's material, and group-discuss on unclear points. This has helped minimize diverse interpretations between individual team members.

Based on the results of the pre-study, we held regular design workshops with the self-help organization to test and validate design ideas as soon as possible. As care practice in institutional care strongly suggests the need for a mobile application, we also held two design workshops with nurses in care homes to discuss the mobile application design. In all design sessions with the users we encouraged them to express their ideas, even very abstract or unrealistic ones. With our help, the participants created paper mockups and design sketches.

For the evaluation phase, we remained in contact with most of the interview partners from the pre-study, and had hoped to enroll them again for further testing of the system in the long term. However, only one care facility was willing/able to join the long-term evaluation.

It was even significantly harder to find participants for the field evaluation than for the pre-study. The reasons are manifold. 1). along with the project progress, the problems of the affected persons had also progressed. They were now either not able to walk, or the caregivers were too afraid to let them walk freely. 2). the institutions were very cautious towards testing the system in real environment, because of the possible philosophical or legal ramifications associated with technology failure. 3). testing the system in real environments brings additional cost to the institutions, including e.g. human resource and time to use the technology, effort to gain a certain amount of expertise with the technology itself, and any additional handling effort if the system is malfunctioning. In fact, lack of available resources is one main reason why many institutions were not willing to participate in our field test.

We finally managed to enroll three environments and tested our prototype there over a time span of 3 to 5 months. These included a hospital ward, an elderly care home, and a family. In all three environments the caregivers conducted care supervision in an “open” way, which meant that wandering by patients was already allowed before our IT intervention and the caregivers had already developed certain measures to ensure patient safety as much as they could. We handed out user diaries to the caregivers and used them as memory aids for the interview visits we had with them every two to four weeks. A more fine-grained description of the three locations will be given in section 7.

4. PRE-STUDY: FINDINGS

4.1 Understanding the complexities of caregiving for persons with dementia in institutions

4.1.1 Patient admission: Bias in the bilateral selection

Taking care of a dementia patient at home is a demanding job for relatives, especially when the patient has a wandering tendency. The physical and mental strain can be overwhelming for family caregivers who often lack professional insight into care management. When they turn to stationary care institutions, patients and the care institutions can in theory choose each other freely and bilaterally. In reality, there is a strong biased power distribution in this bilateral selection. Notably, it is extremely difficult for families to find a suitable institution for the dementia patient with wandering tendencies.

The first issue families consider when prioritizing their choices is the distance of the institution from their home. Very soon they realize that very few of these institutions have a clear care concept for the ‘wanderer’. Their initial choice pool, that is, rapidly diminishes.

One institution, for instance, noted that they would not accept wandering clients because *“we cannot take the responsibility for them”*. This was not, to be clear, because of legal ramifications, but because of a moral concern for the welfare of the wanderer in the absence of a reliable and practical monitoring solution. Another institution, in contrast, which did accept dementia patients with wandering tendency, claimed: *“we are an open house”*. They argued that the doors are open and the inhabitants can leave the house at will. Having said that, they applied a series of precautionary measures, such as heavy doors that are very difficult to open, hidden door knobs, hidden exits behind curtains, and so on. Again, measures of this kind were not universally accepted amongst professional caregivers. Some considered these measures to be a legitimate expediency, whilst others saw them as an affront to human dignity: as manipulative of a group who were not able to distinguish aspects of reality.

4.1.2 Prevention in practice: heterogeneity and controversy

The strategies that institutional care workers use on a daily basis when dealing with the wandering behaviors of dementia patients are highly heterogeneous and contextual. This is partially decided by the complex and volatile situations they face on a daily basis. Decision-making in such conditions is constantly mediated by legal, ethical, and moral trade-offs. In Germany, detailed legal standards have been institutionalized in such facilities to prevent abuses such as tying patients to beds or chairs. Professionals now routinely refer to ‘freedom depriving measures’ and told us about their concern that certain preventive actions may be deemed freedom depriving measures. The standards – although established some years ago – work more as a guideline rather than a solution (although some restrictions on freedom, such as locked bedroom doors, are clearly illegal). In the absence of an unambiguous definition, there is significant uncertainty and confusion, not to mention a variety of moral positions, on the part of professional caregivers and managers when making decisions.

From our samples, such preventive measures fall into 3 categories: 1). constructional measures, 2). technical support, and 3). human intervention.

Constructional measures include tricks such as heavy doors and camouflaged (or hidden) exit. Creating ‘endless corridors’ is another commonly used measure. In one dementia flat share we saw, the corridor was built in a circular form around a public area in the middle. This lets the patient take walks along the hallway, but never reach the exit. Such measures were controversial for care workers and, often, there were quite different perspectives on the acceptability of the measures on view. The ‘constructional’ principle was viewed by some as inhuman: *“This is awful to imagine: you are walking and walking and you never arrive. This can make you even more confused!”* (female relative).

The second category of preventive measures is using technology to monitor patient behavior. The following monitoring technologies have been (or partially) applied in our samples: video cameras, door safety systems, and sensor mats. The professional caregivers’ attitudes towards monitoring technology are more consistent and are characterized as a general reluctance. Their reluctance stemmed from the following reasons: 1). fear that it might be categorized as a ‘freedom depriving measure’, 2). usability issues with the system, 3). distrust in the reliability of the system.

Thirdly, human intervention describes the way in which some caregivers developed measures to keep patients busy and distracted from the urge to wander. Activities such as reading, chatting with each other, eating together, and going for walks together are the most common ones. Keeping patients busy during the day also helps them sleep better at night, which reduces the danger of patients wandering off. Many caregivers told us that they have to constantly keep an eye on the patients’ activities and assess the situation, because *“Most of the time we don’t know whether they have a wandering tendency. Sometimes we can predict it based on the patient’s behaviors”*. This is especially challenging when they are undertaking care routines in patients’ rooms. One solution is to put temporary barriers in the way. Commonly used barriers are e.g. the nursing cart or toilet chairs. The nurses told us this is a compromise, because normally they try to keep the hallway barrier-free so that the residents can walk safely but at the same time they have to monitor while coping with staff shortages.

4.1.3 Problems in finding and retrieving

Patients can, and do, wander. When a patient is presumed to be lost, members of the care staff will be organized to look for the lost one. The approach is normally ordered as follows:

looking inside the building, calling the patient's relatives, looking outside, and finally calling the police. Interviewees told us that some patients have their favorite wandering routes. These routes can be the way home, or a personally favorite path. But there were still many practical problems in coordinating the search and finally bringing back the patient. How to bring the patient back to the institution is another challenge, especially when the patient doesn't recognize the care staff and is reluctant to return to the home with them. Some professionals reflected that they sometimes use 'white lies' to trick the found patients to come back with them, e.g. *"your daughter has just called"*. They mentioned that for each patient there are several 'key words' that typically work well. But these 'key words' are highly individual for each patient. And it requires deep understanding of the patient so that one can apply them appropriately in a challenging situation.

4.1.4 Attitudes towards GPS monitoring system

None of the institutions we interviewed used a GPS tracking system to monitor patients. Despite the fact that they have a need (care staff are over-burdened) the sheer heterogeneity of care concepts/practices makes commercial products unsatisfactory. Inappropriate merchandising of providers to technology non-savvy users is another reason given by caregivers for the reluctance to deal with the technology. Inconsistent attitudes inside institutions also inhibit unanimous acceptance of such technology. At the macro level, legal and ethical standards are vague and subjective, and guidelines are in short supply.

However, did the managers of institutional care who we asked for an interview deliberately invite us to get information by us on the state of the art. All interviews with managers – and many of the interviews with relatives caring at home thus had the form of an informal information and experience exchange space. In many cases we looked up state-of-the-art systems together on the internet and discussed these with our interview partners in regard to their perceived needs. By this – similar to activity- and technology-based procedures with elderly and non tech-affine persons (Müller et al. 2012) – we could build up a common thinking space and help the people rethink their attitudes and ways of reflecting the possible benefit or harm the monitoring technology might have for them and the persons they care for.

4.2 Understanding the complexities of caregiving for persons with dementia at home

4.2.1 Autonomy vs Safety: two entirely opposite cases

The analysis of the interviews with family carers - husbands, wives, sons and daughters - offers very different perspectives on the evaluation and discussion of the autonomy and freedom needs of the affected family member. The difference can be significant. In one case, where care took place in the home, a husband reported that he allowed very little freedom of movement to his wife. While in their home, he wouldn't allow her to be alone in another floor – for fear that she might hurt herself. Being a retired engineer, he developed coping mechanisms for their every-day life: he 'engineered' her eating-, sleeping- and bathroom times with medication. In his understanding autonomy was not a relevant issue to his wife as she was 'no more here' with her mind.

In contrast, the daughter of a woman with medium-stage dementia has built a social network to collaboratively take care of her mother, so that her mother can live independently in her home and conduct everyday tasks – even go to the city – on her own. For the daughter it is vital that her mother feels that she is autonomous – and she has adopted many measures to 'artificially' achieve this, such as: asking shop clerks and bank

officers to give the mother what she wants, but up to a certain level. Sometimes the daughter ‘shadows’ her mother on her way to town. For the daughter, her mother’s ability to maintain a public and independent ‘face’ is of primary importance.

For many of the relatives we interviewed, the classic value trade-off between safety and autonomy is of minor relevance in their decision-making, especially when the disease advances. Many relatives report primarily on the overwhelming burden of concern for the dementia suffering family member. So for them, keeping the loved ones safe is much more important than preserving their autonomy. As the disease progresses, the patient’s mental existence is normally perceived as ‘fading away’, and autonomy becomes less and less important for them (this is not universal. It is a feature of such relationships that they engender a great deal of reflexive concern, contingently negotiated).

4.2.2 Impact of pre-existing family patterns on care concept

In the home context, families tailor care strategies to fit local conditions and needs. Each family has its own habitual familial pattern, such as structure, hierarchy, balancing between genders, and children/parent roles. Our empirical analysis indicates that pre-existing roles can have completely different effects on the care concept when dementia occurs. For example, in one case, a daughter and her mother who took care of the father who suffers from dementia at home reported that the father had always had a dominant role in the family and a strongly independent attitude. Even with the onset of dementia, he continued to assert this dominance. He still took long walks on his own, leaving his family in a self-confessed position of helplessness: *“We cannot hold him.”* (Mrs. C). This, we discovered, is quite common in situations where female relatives have to cope with male dementia sufferers. As an opposite example, in the case of the husband who ‘engineered’ the behavior of her wife, his pre-existing and continuing dominance in the family had actually ‘helped’ him manage his wife’s life with less resistance.

Thus, dementia care is mediated by prior family patterns and the role expectations contained therein. How to design a universal technical support that will work in all familial situations is, unsurprisingly, challenging. Technology support in the family context needs somehow to balance the continuities and changes experienced by both patients and their caregivers.

4.2.3 Attitudes towards GPS monitoring system

Family caregivers tend to be more open about the possibilities of a GPS-based monitoring system. However, the degree to which such a system is required depends very much on the progression of the disease and the coping strategies adopted by caregivers.

As in the institutional context, the interviewed families have a need for technological support and are aware of its existence, but none has bought a commercial product. Some of our users made the frustration with their experience of searching for a GPS solution very clear, such as lack of reliable information channels about such products, or insufficient information provided by the product websites which in addition were perceived as addressing technological specialists only.

4.3 Design Implications

From the empirical results of the pre-study, we were able to summarize the following design implications. Clearly, heterogeneous assumptions demand flexible solutions. Tailorability (Henderson & Kyng 1991; Wulf et al 2008) and End User Development (Lieberman et al 2006, Spahn et al., in this volume) here is of great importance. The system should provide as much

flexibility as possible to allow for divergent attitudes, ethical/legal concerns, and care routines to find their footing in it:

- *Reliability*: reliability is an important requirement for all IT systems, but is critical in this context. Tolerance of system failure is very low, especially in the institutional context.
- *History of paths*: almost all caregivers, no matter whether professional or familial, told us that patients have their favorite wandering routes, and in large degree are predictable. Keeping a history of the wandering routes in system could help identify such favorite routes, giving a hint for the searching for patient. More importantly, provided with the history, caregivers might be able to identify the patients' motives behind the wandering and their reasons of choosing these routes.
- *High flexibility of system configuration*: the constant value trade-off between safety and autonomy requires the system to provide options for the user to tailor the system according to temporal and spatial evaluation of the situation. It should be possible, for instance, to set safety areas (also named as *digital fence*) on the map and prompt notification when the patient leaves those areas. The caregiver should be able to configure the tracker to either automatic update the positions or manually (pulling or polling mode). Also the position update interval should be adjustable. Information on the patient needs to be anonymized to meet the requirements of certain institutions.
- *Support for cooperative monitoring*: caregivers already cooperate with each other to manage the care work in practice and cooperation also happens between professional and familial caregivers. The system should therefore support communication, coordination, and negotiation between them.

For the mobile application we have the following design implications:

- *Elderly-friendly UI*: the design of the mobile application should supply simple design and straightforward user interaction. Many caregivers are themselves elderly and have difficulty in reading small screens and understanding smartphone operations.
- *Navigation function*: It is essential to provide a navigation function in the mobile application to locate the wandering patient and navigate the caregiver to it.
- *'Key words' and integrated contact lists*: the caregiver should be able to access some 'hint' information to help persuade the patient to come back, such as the 'key words' mentioned earlier. In addition, a contact list should be added so that the caregiver can order help via the mobile if needed.

The design decision for the combination of a web portal and a mobile application allows a distribution of function. On one hand, this helps certain functions to excel on their most suitable screen size. The web portal is designed for the PC screen which provides enough space for location monitoring, system configuration, and jobs that are easier done with mouse and keyboard, such as drawing a safety area. The mobile application suits situations that require mobility, such as the navigation function in a patient searching. Having said that, flexibility of access turned out to be extremely important.

5. PROTOTYPE DEVELOPMENT

In the institutional context of this research, actual development of the prototype was the responsibility of a software company who formed part of the project consortium from the start. We conducted regular project meetings every 3-4 weeks with the developers from the

company to transfer our results and design. As a research institute we also developed an iPhone application which was not envisioned in the draft of the project plan.

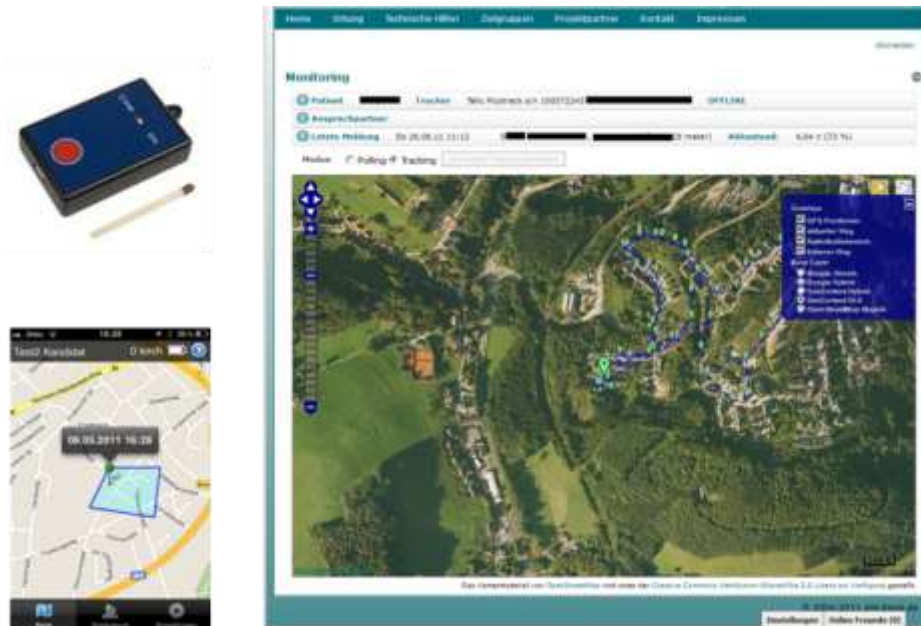


Figure 1. Screenshots of the prototype

The final prototype was a complete GPS-based location monitoring system to help caregivers better manage the wandering behavior of dementia patients. The system consists of GPS-trackers to be carried by the patients, a web portal for monitoring the actual position and adjusting settings (e.g. configuring trackers and defining safety areas on the map), and an iPhone App for mobile monitoring (see Fig. 1).

The prototype featured all of the above-mentioned features, save one: the cooperative monitoring feature. Given that we were partnered with a commercial organization, our design ideas had to be filtered through their interests and this is the main reason why the cooperative monitoring feature was not implemented. Nevertheless, we were able to refine our part (the iPhone App) in multiple design cycles based on several PD workshops together with the caregivers. We experienced, we should say, significant difficulties in working with commercial interests alongside our own research objectives. However, a detailed analysis of such organizational issues is not in the scope of this paper (cf. Randall et al, in this volume).

6. EVALUATION: METHODOLOGY

We rolled out the prototype in three different locations and tested it in real-life situations over a time span of three to five months. These included a family in which the husband is suffering from dementia (age 55), a care home with a focus on dementia care, and a special ward of a hospital.

Deploying the technology was anything but straightforward. Prior to the actual deployment, we conducted several semi-structured interviews in each setting in order to grab a detailed overview of their technology infrastructure and any specific conditions, so that we could make a customized deployment plan for each setting. In the institutions we had at least two on-site meetings to inform management and ward nurses about the evaluation plan. Prior to our visits, all evaluation partners had tried to get information on GPS support technology on the internet but all gave up due to the poor quality of provider websites in terms of

understanding of the technical issues. The on-site visits were audio-recorded and field notes were taken.

Despite detailed preparation, we still faced unexpected difficulties during the technology installation in each location. We had to be very flexible and creative to fine-tune the prototype so that it could be integrated into daily practice. For example, for the special ward in the hospital, we had to deliver an iPad with 3G connection to access the monitoring website because the Internet speed in that hospital was too slow to allow for serious roll-out of the prototype.

We visited the family and the institutions regularly every 2-4 weeks and were 24/7 available by phone in case of questions and problems. We conducted altogether 12 on-site visits and 6 telephone interviews with interviews typically lasting 1,5-2 hours. All the interview sessions were audio recorded with consent and later transcribed. During the evaluation we kept close contact with our testers, and all the emails and phone calls were documented in field notes. Furthermore, we asked the testers to fill in a media diary of their daily experience with the system. The diaries also worked as a basis for discussion in the on-site interviews. The data analysis was approached in the same as in the pre-study. We started with an open code system and regularly held internal analysis workshops.

7. EVALUATION: FINDINGS

The settings: two institutions & a family

The prototype system was evaluated in three locations, chosen because they enabled 'real world' evaluation without endangering patients. A hospital ward, an elderly care home for dementia care and a family constituted such environments. We identified three scenarios of use where different experiences were reported.

House A: Dementia care home

House A is a dementia care institution in a rural area. The house is committed to new dementia care philosophies which include the idea of giving the residents as much space as possible to be mobile on their own. There is large protected area around the house in which they are allowed to walk freely. There is an alarm system attached to the main entrance, and patients with a special wristband passing through will trigger a phone call to the care staff. The manager is of the view that patients should be able to leave the area if they wish to, although care workers are less liberal in their views.

Three young male volunteers, to whom the head nurse had handed the devices, mainly tested the system. Interestingly, these young men were all IT-familiar but saw older professional caregivers as 'lay' users of such technology. The head nurse shared this view, saying: *"older persons [meaning her colleagues] could not use this system, because in this institution they have only low experiences with technology and computers"*. She emphasized this with reference to her colleagues' general problems with care documentation work at the computer: *"my colleagues already have problems with simply clicking the right things in our records."*

House B: Hospital ward

House B is located in a big city and is a big hospital- and care complex. The ward in which we tested the system has a special focus on long-term care for persons with cranial-cerebral trauma and co-morbidities such as dementia. Here, location-tracking services were welcomed but worries were also raised because of the high mobility of the patient. In this

case, a relatively young man, who used to be a marathon runner, suffered from severe dementia as consequence of a car accident. The ward is an 'open ward', which means that locking the doors is forbidden. This patient 'escapes' regularly and is very difficult to manage as a result of his level of physical fitness. A specific limitation of the tracker was its' low precision in indoor positioning, and this patient was often 'lost' in the house, e.g. he happened to be found in the basement, having spent hours in a disoriented state.

On the day we brought our prototype to the house, we noticed that the Internet connection in the hospital was too slow for a sensible field test. As an alternative, we bought an iPad with 3G data tariff so that the staff could use the iPad to access the web portal. Two days later when we visited the house again, they told us that *"the iPad is safely locked in the cabinet [so that nobody will steal it]"*. Because of the high mobility of patients and relatives in the hospital in general, they were extremely afraid of losing the costly device and it was initially locked away unused. We then bought a protection case and a lock for the iPad so it could be securely attached to a desk.

The staff then started to use the system. Several days later we received a phone call from our contact person – a nurse in the house – telling us that the patient was lost for 20 hours, and was found the next day 30 kilometers away from the house. She told us that before this accident happened, the patient was carrying the tracker 24 hours a day, and the battery life of the tracker was inadequate. She tried to charge the tracker in the meantime, and she had no idea how the patient went out without triggering an alarm, and *"in this form we cannot trust the system"*. After investigating the system together with the nurse, we found out that the battery died within the safety area, right before the patient left the house. What we learnt from this case is that the system should send a notification when the tracker battery is low. After discussion with the house, we deployed another tracker for the patient, so that they could simply exchange the trackers, always having one fully charged. After this incident, the system has been used 24 hours a day and our contact person in the ward has reported on several successful instances where the system has helped, and the staff have started to trust the system more and more. The relatives of the patient also started to trust the system and grew dependent on it. The wife of the patient even made a carrying case on her own so that he can attach it to the belt and carry the tracker around more easily (see Fig. 2).



Fig. 2. Screenshots of the prototype

Family C

Here, the sufferer is cared for at home by a spouse. He, a former doctor, lives with his wife and three children aged between 15 and 20. Mr. C. walks the dog several times a day on a

short round in the near neighborhood. The routes he walks along are well known to the family, and are, according to his wife, 'routinized'. Before he leaves the house, he tells his wife or children where he intends to go. The relatives estimate roughly the time he should return. It has already happened several times that the man was not able to return home on his own. That's why a volunteer from a local charity organization now comes 3 times a week to take him and the dog for a long walk. Mr. C., however, very much dislikes the company of the volunteer, because he thinks he is still autonomous enough to walk on his own.

In our interviews with Mrs. C, she told us that the system is extremely helpful for her. She began, she said, to rely strongly on the technology after only a few weeks. She used the system not only at home, but also at work. She said that the system gives her peace of mind as she can see on the map that he is walking on the regular route. But she appropriated the system in a way that preserves as much privacy as possible for the husband. For example, she hadn't used the digital fence at all, as it feels too intrusive for her. And she slightly reduced the frequency of the tracker's position report. She didn't want to constantly track her husband, for her, having a look into the system and knowing that he is safe, is already a great relief.

Some general findings across cases

Some general issues in acceptance towards the trackers were also identified. Firstly, the size of tracker was seen as a problem by the interviewees. Although it is quite small (size of a match box), dementia sufferers often dislike devices attached to their body or clothes. Caregivers would prefer something very small, like a thin bracelet, or in the form of wristwatch or necklace which - as a known artifact to the sufferers - would be better accepted by them. Given the need for battery size, that is in current years difficult to realize.

Given the demand for autonomy, 'open house' philosophies mean that caregivers negotiate the freedoms of patients, where possible, to maximize them. 'Digital fences' are, in principle, extremely useful in this respect. Professional caregivers, however, suggested an additional structuring of the feature into three zones, a green one, a yellow (be alerted, person has left the safe area) one and a red one (act immediately, he/she is in danger). The family carers, unlike those in institutional settings, scarcely used the digital fence function at all.

The system was viewed as extremely useful in the institutional context even when it could not locate accurately indoors, because it helped refine search strategies. Thus and for instance, in the case of the former marathon runner, although the system could not tell the exact position in the building, it nevertheless indicated that the patient was not outside, which greatly reduced the search area, and thus made the search more targeted.

A similar benefit of the technology was perceived by Mrs. C, who argued that because the system allowed her to retrace routes taken, she was able to get a better sense of why her husband deviated from his normal route, thus reduces anxiety. Decreasing cognitive capability has led to situations where the sufferer has been found on a highway (Autobahn) construction site, and unable to explain how he found himself there. As Mrs. C says: *"we do not know even today why he had gone to this Autobahn construction site ... Something must be happened that made him leave the normal route. It can drive you crazy that you do not know the reason why."* Now, with the technology, there is the option to at least to reflect on possible reasons for new path choices.

7 DISCUSSION

7.1 Discussion of design implications

Overall, our proposed solutions have a positive effect on the experiences of dementia sufferers, their families and professional caregivers. Particularly in two of our three test sites, the professional and familial caregivers have grown dependent on the prototype and have shown active appropriation of the technological artefact. Having said that, the sheer complexity of the different situations which occasion concern, the heterogeneous nature of organizational and family routines, and the different moral/ideological commitments expressed by different parties underpin the need for solutions which are both very flexible and practical to implement. In the organizational context, it is clear that these complexities mean that support for collaborative searching and for the flexible definition of 'boundaries' needs to be better implemented. Professional management of issues of autonomy, privacy and safety are constantly negotiated and arranged in accordance with specific and local definitions of patient condition. Solutions must allow tailoring to meet these conditions. Another aspect our long-term and practice-based study shows is the significance of the shape and size of the tracker as well as compromises that have to be comprised and discussed when deploying a practice-based evaluation study. The study demonstrates a high need for individualization of the tracking devices according to individual familiarity with jewelry, wrist watches, etc.

In addition, technical support must fit with the established routines of family and institutional life. Constant monitoring from fixed positions is extremely difficult in many care institutions where there is a constant level of demand on time and a need to be available in different locations. In family contexts, demands include the fact that carers themselves are sometimes elderly, or have other family or work commitments. Even the professionals have problems learning new technologies, especially for the caregivers with senior age. This is exemplary in the case of Environment A, where the prototype was not actively used because of this technology barrier. The relationship between technology appropriation and low IT affinity of caregivers had already been described, e.g. in Pot et al. 2012. Our study augments this problem sphere with describing additional aspects impacting appropriation, such as the high heterogeneity in care concepts and moral and legal standpoints, which also may cause a reluctance in the willingness to use IT in dementia care.

Nevertheless, it would be naive to imagine that technical solutions can solve all problems. As Rogers has argued:

"While most projects are sensitive to the privacy and ethical problems surrounding the monitoring of people, they are not easy to solve and have ended up overwhelming UbiComp research. Indeed, much of the discussion about the human aspects in the field has been primarily about the trade-offs between security and privacy, convenience and privacy, and informedness and privacy. This focus has often been at the expense of other human concerns receiving less airing, such as how recording, tracking and re-representing movements and other information can be used to facilitate social and cognitive processes." [Rogers 2006]

Our long-term field test shows several impacts of the monitoring technology on the cooperative and social process of dementia care. For example, it allows the 'lines of conflict' to be renegotiated. Concerns such as awareness vs. privacy and safety vs. autonomy can be differently managed given location-awareness support. To a large degree, the management

of these concerns is a function of varying institutional and familial arrangements. This is compounded by the evident fact that policy, especially in the institutional context, around 'freedom deprivation' is often ambiguous.

The constant renegotiation of care philosophies is a complicating factor. With Dahl et al [Dahl and Holbø 2012a, Dahl and Holbø 2012b] we see that new care philosophies, such as Person Centered Care [Kitwood 1997], are being used in many care institutions. However, the related practices are not clear-cut. Therefore, we do – slightly different as [Sugihara et al. 2013] who promote Patient Centered Care as “[...] *appropriate for applying the norm of human-centered design*” – recommend to put a deeper look in how differently care theories are being worked out in situated practices.

Thus, autonomy is not a fixed metric. On the one hand, as indicated, this points at the need for flexibility in design technologies in its functionalities and settings. Just as importantly, however, it points to ethical issues in respect of how the researcher positions his/herself in these developing ideologies. If we support changing views of patient care in organizational settings, are we not bound to have a view of how patients are treated in family settings? Can we be comfortable supporting highly 'engineered' solutions like the one described above?

The cooperation with the software company in the consortium has been a further difficulty in conducting this research project. It was especially hard for us to transfer qualitative-empirical results and design suggestions to the company. This discrepancy in design philosophies brought some friction to the cooperation (see Wan et al. 2016). It is our view that agile development processes are much more suitable for environments of this kind. This insight is not always fitting with design approaches of industrial partners who are still strongly influenced by traditional approaches in software engineering (Dachtera et al 2014).

The ability to customize artefacts as well as aesthetic aspects in products for the elderly, and especially in dementia care, has also been stressed elsewhere [Angelini et al. 2013, Wallace et al. 2012] Our inability to extend the tracker to cope with 'indoor' situations limited perceived value in this design case study.

In conclusion, we set out to contribute to a better understanding of the subtleties and complexities entailed in the familial and institutional management of dementia sufferers with wandering tendencies. With a full description of a design case study (investigative pre-study, design, and long-term evaluation) we have established, we feel, a fine-grained basis for understanding of how lines of conflict may occur and how a suitably flexible GPS locating system can aid in their resolution. It is clear to us that technology alone does not provide a full assistive solution and it is always mediated by varied ideological and practical considerations in different contexts. The heterogeneity of caregiving contexts means assistive solutions (both the technology and service around it) must be very flexible and creative, adapting to differing users needs in each specific context. Caregivers in our study found these things in very short supply.

Besides technological features, we also contribute to promoting a new ethos surrounding IT support for dementia management. A planned market roll-out of assistive technology in this sector requires detailed consideration of support for installation, education, legal matters, after-sales service (counseling, adaptation) and so on. The business model of such a product needs careful thought since service before, at, and after sale are at least as important as the technology itself. Again, any recognition of the need to provide other forms of support to caregivers is almost entirely, absent from the philosophy of technology providers in this challenging context.

7.2 Methodological reflections

In this chapter we would like to discuss the investigation of care practices and socio-technical design in the field of dementia care in relation to the theme of this book, practice-based design and its research framework and Grounded Design (Stevens et al., in this volume, Rohde et al. 2016, Wulf et al. 2015).

We conducted our project under the methodological lens of Grounded Design, which bases on Design Case Studies, typically comprising an extensive empirical pre-study, a prototyping phase and a long-term evaluation and appropriation phase. The field of IT for the ageing society, and specifically dementia care, shows some specificities which we would like to emphasize for the pre-study and appropriation phase.

Firstly, the Grounded Design framework builds in its first phase on data gathering techniques such as semi-standardized interviews or participant observation of practices for the formulation of initial design ideas. Under a practice-oriented research paradigm the data to be collected is linked to the situated practices (Suchman 1987) of the target group (in this case the persons with dementia, and when the disease progressed, the familial and institutional caregivers). Randall et al. (in this volume) refer to Reckwitz' (2002) discussion of practice theories. In Reckwitz' argumentation, practice theories are a specific form of cultural theories, which he further differentiates as cultural mentalism, textualism, intersubjectivism, and practice theory. In his reading, these approaches are different in their capturing of the smallest unit of social theory: "in minds, discourses, interactions, and 'practices'" (p.244). Reckwitz confesses that his heuristic concept may not satisfy the rich works of the practice theoreticians he refers to, such as Bourdieu (1977), Giddens (1984), and Schatzki et al. (2001), his heuristic differentiation between the cultural theory approaches is maybe also not entirely helpful to frame research and design work in the field IT for the ageing society, and especially in dementia care. We specifically do see the strict separation between practice and textuality, or discourse, respectively, as a separation which is not helpful. We would suggest a to admit a stronger link between discourse analytic approaches, which focus on symbolic representations and a practice-theoretical lens, which favors the analysis of every-day practices, comprising aspects of embodiment and materiality (Baumann et al. 2015).

Our study, as well as other studies in the field of IT for the ageing society (Müller et al. 2015a,b; Schorch et al. 2016) demonstrate this in the following aspects: Beginning with the issue of access to the target groups (primary end-users ('the elderly'), as well as to secondary end-users (relatives, familial caregivers, professional caregivers, care homes, etc.) and to tertiary end-users (e.g. welfare associations) researchers are often confronted with huge problems in communicating their research objectives and in getting the target groups interested. This is essentially due to a low familiarity with new media in all groups, as well as due to the location of the design projects in a highly discursive field, spanned up in different images of ageing, of varying attitudes towards the potential benefits of new technology as a measure amongst others to assist the elderly in their activities of daily living. Our project in the field of dementia care makes these discourses highly visible: there are different (medical, sociopsychological) approaches and attitudes towards the concept of dementia and what the best treatment of persons suffering from dementia would be (Cantley 2001). The medical and psychological perspectives on dementia care have undergone a radical shift over the last three decades. The concept of personhood (inter alia, and prominently developed by Kitwood, 1997) and the accompanying theory of dementia

have had a profound influence on the development on new care concepts, by providing a philosophical base for the change in therapeutic approaches (Cantley 2001).

Looking at the care practices, our study shows that former approaches in dementia care, based on bio-medical concepts are still at stake, at the same time with the newer approaches, such as person-centered care (Kitwood, 1997), at least in the German context. The concurrency of the different care concepts has concrete manifestations in the attitudes and practices of the caregivers, which we found in both, familial as well as institutional contexts. The strongest manifestation gets visible in the concurrent usage of two different denominations of the wandering behavior in German: “Weglauftendenz” (tendency to run away) and “Hinlauftendenz” (tendency to run towards something). These two notations are strongly linked to ideological ascriptions and accompanying care measures (and finally also in the estimation of the value, benefit or harm of a IT-support system), the first influenced by bio-medical thinking, the latter by newer personhood-oriented approaches. In the pre-study we have described according differences in the attitudes and practices of caregivers.

This shows that actual practices are deeply rooted in educational programmes (both professional education of caregivers as well as in educational offers for familial caregivers at home, their availability and acceptance.

This also means that these care practices in home care as well as in institutional care are deeply rooted in questions of how the policy affects service developments, based on general conceptions of how a society treats persons with dementia and accordingly defines basic concepts, such as autonomy, personhood, inclusion, etc. Comparative studies on national levels pinpoint differences at societal levels: “Attitudes to dementia held by the general public, health and social care professionals, policy makers, relatives and others can influence the ways in which people view this set of conditions, their willingness to pay for medical treatments, and their willingness to see scarce tax or social insurance funds allocated to the support and care of people with dementia” (Knapp et al. 2007).

Against the background of a deep entanglement of situated care practices in a highly discursive field, we would suggest not to see the two theoretical approaches of discourse analysis and practice theory as mutual exclusive (as in Reckwitz’ heuristic), because the neglecting of the discursive field would lead to blind spots in the empirical analyses.

A second aspect in respect to the pre-study phase in the Design Case Study conception which is specific for the field IT for the ageing society is a methodological problem in the beginning of a project. The low tech-savvyness of our target groups (in the case of the dementia care project this was true for a large proportion of the caregivers, both in familial as well as in institutional, professional settings) urged us to think about methods which leveraged access to potential research partners to gain their willingness and motivation to give us interviews or let us participate in their every-day circumstances. We thus had to think about anchor points which would help them to be able to decide to start a cooperation with us – i.e. to build up a common notional space of possibilities between design team and research participants. This led us to complement field study methods such as interviews and participant observation with action-research based methods. In other settings in the field of IT for the ageing society action-research based methods had proven helpful in developing these anchor points together with the research partners, by an early introduction of off-the-shelf products and common activities (such as experience-based participatory design workshops) to help in developing meaningful practices with the devices, linked to individual interests and needs (see, Müller et al. 2012, 2015a,b). In the study at hand, we were not able

to introduce and deploy such an approach to and with our very target group, the persons with dementia; however, it was equally important to help the caregivers to be able to reflect and discuss possible usage scenarios of a monitoring device. In the initial interviews we collaboratively looked at and discussed other off-the-shelf monitoring devices, which often led to an interest to step into a deeper discussion and reflection with us. In the interviews with institutional carers, legal and ethical aspects then opened up as themes that were further reflected. One can say that our first inquiry for an interview or participant observation then sparked further interest in a deeper reflection of the possible benefits but also possible harms such a technology might inherit.

Relating to G. Hayes' (in this volume) notion on our approach to data collection in the pre-study phase is somehow between action research projects and the approach described by Wulf et al. (2015) for the Design Case Study concept. In the field of IT for the ageing society, it is important, to use additional measures to gain access to the field and to interest and motivate potential research partners for project participation (see also the chapter on PraxLabs by Ognowski et al. in this volume). These measures aim at collaboratively identifying anchor points which then influence interest and motivation (in the best case) for a long-term participation. However, we would not say that these measures claim to set the stage for a fully collaborative start of the project, e.g. with co-developing research questions, such as in AR. In our work on IT for the ageing society-field, the first steps are often slow and careful in order to be not too overwhelming for the elderly (or younger non tech-affine) persons.

A third aspect which shows some specificities for the field of dementia care in the context of data collection and (participatory) design is the challenge of communication with representatives of the very target group. Dahl and Holbø (2012b) discuss some strategies of how to involve persons with mild forms of dementia in interview settings with the aim to give them a voice and to prevent a domination of the interview situation by their caregivers. The authors relate their work to newer care philosophies such as Person Centred Care (Kitwood 2001) as also do Sughiara et al. 2013, who say that this concept is “[...] *appropriate for applying the norm of human-centered design*”. As said above, only by researchers trying to follow this newer care philosophies might not be enough, as they are not applied in all care practices and by all caregivers.

Our example of doing research with a couple where the husband suffered from dementia, family C, might illustrate the complexity of such interview settings. We accomplished all interviews and meetings together with the couple. The husband suffered from mild dementia and thus we were able to ask him some questions. However, we only could ask some very simple questions and had to rely on his wife to fully understand their management of their every-day life, their routines and their support needs. Even if we tried to integrate the husband very carefully into the interview situation, we had to accept that the wife was the one carrying all responsibility for both. Thus, even if we tried to give him a voice in the situation, we had to give more space to the wife, as she was the one to organize the everyday life and also to carry a huge burden which we were addressing with the technology. In addition, finally the caregiver decides if they as a family cooperate with us and this means that the researcher's task is to negotiate the situation in a very careful and flexible way.

However, if working with families or professional caregivers of persons with dementia in progressed states where oral communication is no longer possible, researchers have to rely on substitutional interpretations. This may put the researcher in delicate and complex

situations as s/he needs to complement what is being said by own observations (if possible) and has to estimate what is being said. In the description of the pre-study we described two opposite cases of familial care. In the case of the interview with the husband of a woman with dementia, who 'engineered' the everyday life of his wife, there came up awkward feelings in the researcher on the ways he treated his wife. This resulted in a personal and emotional affection and burden in the researcher, as further questions arouse, such as if there was the need to do something further (e.g. to try to share information on personhood-oriented ways of caring or even to inform a local authority). In other interview situations, relatives started crying, which put also emotional burden on the researcher.

These examples demonstrate the need for further reflection of how to be well prepared for these sensitive settings of care of chronically ill persons. This is especially important against the background of research projects which integrate university education.

8 CONCLUSION

In this work we presented a practice-based design process of a GPS-based monitoring system to be used by persons with dementia suffering from a wandering tendency. GPS tracking, being an established technology, remains rarely used in dementia care in practice. We investigated current care practices, IT design options, and the appropriation of GPS technology in dementia care and assessed the practical and ideological issues surrounding care to understand why. This design case study consists of three phases: (1) a qualitative empirical pre-study, (2) a participatory design and prototyping process, and (3) a long-term field evaluation and appropriation study in three environments. What comes to the fore is the need for IT design to reflect upon complex ideological and practical issues that form part of a moral universe where sensitivity is crucial.

Methodologically speaking, we propose some adjustments to the Design Case Study approach by (Wulf et al. 2015) in order to accommodate some specificities of design in the field of IT for the ageing society and especially for the field of dementia care.

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