

*DEALING WITH WANDERING IN
DEMENTIA CARE: A DEVELOPMENTAL
STORY OF DESIGNING A GPS
MONITORING SYSTEM AND ITS
CHALLENGES IN A WIDER CONTEXT*

Dissertation

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ABSTRACT

This dissertation documents a developmental story of the design and evaluation of a GPS monitoring system for late phase dementia patients with wandering tendency. The research was carried out in both familial and institutional care environments in over 2 years. Despite the widespread of GPS technology, its usage in dementia care at date is still very low. This work takes a socio-technical stance on development and appropriation of GPS technology in dementia care and assesses the practical and ideological issues surrounding care to understand why.

The results include: 1) Results from qualitative user studies from which design ideas, implications and requirements for design and redesign were developed. 2) Description of the politics, negotiations, and challenges encountered in the project at hand. These processual matters had a powerful impact on the product that was finally envisaged. The processes in question illuminate the way in which design outcomes are arrived at and to foster discussion about how ‘best practice’ might possibly be achieved.

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LIST OF ABBREVIATIONS AND ACRONYMS

AD	Alzheimer's Disease
ADL	Activity of Daily Living
A-GPS	Assisted GPS
CDR	Clinical Dementia Rating
CSCC	Computer Supported Coordinated Care
CSCW	Computer Supported Cooperative Work
EPR	Electronic Patient Record
GPS	Global Positioning System
GTM	Grounded Theory Method
HCI	Human Computer Interaction
ICT	Information and Communications Technology
LBS	Location-based Service
NMDA	N-methyl-D-aspartate
PACS	Picture Archiving and Communication Systems
PD	Participatory Design
RFID	Radio-frequency identification
RSSI	Received signal strength indication
SME	Small and Medium-sized Enterprise
UWB	Ultra-wideband

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1 INTRODUCTION

1.1 The Big Picture: Demographic Change

According to the *World Population Prospects* report [120], the world's population in all countries will undergo a significant structural shift to the year 2050. The projected percentage of the population aged 60+ will reach 21.5 percent in 2050, from 12.3 percent in the year 2015. The percentage of the 80+ will reach 4.5 percent in 2050, from only 1.7 percent in 2015. People around the world are living longer, as medical treatment and associated technological support keep improving. Europe's population will continue to have the highest median age among all continents from 2015 (41.7 years of age) through to 2050 (45.1 years of age). Combined with low birth rates, this brings about significant changes to the structure of European society. Report shows that Europe is the only continent that will see a declined population in the year 2050 than in the year 2015 [120].

Demographic change in Europe is influenced by the following features: 1). An ageing population, 2). Low birth rates, 3). Changing family structures, and 4). Migration. All in all, it will impact our economy, social security, healthcare systems, and many other aspects of our lives.

Ageing and healthcare, which is relevant to the topic of this work, see great challenges and opportunities in the next decades. On the one hand, the ageing population means higher demand for healthcare resources. Decline in birth rate and in labor force will create a fiscal shortage which exacerbates the situation. On the other hand, there are huge opportunities in terms of innovative policy with respect to new technologies, better services, and novel business models. The European Union

has invested huge financial resources in health-related ageing research and it will continue to be a vital part of EU's framework programs for research [46].

1.2 Dementia and Alzheimer's Disease

1.2.1 General Information about Dementia

Dementia is one of the major life-limiting illnesses that mainly affects the elderly population. Dementia is an umbrella term for a wide range of brain diseases that cause a negative impact to the patient's abilities to fulfill daily tasks independently. Worldwide there are estimated 35.6 million people who suffer from dementia in the year 2010. WHO report projects this number to be reaching 65.7 million in 2030 and 115.4 million in 2050 [3] - a staggering trend. In the case of Germany, there are already more than a million people who are living with dementia. By the year 2050 the number of the affected will climb to 2.3 million [13].

Alzheimer's disease is the most common type of dementia, covering from 60 to 80 percent of all dementia cases. But for one patient, there may exist more than one type of dementia, which makes the diagnosis of possible cause normally very problematic. Progressive memory loss, disorientation in time, loss of spatial orientation, communication deficit, and progressive loss of one's own personality are the most typical symptoms of Alzheimer's disease. A person's consciousness is usually not affected. The disease is associated with the accumulation of plaques and tangles in the brain, changes that are accompanied by damage to brain cells, and their subsequent death. The older a person is, the more likely they are to develop Alzheimer's. Alzheimer's disease has grown to be a major cause of older adult deaths (about one third) and this percentage is expected to rise in the future [125].

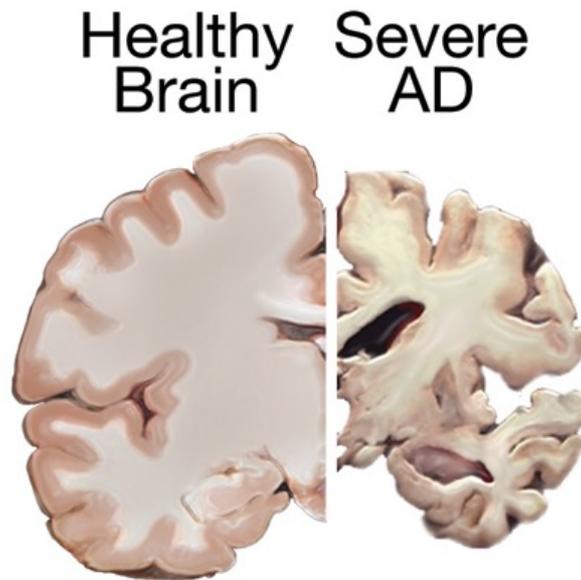


Figure 1. Cross sections of the brain showing shrinking of brain tissues caused by Alzheimer's disease

1.2.2 Causes

Dementia, in general, is caused by damage to brain cells which can occur in several areas of the brain. The damage interferes with the communication between brain cells. When brain cells cannot communicate normally, thinking, behavior and feelings of the person can be affected. The negative impact of dementia varies from case to case. Depending on which part of the brain is affected, the brain functions will be affected accordingly and the presented symptoms will vary [5].

The reasons for Alzheimer's disease have not been completely comprehended yet. Genetic mutation is perceived as a typical cause of early-onset Alzheimer's disease. Late-onset Alzheimer's can arise from a series of brain changes that happen over decades. Alzheimer's disease is believed to be associated with an accumulation of clumps of protein in the brain, which are known as "plaques" or "tangles". The plaques and tangles affect the chemicals that carry messages between brain cells, thus, the connections between brain cells are gradually lost and less neurotransmitter chemicals are available to carry messages from one brain cell to another. Hippocampus, as the central part for memory and learning in the brain, is mostly likely to be the first victim of this progressive damage. For that reason, memory loss is in most cases the first symptom of Alzheimer's disease. Cerebral cortex, which is

responsible for processing thoughts and many of the complex functions of our brains, such as storing and retrieving memories, calculation, spelling, planning and organizing, is particularly affected by the shrinkage of brain cells. AD patients will typically experience a decline in these capabilities sooner or later.

Statistics show that the older people are more likely to be affected by Alzheimer's disease, but it's worth noting that Alzheimer's is not a part of normal ageing, and why the disease largely strikes older adults remains a largely unanswered question.

1.2.3 Diagnosis

Alzheimer's is diagnosed through a set of medical assessments. Physicians can almost always determine whether a person has dementia, but identifying the exact cause of the dementia would require further and careful medical evaluation. Dementia is often very difficult to be diagnosed, especially when it's in the early stages. A diagnosis of dementia requires that at least two core mental functions be impaired enough to interfere with daily living, which include: memory, language skills, ability to focus and pay attention, ability to reason and problem-solve, and visual perception. There seems to be no unanimously defined set of tests, tools and methods for Alzheimer's diagnosis. In most cases, doctors may do the following to evaluate from different aspects of a person's situation:

- conduct standard medical tests such as blood and urine tests
- mental status testing: conduct tests of memory, problem solving, attention, counting, and language
- a thorough review of the medical history
- physical and neurological exam
- Ask the person or family members whether there are signs of changes in personality or behaviors

The Clinical Dementia Rating (CDR) [89] is an internationally accepted scheme to describe the different phases of the disease: "none", "questionable", "mild impairment", and "severe impairment". The diagnosis of Alzheimer's disease is normally a time consuming and complex process, and it involves expertise from several areas such as neurologists, geriatricians, psychogeriatricians, psychiatrists, and neuropsychologists. But a definite diagnosis of the Alzheimer's disease can only be achieved by examination of brain tissues in an autopsy after death.

1.2.4 Treatment

Alzheimer's disease has no known medical cure as what we know today. All treatment to date can only help postpone the progression of the symptoms and prolong the independent life the person as much as possible.

Currently there are 2 mainstream types of drugs to treat memory symptoms:

- Cholinesterase inhibitors: acetylcholine is a neurotransmitter for cell-to-cell communication in the brain that is gradually drained by Alzheimer's disease. Cholinesterase inhibitors work by preventing an enzyme (acetylcholinesterase) from decomposing acetylcholine in the brain, which leads to increased acetylcholine thus boosts communication between nerve cells. But as a side effect, other emotions, such as agitation or depression can also be affected because of the boosted cell-to-cell communication. All prescribed cholinesterase inhibitors nowadays (e.g. donepezil (Aricept), galantamine (Razadyne), and rivastigmine (Exelon)) work in a similar way, but the effect may vary according to individual situation.
- Memantine (Namenda): Memantine is an N-methyl-D-aspartate (NMDA)-receptor antagonist to block glutamate - a side product of Alzheimer's disease - from causing further damage to the brain cells. Memantine is subscribed for the treatment of moderate to severe Alzheimer's disease. Memantine may reduce the symptoms associated with Alzheimer disease, but it's not a cure for Alzheimer's disease.

Non-medical treatments are commonly seen from familial to professional care situations, but vary from case to case. In the following chapters of this dissertation we will shed light on some of the non-medical interventions that care institutions may undertake in their everyday care practice.

1.3 Dementia Care and Wandering Management

Many people with dementia feel the urge to walk about. 6 in 10 people with dementia will wander, and it happens at all stages of the disease. The loss of spatial orientation and memory ability means that people with dementia have a greater risk of getting lost [84]. Such situations cause anxiety and even more disorientation for dementia sufferers, and sometimes can lead to life-threatening circumstances [48]. Caregivers of dementia patients who wander often are under overwhelming stress,

as the patients normally need constant company. As the disease progresses, it will require constantly increasing help and support from the caregivers, professional and otherwise. In Europe, 75% of Alzheimer's patients choose to live in the home environment, and 25% live in nursing homes [4]. Several reasons led to this situation: 1). Public care infrastructure is not sufficient for the increasing demand of institutional dementia care. 2). The patients prefer to stay at environments that they are comfortable with and feel more settled in, to be taken care of by people they are familiar with. 3). Care at home is much cheaper than in institutions. E.g. in Germany, nursing homes cost nearly double the cost of caring at home plus external care services [134]. In the following chapters we will reflect on this more in detail.

1.3.1 ICT Support for Dementia Care

In research, the dementia patients have always been under the spotlight of most research studies. Family caregivers haven't yet received enough attention from the researcher's perspective. As indirect victims of the disease, family caregivers bare enormous physical and emotional burden. And studies show that family caregivers of dementia patients at home are often elderly themselves (e.g. in US: average age of 48, and 51% of them are over 50 [2]) and suffering from other ailments. Most research thus focuses on maintaining the independent living of the patient using medical and socio-therapeutic approaches, which should in turn help ease the burden of caregiving in a wider sense. Examples include support for orientation and safety, and alleviation of co-morbidities such as depression and behavioral change.

Wandering management, as a key feature for wellbeing at home care, has received considerable amount of attention in research. Position tracking system for dementia sufferers, at a first glance, should be able to boost safety and autonomy of the persons with dementia, and reduce constant accompanying burden for the caregivers. It seems to be beneficial for both the care receivers and the caregivers. However, in the first trial of a global positioning system (GPS) technology to locate missing persons, 5 out of the 11 respondents dropped out of the trial before the end (even though this test mainly focused on validating the accuracy and performance of the system in controlled environment) [86]. As of today, GPS technology has become both mature and ubiquitous, and there are a handful of commercial GPS tracking devices on the market, but they are seldom bought and used to manage wandering behavior [103].

The initial motivation for this work, then, is to understand why the uptake of GPS technology in dementia care remains so low. And a key contribution of this work is a more profound understanding of the sociotechnical factors which make GPS deployment so problematic in reality.

Ethical and legal concerns are no doubt key factors, and has received some attention in various studies. Essén is one of the pioneers addressing the dual nature of electronic surveillance by nuanced empirical research into how senior citizens experience electronic surveillance. This study supports the view that monitoring technology can be both enabling and constraining [45]. In the field of dementia care, the dual nature of the monitoring technology has aroused heated discussion on the value conflicts between awareness against privacy, and safety against autonomy [75, 76]. Recent work has demonstrated how embedding new technology in everyday life implicates a set of value judgements and attitudes about taking decisions on behalf of another person [33, 34, 77].

1.4 About this dissertation

This dissertation documents a developmental story of the design and evaluation of a GPS monitoring system for wandering management with late phase dementia patients. The research was carried out in both familial and institutional care environments over more than 2 years. The initial motivation for the research, as stated, really stemmed from the realization that position tracking technology's take-up in reality has been underwhelming, and a desire to both understand better what the reasons for that might be and provide appropriate solution. Although some research work has already shed light on the lack of acceptance of available services by caregivers in general [19] and more specifically of tracking technology in dementia care [8], we have lacked a nuanced understanding of the social, ethical, and legal universe in which caregivers are practicing care, and the subtleties and complexities in their practice which eventually impacts on attitudes towards tracking technology.

This series of studies thus took a qualitative empirical approach and aligns itself with the practice-based design research framework [91, 107, 112, 130, 131, 132, 133]. It is motivated by a core assumption that the 'practice turn' in HCI and elsewhere will provide valuable insights into the design and appropriation of a new technology. The research took part in 3 phases: 1). Pre-study: a qualitative empirical

investigation in both professional and informal care environments to gather in-depth understanding of care practice. 2). Design & Development: an iterative process to develop the prototype of a GPS-based position tracking system with continuous user participation. 3). Evaluation: deploy the prototype in real environments and observe how users use and appropriate over a long-term period.

In a wider context, the research was conducted in the framework of a federally funded research project in Germany where industry and academia work together towards a common goal, and ultimately aiming at bringing the outcome of the project to the market as a product or service. In Germany and the wider EU, research projects as such have to conform to certain framing assumptions governing the pairing of partners from academia and industry. This project, for example, consisted of a research institute from the field of Human Computer Interaction (HCI) and a small and medium-sized enterprise (SME) with the expertise of location-based service (LBS). While such cross-disciplinary collaborations offer considerable potential in respect to the melding of heterogeneous experiences and expertise, they also require careful handling of the competing values brought in by partners with different motivations and project management practice [32]. That is, the process of moving from the gathering of requirements to an ultimate near-to-market product depends both on the quality of our understanding of what those requirements might be and on the nature of the political and organizational processes entailed in development. In what follows, I show how both matters have been under-researched in the context of dementia care. In the literature on software design with user participation, there are relatively few examples which demonstrate exactly how the practices of users and the practices of research participants at an organizational level are mutually elaborative in the evolution of a design solution. Such a meta-perspective has seldom been offered in the context of healthcare and this work will also reflect on these meta-perspectives.

The contributions of this research include:

- A fine-grained understanding of attitudes and practices in GPS-based wandering management in familial and institutional care.
- A better understanding of the sheer complexity of the different situations which occasion concern, the heterogeneous nature of organizational and family

routines, and the nuances of moral/ideological commitments expressed by different parties.

- Implications for successful assistive technology in such sensitive contexts which include, but go beyond, technology itself.
- Opening up discussion about parameters which may influence successful large-scale research projects in assistive technologies for sensitive settings.

2 STATE OF THE ART

2.1 Overview of Healthcare Research in CSCW Context

The Computer Supported Cooperative Work (CSCW) research field has had a strong interest in healthcare since its inception (e.g. [43]), with its mission of understanding the cooperative manner of care practice and designing computer artefacts to support this work [47]. Healthcare settings turned out to be highly complex, dynamic, and cooperation intensive in nature, which provides an ideal testbed for CSCW researchers. Together with the ever-growing awareness of demographical change towards an older population, recent years have seen a blossoming of technological development to support healthcare in various contexts.

In institutional healthcare, ensuring sufficient quality while providing efficiency gains in caregiving has been a key interest for Information and Communication Technology (ICT) development. The Electronic Patient Record (EPR) was introduced by Weed [124] back in the 1960s and it has been the core component for technology development in various sectors of healthcare. As the technology has developed from its earliest implementations, and as its limitations have become more evident, recent studies then put more focus on the appropriation of EPR in real life situations, investigating how EPR was actually used in real environments and the potential sociotechnical problems that might emerge from practice [16, 57]. Other enabling technologies such as radiology, prescribing systems, and nursing care plan systems have developed along the years and are being steadily used in many scenarios [47]. The main problem of ICT development in the institutional

context, however, is the insufficient interchangeability and compatibility between them. While each system may operate well in its specialized sector, it's often hard to achieve a large-scale integration and standardization between different systems or departments, limiting the success and adoption of such systems in a wider scope [41, 60, 85].

For care in the home context, recent years see fruitful research focusing on empowering people to live independently at home as long as possible (ageing in place). Technologies to support telecare and telehealth scenarios have continuously helped self-care and supported care in the community and at home [36]. One of these scenarios - telemonitoring - is for patients with chronic diseases to monitor their own health condition and collaborate with doctors and caregivers to make sense of their living condition [11, 81, 6, 24]. Supporting social interaction and the sense of belonging for the elderly so that they can continue living at home for as long as possible is a central aim of the European research agenda (e.g.: Active and Assisted Living Programme - AAL). Works such as [53, 68, 121, 122] are designed to help older people live independently even in circumstances where they are experiencing cognitive and/or physical decline.

It is becoming more and more clear that technological development in the healthcare field faces not only technical challenges, but also those to be found in areas of sociality. Recent studies have progressively recognized that the design, use and management of such technology is a sociotechnical challenge [10, 47, 69]. For care at home, family members and care workers normally need to work in close cooperation to assure that adequate and appropriate care is provided. Meanwhile, different stakeholders may hold competing values and attitudes [26], coming from different backgrounds and are rarely co-located [1]. They may also have different agendas [9]. To call for broader attention to support the coordination needed in care at home, Consolvo et al. advocated the term CSCC (computer supported coordinated care) and focused on using technology to aid the elder's entire support network [28]. Other research work has focused on the information sharing between the network of actors involved in the home care process and its challenges and opportunities [93, 98].

2.2 ICT for Dementia Care

ICT development to support the caring of dementia patients falls into the following categories:

- Enabling tools: to help retain the impaired function such as memory aid. Unlike simple task and time-based reminder systems, dementia care requires more sophisticated, intelligent and context-aware guidance systems. For instance, the MAPS system is a prompting system to help cognitive disability sufferers carry out everyday tasks that they would not be able to achieve themselves [22]. Dementia mainly affects short-term memory, the project CIRCA attempts to stimulate the retained long-term memory of people with dementia to help with verbal and non-verbal communication [56]. The Memory Glasses [38] is a context-aware memory aid wearable, and its test shows that subliminal video cuing system is an effective way to provide just-in-time memory support with low distraction, and even incorrect subliminal cues can actually improve performance.
- Monitoring systems: normally achieved by sensors to detect either physiological parameters or environmental contextual factors. Emerging integrated sensor networks then take use of multiple sensors and make sense of data from different sources to infer certain activities, e.g. fall detection, detection of activity of daily living (ADL).

An extensive review of commercially available and emerging assistive technology applications (including intelligent cognitive devices, physiological and environmental sensors, advanced sensor networks, and etc.) for dementia care indicated that most of these technologies were developed for a young population with non-progressive brain injuries. Technologies that are tailored to irreversible dementia care are actually scarce [12].

2.2.1 Dealing with wandering behavior

To deal with the prevalent behavior of wandering, different strategies have been implemented, such as pharmacological intervention, behavioral therapy, music therapy, and building construction modification. In ICT support, mobility detection is described as valuable application for dementia care [110]. CareWatch, for example, integrates motion, door opening and bed occupancy sensors to detect

motion and alert caregivers through text or audio alarms [108]. Electronic tracking systems enable real-time locating of the patient, thus allowing caregivers to manage crisis situations and reduce anxiety and psychological burden. A pilot study focusing on the feasibility, acceptability, and effectiveness of the use of GPS system provides benefits to the caregiving of early-stage dementia with relatively low wandering behavior [100]. But, as position tracking solutions strongly depend on the access to patient's private information (in this case the real-time position), it is not surprising that position tracking technologies also raise serious ethical considerations surrounding the dilemma of safety and autonomy, privacy and awareness.

The debate around security and autonomy has generated a handful of studies on the topic. One of these studies investigated the perspectives of different stakeholders on the conflict between prevention of harm and patient's autonomy in wandering management. Results show that the professional caregivers tended to prioritize safety, while familial caregivers value patients' autonomy more [103]. In Landau et al.'s two related studies, the authors addressed the issue of who should decide whether a tracking device should be used. Results show that the decision to use GPS technology to track the real-time position of a dementia patient raises serious ethical dilemma between personal safety and autonomy. Professional caregivers thus are reluctant to assist family caregivers to make decisions, which is experienced as frustrating by the family caregivers [75, 76]. Dahl and Holbø similarly investigated the attitudes of professional stakeholders involved in municipal care on the use of GPS for tracking dementia patients. The authors discussed the dilemma between tracking efficiency and privacy preservation. Results show that the level of details required to achieve efficient tracking is intimately linked to the purpose of use, and any positioning data that were irrelevant for the immediate situation could be perceived as violations of a patient's right to privacy. Professional stakeholders tend to have nuanced views on the dilemmas related to GPS tracking of patients in dementia care and successful design must take into consideration these nuanced yet important perspectives [33].

2.3 Methodological Challenge for Research in Sensitive Settings

User feedback is a key success factor for software design nowadays, the importance of involving user from an early phase of the design and continuously reflecting user

feedback into the design cycle is now a common practice. Participatory Design (PD), for example, has been a well-established research discourse with its earliest projects tracing back to the 1970s [18, 27, 90]. PD is a process of mutual learning among different stakeholders including users and designers [18], which requires flexible forms of user involvement with a wide range of available tools. The involvement of elderly adults, and specifically in our context, both those suffering from dementia and their caregivers, who often have little experience with ICT has rarely been dealt with [94]. Prior studies have shown successful instances of involving people with early-onset dementia into the design process [59, 61, 103] using facilitating techniques such as known environment (like at people's home) and the presence of familiar faces. In a similar setting, that of working with people with amnesia (who are not necessarily elderly), Wu et al. suggested a set of techniques to support memory during and between design sessions [128]. 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 otherwise be unheard [34]. There are few studies that deal with interventions in the case of late stage dementia case.

As the employment of GPS and other sensor-based technologies in dementia care raises a debate around ethical concerns, some researchers start to view this issue through a value-sensitive design [51] lens. Historically, until the end of the 20th century, technology was generally considered as value-neutral. Technology itself, that is, does not incorporate any particular values. It's the use of the technology that will support or diminish certain values [49]. This conceptualization was challenged by theorists who have argued that the users and the technology have a mutual influence on each other during use [42, 99]. The notion of value-sensitive design emerged in the 1990s as an information system design methodology which emphasizes ethics and human values as a part of the design process, and that balancing the competing values of different stakeholders plays an important role in design [51]. But the definitions of key values such as autonomy, privacy, or security are highly situated in different contexts and across different care philosophies, which makes identifying values for the field of dementia care even more complex [126].

2.4 A Holistic View of the Research Process - Meta-Level Reflection

As long as a computer artefact is to be developed and deployed in a real environment, the design of a technology will be influenced by the organizational structure, processes and constraints of the project in which the development work is conducted. At this point, the wider context of the project has its impact, all the stakeholders that have driven and influenced the end-result of the development should be taken into consideration. The dissonant understandings between diverse stakeholders across academic and commercial backgrounds is more or less foreseeable during project progress due to the different attitudes and goals every partner brings in, outcomes which are seldom wholly clear in advance [32].

“With regard to the debate on the changing nature of science, our results suggest that within an institutional setting such as a joint research project, there are still epistemological and organizational barriers that are significant.” [32]

There is no shortage of methodological deliberation in HCI/CSCW aiming at better involvement of future users, e.g. with PD methods [58, 23, 70]. Even so, a perspective on reconciling the interests of stakeholders in a cooperative project from a meta-level has not been extensively worked out. The literature has mostly just touched the surface of this perspective by identifying different interests and values. However, little is known about how the decision and negotiation between competing values have driven the development over a project lifetime. The argument for practice-oriented HCI research [73, 131] which recognizes stakeholder interests and performances and how related decisions impact on the final design product has, as yet, produced only a few papers with explicit insights into the social and organizational production of a design outcome [20, 32, 91].

Here, I do not attempt to deliver a fully-fledged project ethnography of our design project but want to examine, at least in outline, the development steps taken and the way in which decision making and negotiation landmarks of the project team molded design outcomes. This is important because there exist a variety of attitudes and approaches in thinking about a potential technical solution for wanderers in the minds of designers and engineers as much as in the universe of caregivers. Specific beliefs and visions emerge which are shaped by a number of factors; how the project

has been initially set up needs to adapt. It is my aim to display these manifold interdependencies and how they impact on progress.

3 CASE STUDIES IN THE DEVELOPMENTAL STORY

- **Chapter 4: Caregivers' attitudes towards location-based service.** As the first step of this series of research, this chapter reports on the results of the empirical pre-study where we studied how family and professional caregivers cope with wandering relatives or patients, and identified social issues in the realm of the development, acceptance, adoption and use of LBS in dementia care. This chapter has been published as a paper in the GROUP conference, 2010, November 7–10, 2010, Sanibel Island, Florida, USA: *Claudia Müller, Lin Wan, and Dalibor Hrg. 2010. Dealing with wandering: a case study on caregivers' attitudes towards privacy and autonomy when reflecting the use of LBS. In Proceedings of the 16th ACM international conference on Supporting group work - GROUP '10. New York, New York, USA: ACM Press, 75–84.*
- **Chapter 5: A deeper look into institutional care workers' strategies in dealing with wandering.** The first case study in this series of research (as reported in chapter 4) shows a great diversity in professional caregivers' attitudes and rationales in the institutional care context. We felt the need for a deeper look into the institutional care workers' day-to-day care strategy and practice to help us understand why. The second step of the research hence focused on the institutional care workers' actual strategies and practices in dealing with wandering dementia patients. This chapter has been

published as a paper in the 7th International Conference on Pervasive Computing Technologies for Healthcare (Pervasive Health), 2013: *Claudia Mueller, Lin Wan, and Volker Wulf. 2013. Dealing with Wandering in Institutional Care: Exploring the Field. In Proceedings of the 7th International Conference on Pervasive Computing Technologies for Healthcare. IEEE, 101–104.*

- **Chapter 6: A holistic view of the research.** In this chapter the whole process of research was recapped and presented as a “clear design study”. This chapter has been published as a paper in the 32nd annual ACM conference on Human factors in computing systems (CHI), 2014: *Lin Wan, Claudia Müller, Volker Wulf, and David Randall. 2014. Addressing the subtleties in dementia care: pre-study & evaluation of a GPS monitoring system. In Proceedings of the 32nd annual ACM conference on Human factors in computing systems - CHI '14. New York, New York, USA: ACM Press, 3987–3996.*

- **Chapter 7: Going beyond research: design process taken as a whole.** Research in the field of practice-based design [73, 131] calls for attention to overall project activities, investigatory and otherwise, in a broader sense rather than simply reporting on the results of enquiry or the final results of research & development projects. This ‘practice turn’ in HCI is based on the assumption that all the activities of organizational actors, as well as those they study, in a cooperative project might contribute to the formulation of design goals, and that the process of investigation needs to be looked at as a set of practices right from the start. In this chapter we go beyond reporting only on the academic perspective of the research process, but also taking into consideration the whole project activities (including the industrial partner) within the funding frame that we believe had an impact on the final result. This chapter has been published as a journal paper in the ACM Transactions on Computer-Human Interaction (TOCHI), 2016: *Lin Wan, Claudia Müller, David Randall, and Volker Wulf. 2016. Design of a GPS Monitoring System for Dementia Care and its Challenges in Academia-Industry Project. In ACM Transactions on Computer-Human Interaction (TOCHI), Vol. 23, Issue 5, Pages 1-36.*

4 CAREGIVERS' ATTITUDES TOWARDS LOCATION-BASED SERVICE¹

¹ This chapter has been published as a paper in the GROUP conference, 2010, November 7–10, 2010, Sanibel Island, Florida, USA: *Claudia Müller, Lin Wan, and Dalibor Hrg. 2010. Dealing with wandering: a case study on caregivers' attitudes towards privacy and autonomy when reflecting the use of LBS. In Proceedings of the 16th ACM international conference on Supporting group work - GROUP '10. New York, New York, USA: ACM Press, 75–84.*

ABSTRACT

We present an empirical study that is being conducted in the context of developing a GPS locating system for individuals with Alzheimer's disease (AD) in Germany. A disposition of wandering is one of the most problematic symptoms as it fosters anxiety, disorientation and can even lead to life-threatening situations. Our qualitative empirical study contributes to the research on social phenomena which reveals some technical implications for the development of location-based services (LBS) in dementia care. We demonstrate that common concepts such as the dilemmas "awareness vs. privacy" in general and "safety vs. autonomy" in the context of monitoring systems for wandering patients need to be tackled from practice-based views. Our study attempts to understand caregivers' practices and attitudes towards these concepts.

4.1 Introduction

In this paper we provide an empirical study that is being conducted in a project which aims at the development of a GPS locating system for caregivers of individuals suffering from the Alzheimer's disease (AD). In Germany, where the project is located, more than 1.1 million people are affected by this disease. Symptoms of AD are progressing memory loss, disorientation in time, loss of spatial orientation, and progressing loss of awareness of the own personality – a process which currently can neither be averted nor hindered. A disposition of wandering is one of the most problematic symptoms as it fosters anxiety, disorientation and can even lead to life-threatening situations [48]. For caregivers the wandering symptom may cause overwhelming stress since ambulatory dementia patients must often be under constant watch.

We aim at developing applications which allow the localization of people suffering from dementia. The design of these applications touches a highly sensitive issue: These applications intrude upon the privacy of persons who are not able to give their consent for being monitored. This means that decisions on the usage of a monitoring device need to be taken by someone else, e.g. the caregiver or a close relative. Furthermore, people base this decision on certain criteria which stem from the very social context.

Research has already shown that the use of location-based systems (LBS) is highly socially embedded. People develop and accomplish different strategies to personally deal with the inherent trade-off between (keeping) privacy and (fostering and installing) awareness in social networks [118]. Related research has elicited concepts, strategies, and motives which are related to privacy issues from the users' point of view.

Concerning privacy issues in the application field of dementia care, literature provides a core dilemma reflected by caregivers' attitudes towards LBS for persons with dementia: The safety of the persons versus keeping their autonomy [75]. This is an important aspect to understand how caregivers classify privacy issues from this certain user perspective. It was our attempt to research into attitudes and practices in dementia care concerning wandering behavior and potential LBS support. By doing so, our results confirm that the named dilemma is important in the context of LBS usage for persons suffering from dementia. However, we wish to contribute to a more detailed understanding of what "safety" and "autonomy" means against the background of different attitudes, practices and conditions of care situations.

We accomplished 21 semi-standardized interviews on the basis of a Grounded Theory approach [113] with family caregivers and professional caregivers working in daycare and nursing homes. We describe the core findings of our research to illustrate and reflect aspects of "safety vs. autonomy" which have not been discussed in the literature so far. We expect a significant impact of the qualitative work on the development, acceptance, and usage of location technologies in the application domain.

The next chapter provides a literature review on location-based systems and privacy – discussing general important aspects and particular privacy concerns of our target group. Then we explain our methodological approach in more detail and subsequently report on the results of our empirical case study. Eventually, we discuss in how far our findings guide us to the next technology development steps and finally, a conclusion is given.

4.2 Related Work

A common concern of ubiquitous systems is that awareness has often conflicted with the desire of privacy. Privacy issues are not trivial even in everyday applications. In the domain of dementia caregiving, the situation becomes trickier.

As many elders who suffer from middle or severe dementia are no longer self-responsible, then who should make the privacy-related decisions?

The tension between awareness and privacy has always been hotly discussed in CSCW research. Awareness supports cooperation while at the same time it makes personal behavior visible [15, 17, 44, 129]. Back in 1996, Friedman first introduced the approach of value-sensitive design [51]. Camp et al. refined this approach in 2006 by suggesting risk profiled data collection, data filtering before storage, and taking user groups' requirements into account during the design as a concrete approach [21]. They introduced three principles for privacy preservation in ubiquitous systems: transparency, consent, and correction. For our research focus on dementia caregiving, consent and correction are both problematic issues. Firstly, the principle consent means that the data collection could occur only with the consent of the monitored persons or their caregivers. It is hard to clarify, who (the patient or the caregiver) has the right to permit the consent. Secondly, principle correction means that incorrect data can be altered or removed. However, the patients may tend to alter data or erase data by mistake. Kobsa argued that it is hard to find a uniform solution for privacy demands since both user preferences and legal stipulations are too heterogeneous. He suggested that a personalized privacy level could be a solution to these problems [72]. While there is a fair amount of theoretical research on privacy preserving in design, there are only few practical methods for providing users with a proper privacy level. Hong et al. proposed privacy risk models as a general method for refining privacy from an abstract concept into a set of concrete concerns for a specific domain and community [65].

Taking care of elders who suffer from AD involves even more privacy issues. Those who live in professional assisted living facilities often lack privacy. In assisted living environments bathrooms and bedrooms are often shared rather than private [82]. Although there are also non-shared environments, nursing home residents are often assisted by caring staff in activities that are normally seen as private, e.g. bathing. The situation of home caregiving is quite different then. Aging close to home is preferable for several reasons. It is normally less expensive for a person to reside in their home rather than receive professional care at an assisted living facility. Elderly overwhelmingly prefer to stay in their own home rather than move to unfamiliar environments.

However, home caregiving still cannot be exempted from privacy concerns. For example, designers of home caring systems commonly assume that using visual sensing devices to monitor residents as a means of ensuring safety is unacceptable because of privacy invasion [62]. An alternative approach is to track the potentially wandering elders with always-on and always-worn trackers [52, 66]. The concept of tracking people with GPS data exists in many social LBS systems, e.g. Foursquare [50] or Google Latitude [55]. As long as these products are aimed at ordinary user groups, the privacy issue is handled quite well, as these users have full control of their positioning data; they are fully responsible of whether they would like to be tracked. But in the case of tracking AD patients, many things can go wrong. For the sake of privacy, we may let the AD patients decide whether they should be tracked or not. But from the safety perspective, as they are no longer self-responsible, one could ask if their decisions still count? There is always a dilemma between safety and autonomy from the perspective of the caregivers. Corresponding studies exist, but without uniform results. In the study of Landau et al. [75], professional caregivers attached higher respect to a person's autonomy and would rather restrict the support of GPS tracking. However, family caregivers claimed that dementia patients in nursing homes were overprotected [104]. Professional caregivers in nursing houses preferred safety to autonomy when patients were under their care. It is thought that such a contrast in different views between professional caregivers is due to the different stadium of dementia patients. Those in late stadium moved to nursing houses because they needed more safety [104]. Interestingly however, not all situations can be clearly weighted toward either safety or autonomy. There are also situations with intermediate positions or where these two perspectives co-exist. There is still much for us to research on that.

From a technical perspective of view, the major concern of location privacy is the potential abuse of clients' location data, which may imply sensitive personal information. To support location anonymity, existing research reduces a location resolution by ensuring that each location reported to a service provider is a cloaking area that contains at least K mobile nodes. The work of Xu et al. in 2007 [135] introduced a strategy especially for continuous LBS applications, which require a frequent location update. The goal of this work is to provide a given level of anonymity protection and to keep the cloaking area as small as possible. In the paper of Chow et al., the privacy in 5 different system architectures was discussed [25].

How to anonymize personal locations and how to provide users with high quality services on the basis of anonymized locations were the important research questions discussed. However, for the application field of dementia care there is too little knowledge on related appropriate technological support, as well as on the social handling and reflection of privacy issues from the users' (mainly caregivers') point of view. In order to be able to regard attitudes, concerns and reflections of caregivers towards privacy and autonomy issues, and to reflect them against the background of a wider societal and social background in Germany, we used a qualitative research design explained in the following chapter. Some reflections on technological features in LBS based on the empirical study will be given in the discussion chapter. However, this paper mainly aims at describing empirical results from our study.

4.3 Research Methods

Since our research goal is to elicit practices, attitudes and reflections on dealing with wandering behavior of persons with dementia we chose a qualitative-empirical interview study. We accomplished 21 semi-standardized interviews on the basis of a methodological framework informed by Grounded Theory methodology [113]. From the findings in literature we started to scrutinize two relevant fields and searched for according interview partners – namely family caregivers who live with their dementia suffering relatives at home, and professional caregivers in retirement homes. During the interviews we detected the need to scrutinize more among the two groups. We learned that differences exist in coping with the every-day life of a dementia suffering relative in the familial context. For example, when the caregiver is a spouse, or an adult daughter or son, or simply differences between being a male or female caregiver.

In the course of the interview phase we also learned that we had to differentiate more exactly among professional caregivers of nursing homes for a deeper understanding of the handling of individuals who suffer from dementia. We differentiated between professionals who are working directly with the patients, such as nurses on a ward and persons in management positions who do not have much of a direct interaction with the patients. Thus, we subsequently looked for related interview partners by constantly comparing the materials gathered and analyzed. All in all we interviewed 6 family caregivers (4 female and 2 male: 2

wives, 1 husband, 2 daughters and 1 son-in-law). On the part of the professional caregivers we interviewed altogether 15 persons, among them 6 worked directly on a ward with the patients and 9 were in management positions. In addition to the interviews we met regularly with a local self-help organization which also helped us with finding interview partners. It also provided us with a good amount of leap of faith that we needed for getting in touch with caregivers who carry a high work load and, in the most cases, are rather critical against technological support, mainly due to their low technical affinity.

Each interview lasted between one to two hours and was audiotaped when allowed to. Some interview partners did not permit the audio record. In these cases, detailed interview notes were elaborated upon immediately after the interview. The audio material has been transcribed and all interviews have been analyzed by using the coding paradigm of Strauss & Corbin (1990). We were mainly interested in conditions, context, strategies and consequences of activities the caregivers reported. We were also interested in reflections of their individual way of practicing care, especially in regard to technological support. None of the interviewees were using GPS technology at the time of the interviews, but all had reflected on the question of a potential usage before. This is a quite representative situation for Germany. Interestingly, there are some providers of GPS locating systems on the market. However, the target group of such providers is made of technologically skilled persons who exactly know what to look for and how to use such systems. For people who lack advance technical skills, the market appears rather transparent. In addition, due to the general low technical affinity of caregivers and in familial cases due to the often higher age of the caring partners such technologies are concurrently only seldom being purchased and used.

4.4 Empirical Results

4.4.1 Professional caregivers' attitudes and practices

4.4.1.1 Each individual case needs to be precisely considered towards the question of whether they may be allowed to wander outside

Regarding the question "which extent of autonomy is a person with dementia ascribed to (e.g. leaving the home on his or her own)?", most of the professionals say that each individual case needs a precise consideration "*whether it is justifiable*" (Int. Hr. V..) and whether it would be a case for a technological support. The basis

of the assessment is an exact observation of the affected person: *“You need to see which person it is? It needs to be reflected in every case of wandering...it is important to ask: does he or she feel comfortable when he or she is allowed to leave the house?”* (Int. Hr. V.)

Interestingly, many of the professional persons do not reflect that question in the first line due to the actual cognitive skills of the patient but due to the degree of their wellbeing, as one professional illustrates this with one example: *“I remember Mrs. F.: she was so stranded that I nearly had tears in my eyes [when I found her standing disoriented on the road]. In this case I would decide: no! She was standing there and did not know where she should go now. She was so glad when I started talking to her and accompanied her back to our house.”* (Int. Hr. V.)

On the other hand he imagines that for other patients, who enjoy being allowed to leave the house on their own, technological support would be a good help: *“I could imagine other people with dementia who were glad of being let alone.”* Another professional person even mentioned certain happiness in the face of dementia patients which she recognized when being brought back to the house after they had managed to “escape”.

4.4.1.2 “Each person has a certain risk of life”

This kind of opinion for wellbeing of the dementia sufferers is being stressed especially by professionals in managing positions as the most important decision criterion for whether they should be allowed to leave the house on their own. As such, this accepts a possible degree of endangerment, e.g. due to road traffic: *“Each person has a certain risk of life, regardless of dementia or not; and this has to be accepted. When she is walking to her shop at the corner each day and this makes her happy... it is important for her...it is a well-known place to her...this gives her day a certain structure and by this, gives her a sense of security.”* (Int. Fr. O.)

Another manager of a retirement home defines the question of providing freedom to dementia patients and the according discrepancy of being responsible for their safety from a quite extreme point of view: *“Ok, one should not provoke that patient leave the house on their own. But on the other hand you must see: what is our most precious asset? People have demonstrated for the freedom of will and today people still demonstrate for that. It is a precious good that we can utter our free will. And*

when a person says that he or she wants to go outside and not only into the [protected] garden, that he or she wishes to leave the house on his or her own, then I need to let him or her go. And when I cannot manage to convince him that the garden would be the better option then I must let him/her go.” (Int. Fr. L.)

These comments show that our first idea that it would be a good idea to preventively give a GPS system to all wandering patients to guarantee their safety and to reduce the caregivers' burden does not always match the attitudes and estimations of the caregivers. The question of safety is not always a reason for evaluating a technological device as helpful. That is why a technological device is not seen per se as helpful – and this is not evaluated primarily against data privacy concerns.

However, these statements need to be regarded against another finding in this context - that these more “liberal” positions were mainly uttered by professionals in managing positions who argue from a background of actual standards of dementia care that favor a patient-centered, subjective approach. In addition, managing personnel often argue against the background of legal aspects. Nursing homes are regulated by law to very carefully deal with freedom from restraints. In Germany, in the last decades detailed standards have been institutionalized and controlled in such homes to prevent the elderly from being illegitimately fixed (e.g. fixed in bed or in a chair). Fixation still comes up when discussing new, more subject-oriented care concepts which strongly focus on the patients' wellbeing.

Having said this, the former utterances appear as attempts to provide a certain “political correctness” by the management personnel. This seems to be even more the case when looking at the according utterances of non-managing personnel. Caregivers who work in direct interaction with the patients and who therefore are more in a permanent concern for their safety, often think differently of letting people go when they express this wish. These caregivers rather consider safety concerns and worry about the patients getting lost. A deliberate and active “let them go” attitude is often not evaluated to be a realistic option when the patient has reached a certain degree of disorientation.

4.4.1.3 External factors: Care concepts and images

In this section we will elaborate a bit deeper into the topic of changing dementia care concepts and their relation to societal exchange processes and perceptions. It is

important to understand concepts of professional caregivers towards possible usage and acceptance of technological aids for patients who wander.

4.4.1.3.1 *The feeling of happiness of the patient versus possible loss of reputation to the care provider*

An interview partner in a management position tells the story of an inhabitant who had left the house unperceived and managed to take a train and travel to her hometown, 500 kilometers away. When she arrived at that city, some people got attentive and brought her to the police. There, she was not able to say her name and her destination, but she remembered the name of the nursing home she lives in 500 kilometers away. Finally, police organized a return transport by taxi. *“We and she were so lucky that she at least could remember the name of our house. But all in all, she looked so happy when she took off the taxi. She had a real feeling of happiness.”* (Int. Fr. L.) The interviewee stressed the patient’s feeling of happiness in order to stress the fact that to her a certain level of freedom and autonomy is still important when having dementia.

But her subsequent utterance relativizes this when she reflects on the danger of affecting the reputation of the home. She refers to a general perspective taken by the German press towards nursing homes, which are quite fast in developing negative banner headlines: *“When this lady came back I thought of what could have happened! You immediately think of the news headlines: ‘Nursing home loses inhabitant.’ This is very bad for our public reputation.”*

The fear of a damaged reputation is an important topic for all managing personnel in the sample. Reflection on the usage of monitoring technology is in most cases related to these concerns. Here, concerns on data protection and according negative resonance in the press is being mentioned as a factor for a rejection of monitoring devices.

4.4.1.3.2 *“All inclusive” expectations of the relatives do not match the real conditions in nursing homes*

Expectations of some relatives of the inhabitants of nursing homes are being seen as another issue which frames the handling with wandering persons: *“It is impossible to constantly watch a person 365 days per year; 24 hours... we cannot give you a guarantee. But there is this frequent expectation: we pay for our relative and this all-inclusive package includes that all doors are permanently closed.”* (Int. Fr. H.)

These high aimed and from her point of view unrealistic expectations as a consequence would lead to unfair assessments of nursing homes. To her, this often leads to the fact that even managers of nursing homes do sometimes not handle this issue in a fair way: *“Every manager who says that in her house nobody ever has managed to escape must be lying.”*

Here, a clash understanding of good care between professionals and relatives is obvious. Due to their emotional bonds and related sorrow and anxiety relatives of inhabitants predominantly focus on safety aspects. In contrast, due to a concurrent alteration of care concepts in Germany towards a more subject-centered and autonomy focused care approach many care professionals have different claims and values concerning this point. Also, regarding the interviews with relatives who care for a patient at home we have learned that the modern concepts of healthcare are noticed and practiced rather seldom.

4.4.1.3.3 Human resources hinder the implementation of autonomy-oriented care

“To put a GPS device on every wandering inhabitant is too extreme to my mind. Because I think that certain people who have this strong impulse need to be given the freedom to wander. You cannot keep these persons here permanently.”

This very tolerant and patient-oriented remark is being relativized by the same interviewee with the permanent problem of the deficit of personnel in German nursing homes. This deficit is one of the main reasons why a suchlike position often cannot be practiced, as it is impossible to assign every wandering person an assistant who joins her/him on her/his way outside the home. However, this thought of assisting wanderers is being seen as a form that offends the freedom from restraints, as not every one wishes to be accompanied all the time. On the other hand, a GPS device – even when it is not liked in general against the background of modern care concepts – is being taken into account as a possible solution against the background of the human resources situation.

4.4.2 Collaborative caregiving

4.4.2.1 Every-day caregiving and collaborative activity in retrieving patients/relatives at home

Taking care of the wandering patients is a challenging job for the family caregivers. Because of this huge demand of time and attention, the caring work is normally

taken by more than one family caregiver. Most of these caregivers are the children or spouse of the patient. In some extreme situations, e.g. both the parents are suffering from dementia, sometimes a professional caregiver is hired to live with the parents and help with the caring work. The caregiving work is distributed in a way which is similar to a shift work. That means that there is only one caregiver at a time to keep an eye on (one to one). In the meantime, the other caregivers can relax and enjoy their pastime.

“If my mother is not there, then I will keep an eye on father. For example, when he’s back from the walk, he often cannot open the door, although he has the key with him. Then I will open the door and let him in.” (Int. Fr. B)

Things become serious if the wandering patient gets lost. All the caregivers will be engaged in looking for her/him. In some situations, other family relatives or neighbors will also be asked for help. *“I suddenly noticed that she is not by my side. I called my son, he came and searched nearby roads with the car and didn’t find her... Neighbors also helped us look for her. And one neighbor finally found her and brought her back.”* (Int. Hr. B.)

When we look into the situations in stationary professional caregiving institutes, things are only a little different. Most of the time, the professionals are working collaboratively taking care of a group of patients (group to group). In some cases, another group will take over the job temporarily so that one group can have a rest. *“Sometimes we send the patients to the XXX-group. They will talk with our patients, or sometimes have dinner together with them. That really gives us some relief.”* (Int. Fr. I)

When a patient happens to be wandering out of the institute, similar to the situations of family caregivers, all the professional caregivers will be gathered and organized to look for the lost patient. The approach normally goes in this order: looking inside the building, call the patient’s relatives, look outside, and finally call the police.

None of the interviewed family or professional caregivers has mentioned any communication/collaboration systems to be used when looking for the wandering patient. The lack of communication could result in a low efficiency and accuracy in wandering finding.

We asked the caregivers about their experience with patients who get lost. Almost all the interviewees told us that patients always have their favorite wandering routes. These routes can be the way home, or a personally favorite path. *“We need to look into the biography of the patients: where do they live, before [they move in our house]...Because if they are wandering, they may just go home.”* (Int. Fr. K)

“... because people often have certain routes, where they would like to take a walk. She told me that she has found a nice path in the field, and she'd like to take a walk there...Now I know that the real situation is not what she told me...If I had a system [to analyze her history path], then I could know which direction I should go [to find her].” (Int. Hr. W)

4.4.2.2 Changing decision-making processes in professional contexts: new responsibilities

The professional caregivers do not feel a lack in their competences when deciding on the question if a patient should be allowed to leave the house on her/his own. Often named criteria are state of the wellbeing of the person (does she feel good when she is on her own) and the level of endangering due to the severity of the dementia and their general behavior (does he/she always take the same path). But for the decision of the question on the usage of a monitoring system some see problems in their actual professional competences. They feel that this decision is going beyond their competences and also their responsibilities. One of the professionals sees his job here rather as a moderator of the decision process:

“What do the relatives think about a potential GPS support, and what do the children want? It is my job to organize the care and to make sure that everything is being accomplished correctly. For the philosophy of life...if a person is being given the freedom to walk through the front door, staffed with a GPS system, and this is a philosophy...I feel overwhelmed with that. I would rather see myself as a moderator of such a decision-making process among the concerned parties [i.e. the spouses, children, attending doctors, nurses]. I could introduce such a technology and say ‘Look, we have such options, how shall we proceed now?’”. (Int. Hr. V.)

4.4.2.3 Need for strengthening security of decision-making

Another professional stresses the aspect of the need for securing the right decision. This nursing director bases her argument on the problem of intervening in personal rights when the person is not able to give his or her consent. That is why she – as

well as her colleagues – stresses the common decision on “*what to do on behalf of the wellbeing of the patient*”. For her a common decision process is important independent from the question of GPS devices. To her the intervention in personal rights is a daily concern when caring for patients. And a common decision-making process is to her a supplementary and important aspect of taking decisions safely:

“We reflect a lot: measures are always discussed with the attending doctor, with the relatives, and, if possible, with the patient. All try to find a good solution for the wellbeing of the patient. It is a system of persons who all know the patient and his needs very well.” (Int.Fr. P)

In this case, security must also be regarded in the sense of legal security. The interviewee reflects in this context on the problem of dealing with the patients’ right of freedom from restraints, such as fixation of the inhabitants in bed or in a chair, but also bed rails. The handling is defined by law and supervised by district judges. However, the level of austerity sometimes varies between judges. This makes it hard for the interviewee as she has to report to two different judges. This is due to the fact that the inhabitants have lived in different districts before they moved to the nursing home. In this situation the nursing director feels a high pressure due to sometimes different requirements by the different judges. That is why her main strategy is to pool the responsibility for important decisions on different shoulders.

4.4.2.4 Different care concepts influence cooperation between professional and “lay” family caregivers

In contrast to the approach of involving family relatives in important decisions, such as the usage of a locating device, there is also an attitude among professional caregivers which is directed to the evaluation of family care concepts of being not right and not good for the patient. Often professionals find relatives often too anxious and too much personally bound with the patient which leads too often to extreme interventions in the personal rights of the patient. By this, they fear that relatives might opt for a GPS locating device too quickly.

“Relatives are much more anxious, which is clearly grounded in different forms of proximity and distance to the dementia patient than in our professional case. It is our job to guide them the right direction and to say ‘hey, as a professional I can take the responsibility for that, and you should accept that for you, too.’” (Int. Fr. W)

In some cases the professional persons even see themselves as advocates for the patient. Especially in the early phases families feel shame for the disease and often try to “hide” the affected person from other people:

“Sometimes the hair dresser is the first person who gets the information that there is something wrong with the husband, when she says ‘I locked my husband at home because I do not know where he will be running.’” (Int Fr. U)

4.4.3 Family views: Safety versus Autonomy?

4.4.3.1 The autonomy aspect is of minor relevance

For some of the interviewed relatives who care for their relatives with dementia at home the classic value trade-off described in literature between safety and autonomy is not of such a high relevance. In the light of the heavy burden and sorrow for their relatives, especially in progressed states of the illness and according to strong disorientation and their mental and personal “elimination” the relieve of the relatives from the desperate sorrow in case that the patient gets lost is clearly standing in the foreground.

The potential usage of a locating device is here predominantly seen as a possibility of relieve in a heavy situation. Having experienced a situation where the patient got lost, the wish for a support (be it technologically) rises: *“It is such a big panic. It is similar to when you lose your toddler in the city. You are petrified.”* (Int. Hr. B)

The same comparison to the situation with a toddler one is completely responsible for is being drawn by another daughter of a dementia patient in order to strengthen her argument that the fear of invading the person’s personality is of no relevance in this special situation with a person with dementia.

4.4.3.2 Safety for the dementia sufferer...and the family caregivers, too!

Another daughter of her dementia suffering mother in an early stadium, but with changing states of disorientation, regards this point from a very different point of view: *“For caring relatives such a system would help. It would provide more safety to the caregivers.”* (Int. Fr. S)

Safety, in this case, means to her more inner peace of mind when her mother is going to the city on her own. For another daughter the case is similar: Her father has dementia and walks several kilometers every day and his wife and the daughter often do not know where he is and if he is doing well. A locating system would be

of great help especially for the mother who is mainly responsible for his care. Meanwhile, the family has established a “familial monitoring system”: The father often takes the same paths passing some of his siblings’ houses and sometimes takes a short rest there before running away again. After his visit, his siblings call his wife for a short status report explaining that he has been there and in which direction he left.

This case also shows another category which is important in dementia treatment: His wife and daughter are permanently worried that something could happen to him on his walk, e.g. to run into a car. However, they do not see a possibility to change the situation: “*We cannot hold him.*” (Int. Fr. C) This mirrors the often occurring helplessness of female relatives against their male relatives, against their often occurring resoluteness and dominance. On the other hand, the care of wives with dementia often is easier for their husbands, as women are often more “manageable”. This can be explained against the background of the family history and former familial distribution of roles.

4.4.3.3 More freedom for both parties

In such families where the dementia sufferers are still allowed to leave the house on their own this often happens under direct attendance or clandestine observation by the relatives, who follow them or who integrate others in the observation, as previously reported.

“*With a GPS system there is more freedom for me, too*” a daughter of a dementia suffering mother says. She points at heavy qualms which she has when she clandestinely follows her mother to control where she is going to and if she is doing well:

“*With a GPS system I could tell her ‘ok, then go on your own when you feel cramped by me.’ But I would have the possibility to see what she does so that I could intervene in case of emergency and get active.*” (Int. Fr. S)

Besides the emotional relief, she also values the freedom which could be given to the patient: “*This would be something which would give more freedom to both, the patient and the family relatives and all who are dealing with that. This looks like a good approach to the whole story.*” The aspect of freedom provided by a locating system also has another dimension in the daughter’s reflection. She sees in it the

possibility to give a bit of autonomy back to her mother – or at least the possibility to give her the feeling of self-determination:

“I could give her the feeling of freedom back. I can let her go without saying that I want to accompany her, so that I could wait for her to propose ‘Why don’t you join me?’ Or that I can offer it but do not have to go with her if she does not want me to.” Here freedom involves the notion of giving a bit of responsibility and autonomy back so that she is able to make own decisions again. The patient would gain back a piece of control.

The interviewee also draws the comparison to parenting, but from another perspective than before: Not in the sense of responsibility for a toddler but rather in the sense that in the adoption phase of a locating device the patient’s autonomy must be redeveloped step by step and the daughter has to give back control step by step herself: *“...it is similar to how I did this with my children where I also said: I must give you the feeling of freedom which give you a frame for action. It is your freedom, but only up to certain points. For example, when I let her go to school on her own but then call a friend to ask if she passed their house. It means to give the child – or the patient – a feeling of freedom, but I need and have a certain security, though.”*

The interviewee explains a fourth aspect of freedom insofar as when her mother has left her house she then is able to quickly clean the house. This is problematic when she is there: *“the benefit when mom is not there is that we then can clean things in her house then. For when she sees that we are wiping or so she always gets angry and asks us why we are doing her work. She thinks she is cleaning the house regularly on her own. But effectively she has not touched the cleaning cloth for more than one year.”*

Here the daughter also responds to her mom’s imagination. It is the same patient-oriented interaction principle as she would apply in the imagination of the potential profit of a GPS system. The daughter accepts and responds on the basis of her mother’s imagination and positions her activities around her mother’s imaginations in order to give her mom a feeling of control and autonomy. However, this action could also be an indicator for the wish of the daughter to keep her mother’s and her own “normality” as long as possible by interacting with the imagination of the mother. Regarding this kind of interaction against the background of general coping

strategies of adult children when parents age, often there happens a shift of roles. Children have to take over the parent role and need to “grow up” and often feel overwhelmed with the new role. In case of the interviewee the reflection on the possible usage of a GPS systems seems to her to be able to go back to the role of the daughter for short-term.

4.4.3.4 Ongoing negotiation processes

Likewise the caregivers need to observe the status of their relatives and patients constantly for deciding on how much freedom they can give them without endangering them. An interviewee reflects on how she would start with the adoption of a locating system:

“I could let her go but the first times I would turn the system on and immediately would look where she is. Then, step by step, I would be calmer and then could see that she has a certain time frame until I expect her back. Then I would control the system less and less and only every now and then.”

Generally speaking, we must think about system functionalities which provide the option to control the patients as less as possible once a practice has been established. On the other hand, the timeframes need a re-evaluation when the disease progresses.

4.5 Discussion

The empirical study indicates that in the field of LBS support for the care of dementia patients who wander, the trade-off between awareness and privacy needs to be reconsidered. In [76 Landau 2010] and [73 Landau 2009], from a medical research point of view another dilemma between safety and autonomy has been figured out as being the relevant stance in the context of dementia care. Here, autonomy is being regarded as an aspect of privacy for the special setting of dementia care. Our data shows that this relationship can be regarded from two viewpoints and by this, changes the relation. That is why we see a shifting boundary in the reflection of this relationship: On one hand, an intrusion on the personal data (e.g. location privacy) can be regarded as a limitation of autonomy; on the other hand, a monitoring system provides the potential to strengthen the patients’ autonomy by giving them self-decisions on leaving the house when they want to or taking a walk on their own. This would be an activity-based perspective from the perspective of the patients. To clarify these blurred boundaries of the concept

“autonomy”, it will be helpful to regard other concepts and phenomena which the interviewees subsume under the terms “autonomy/privacy”.

Firstly, we recognized that different ways of handling and interpreting autonomy aspects relate to macro and micro level issues: How a caregiver positions himself/herself in the field of discourse is dependent on his or her personal knowledge on dementia caregiving, and on the actual perceived load of burden. On a macro or societal level, by literature analysis and by means of the interview analyses certain societal “trends” in dealing with dementia can be figured out. We can resume that the disease still does not have a “public face” in Germany, despite of political and other campaigns, such as in other countries, e.g. the UK. Since 1996, campaigns triggered by a study of [54] with the slogan “Hearing the voice of people with dementia” have brought forward immense results in societal and political work to bring interests and perspectives of patient to the stage.

In interviews with families we learned that here in Germany we are still quite far away from the institutionalization of innovative ways for the inclusion of patients. The same is true for accepting and valuing them with their certain perspectives and behaviors and looking more at their resources than deficits. We already got in touch with this certain societal wind in Germany when we had quite some trouble in finding family caregivers who were willing to talk to us. By means of help of the formerly mentioned self-help organization, we finally found our interview partners. But strikingly, we are still looking for patients in an early stadium who are willing and able to discuss with us on the technology development and requirements from their point of view. We do not like only talking about patients, but at the moment we have no other chance. This is especially due to the handling of caregivers on the micro level of each family or subject which is influenced and framed by the societal trends. As dementia is often dealt with as a taboo with according consequences in Germany, affected persons and caregivers feel ashamed and it often takes quite a time until people visit a doctor and by this open them up to the system of several help offers. Linked to this is the fact that relatives start looking for help when the situation gets extreme or they are overwhelmed with the burden of care. A big problem with spouses is that due to the strong emotional bond and a lack of modern care concepts the caring person often come to a point of giving him/herself fully up and seeing no personal space for rest anymore and no one for the loved one, too.

This has consequences for the potential usage of a system itself: on one hand for some family caregivers the potential benefit seems to be perfectly clear in a situation which has become a very desperate one. On the other hand, for people in early stadiums where the system could provide a real enhancement of personal freedom and safety, people are often not open to look for suchlike help systems. This is mirrored by the fact that similar systems are available on the market but only few people actually use such systems. Certainly, there are also other reasons for that: main caregivers of patients at home are elder people who have only low or no affinity to new media and ICT. Thus, this requires the system to be very simple in usage.

In the attitudes of our interviewees towards the usage of GPS locating technologies for wandering persons we came to a kind of a paradox situation: On one hand, the tracking is standing in contrast to modern autonomy-oriented dementia care conceptions. Here the argument is that tracking as an invasion in the personality of the patient impairs the autonomy. On the other hand, in some cases a GPS locating system is seen as fostering autonomy, e.g. when it helps that people can leave the nursing home, even despite a bad personnel situation. The same is true for home situations when interchanged parent-children roles may be switched back for a certain period of time and by this more wellbeing is being achieved for both, the patient and the caregiver.

On a micro level, from the professional care givers' point of view one result is that autonomy is more a topic in management but not so much for the caregivers on the actual ward. Direct vs. indirect caregivers have different viewpoints on the basis of their demands in their daily practice and by this, provide different concepts of thinking and dealing with autonomy. Linked concepts and phenomena which have been revealed in our study are:

- *Wellbeing and burden of the patients*: The estimation of the degree of wellbeing and joy is one important criterion for the decision of how much autonomy is a patient given in the sense of a permission to leave the house on her/his own. The privacy question in the case of using an LBS solution is only a secondary concern here.
- *Severity of illness*: The stadium of the illness and the degree of disorientation surprisingly are not the most important aspects which are being assessed for

the decision whether a patient is allowed to leave the house. At least the indirect professional caregivers rank this aspect after the wellbeing/"quality of life" issue.

- *Responsibility of the caregiver*: Responsibility is an aspect which is linked in different ways to the question of whether a patient is given more autonomy (to decide on his/her own to leave the house alone): Firstly, [76] found out differences in the feeling of the burden of responsibility for caregivers working in a nursing home or working in home care contexts. In nursing homes, the nurses feel more responsibility for the patients than in home care contexts as there the responsibility is shared with the relatives. Thus, the authors mention a shift in the safety-autonomy dilemma: the nurses in nursing homes have a stronger focus on their patients' safety while the home care nurses stress the importance of autonomy more. They are able to do so as they share the responsibility with the relatives at home. In our sample we found this shift in the professional context in the differentiation of direct caregivers and indirect, managing personnel. Here, it is the managers who all stress the point fostering the patients' autonomy. This is based on different aspects. Firstly, it is based on other demands of their daily work, such as public relations. Second, it often is related to another educative background and state of the art knowledge of dementia care concepts.
- *Workload of the caregiver*: Workload is the contradicting factor to the formerly said: Even though a nursing home is based on new patient-oriented care concepts, the actual workload of the nurses hinders to respond to patients' wishes to go outside the house.
- *Communicative strategies/public relations*: our study has revealed that an attempt to provide "political correctness" is strongly linked to the reflection of the patients' autonomy and their privacy. But in the interviews it is twofold: firstly, autonomy is equalized with privacy when managers are afraid that they might not act legally in terms of data privacy issues. On the other hand there is the aspect of political correctness on the basis of the adoption of new dementia care paradigms: in this regard, the system could give the patient more autonomy in the sense of freedom of own decisions, more humanity and quality of life.

- **Legal aspects:** the formerly mentioned aspect is strongly linked to legal issues and it is the same twofold point of view: it is privacy in the sense of data protection on one hand and the patient's autonomy in the sense of the right of self-determination, self-reliance and humanity on the other. Some interviewees related their perspectives to the fundamental law which says in its first paragraph: "*The dignity of man is inviolable*". Both perspectives, the data protection and the self-determination perspective, are directly linked to this law. This means a decision must be made in every individual case on what is the higher good in the special case. The interviews revealed a general and high uncertainty towards legal aspects of monitoring patients. That is why the interview partners looked for other decision criteria to assure their points of view towards LBS.

The bandwidth of concepts and attitudes towards questions of autonomy and privacy from the family caregivers' points of view is similar to the formerly mentioned aspects. However, there are some significant differences:

- *Legal aspects* do not play a significant role as the relatives often have the tutelage on their wandering relatives and as such have the right to decide on the question whether an LBS system would help to increase the patient's safety/autonomy. In this regard, it is more important to reflect the relatives' concepts and thoughts on autonomy itself.
- *Individual burden:* the individually perceived burden and the linked emotional bonds influence the relatives' perspectives on how to deal with their patients' safety or autonomy: The bandwidth in our interviewed families is from the point that questions of autonomy are of no relevance up to the perceived stress of autonomy or return of control in the mother's hand. Safety is a big issue and concern of family caregivers but it is also dealt with differently: from the practice of not letting a patient out of sight – even not inside his/her own house up to the feeling of fear and helplessness when patients leave for walks and cannot be held back by the – often – female spouses or children. Others find intermediate ways along a line of signaling autonomy but fabricating safety at the same time, when for example clandestinely following the patient on their walk.

- *Gender*: Gender aspects often influence the way people deal with their relatives' dementia. Especially wives often are more "tolerant" when their dementia suffering husbands attempt to wander outside the house. This is often due to traditional family roles and linked to a perceived inability to hold their more dominant wandering husbands back. In contrast, husbands often find it easier to establish a safe environment for their wives, but nevertheless the fear of them "escaping" from the house and getting lost is high, too. Regarding the handling of autonomy this means that often incapability leads to give a rather unintended freedom on one hand, and on the other, autonomy is not a relevant aspect from the husband's point of view. This aspect is linked to the next issue, which is:
- *Relationships between professional caregivers and relatives*: Here the view onto autonomy is somewhat twofold. On one hand, in homecare settings, the relatives carry the highest burden and responsibility for their patients. The relatives also are important for decision making processes when the patients live in nursing homes. On the other hand, some professional caregivers see the need to bring training of new dementia care concepts to the relatives. They find it important as in some cases they perceive that relatives do not acknowledge their wandering relatives' autonomy rights and needs.
- Another important structuring aspect is the difference in *being a spouse or a child of a dementia patient*: Due to the problematic of a shift in roles children often are more aware of autonomy issues of their parents as they feel bad when starting to control or to lie at their parents. In our sample, daughters wished to intensify humanity for their parents, e.g. by using a LBS for giving a piece of control and self-determination back.

Despite the limited size of our sample we could demonstrate that in LBS research for dementia care we need to open up common concepts of privacy/awareness and dilemma in the medical literature on "safety-autonomy" and base related technology development on more practice-based attitudes and insights, as given in this study. The concepts "privacy" and "autonomy" are socially embedded in various ways and links from the viewpoint of the caregivers. In addition, they are influenced by macro-level, societal trends.

Technologically speaking, it has become clear that a system should in its functionalities react upon various contexts, strategies, and conditions of individual

ways of coping with a patient's or a relative's disease. For example, in LBS it is state of the art to draw a security area on a map. When a person leaves the area, an alarm is sent to the caregiver. What we see from the interviews is that we must reflect upon how to better support varying user needs in the realm of providing autonomy, e.g. in tailoring more fine-grained scales of autonomy provision, and which may be easily adapted to the actual and daily status of the patients. In support for that, a system should be customizable not only to the direct users (caregivers who track), but also to those indirect users (patients who are tracked). Here are some examples: A customizable radius of masking area provides the flexibility to switch towards safety or privacy. The frequency of tracking, i.e. how many GPS position reports should be sent back to the server in a certain time interval, can be a personalized factor as well. Furthermore, it would be beneficial to have personal time plans. Tailoring the time plans should also take the patients' habits into consideration, as regularity of patients' wandering has been notified in our interviews. Finally, historical logging and its level of detail should be customizable as well. Such history of data might provide with novel implications on wandering behavior. Almost all the interviewees told us that patients always have their favorite wandering routes. These routes can be the way home, or a personally favorite path. Interestingly, there is some inconsistency between what the patients say and what the patients do. They may say that they like to walk in certain routes, but in practice it could be totally different. These findings show that, firstly, the data of history path is very helpful for the caregivers to find a wandering patient. Secondly, this data should be based on a long-term statistical summary with the help of a system.

Supporting collaborative care is another critical issue which needs to be integrated in a localization application for the patients. For many caring activities, the search for a lost patient happens in a collaborative manner as well. This is true for institutions of elder care but also for family care settings. This implies that the formerly clear job responsibilities will probably be reconsidered in the course of the technology development, implementation and appropriation. In family settings, loosely-coupled help systems will be changing into more fixed roles and responsibilities when adopting LBS for common care. These changing organizational patterns point at the need for an action research-based user centered design approach in the following steps to successively co-develop the technology and changing practices. Especially for collaborative retrieving situations when a

wandering person is lost, a collaboration support will be of great help. Lack of communication could result in low efficiency and low accuracy in finding. This empirical finding indicates a need to better understand and support collaborative activities in search for lost dementia patients.

Overall, measures of coping and caring for a dementia patient need constant reflection, evaluation and, if needed, adaptation. The same will be true when it is made use of an LBS system.

4.6 Conclusion

We studied how family and professional caregivers cope with wandering relatives or patients, respectively, and especially with wandering behavior which is often a challenging burden for all actors involved. From the analysis of 21 interviews with caregivers at home and in nursing homes in Germany, we contribute to research on social issues in the realm of the development, acceptance, adoption and use of LBS in dementia care. We took notice of concepts for addressing social issues in general LBS research – i.e. awareness and privacy – and concepts stressed in the medical literature as being the caregivers' core concerns when reflecting the use of monitoring systems for the prevention of wandering – i.e. autonomy and safety. Our findings show that these common dilemmas exist in a blurred state as seen from the practice-based qualitative data. The study contributes with empirically-grounded aspects of the social embedding of practices and attitudes towards privacy and autonomy in dementia care. It also reveals some technical implications for the development of LBS in this domain.

5 A DEEPER LOOK INTO INSTITUTIONAL CARE WORKERS' STRATEGIES IN DEALING WITH WANDERING²

² *This chapter has been published as a paper in the 7th International Conference on Pervasive Computing Technologies for Healthcare (Pervasive Health), 2013: Claudia Mueller, Lin Wan, and Volker Wulf. 2013. Dealing with Wandering in Institutional Care: Exploring the Field. In Proceedings of the 7th International Conference on Pervasive Computing Technologies for Healthcare. IEEE, 101–104.*

ABSTRACT

We will present a case study on institutional care workers' strategies in dealing with wandering dementia patients. We will highlight their day-to-day practices, permanently balancing conflicting demands around keeping harm away from residents with wandering behavior. The risk of harm is multifactorial and also socially, culturally and organizationally defined. A closer examination of how the staff uses non-tech, lowtech and information and communication technology (ICT) artefacts in their daily practice helps us gain a better understanding of their practical problems and rationales for further ICT design.

5.1 Introduction

This case study focuses on the strategies the institutional care workers use on a daily basis when dealing with the wandering behaviors of dementia patients, and how they have adapted to the situation and finally developed these strategies. Wandering behavior, which is common in people with dementia, is sometimes regarded as beneficial, as it is often the last way to express oneself when the disease has progressed quite far. On the other hand, it is likely to cause physical harm, emotional distress and death [104]. The caregiving for dementia patients with wandering behavior is often an overwhelming burden and a demanding challenge for the institutional caregivers. When caring for people with dementia, it always comes to a situation of collision and excess of autonomy bounds, which arouses controversy around privacy concerns.

While there are guidelines and standards of care, as well as legal basis and in-house standards, there is still much uncertainty when they are actually used in daily practice. As Lucy Suchman has pointed out, people's behavior is "highly dependent upon its material and social circumstances, focusing on moment-by-moment interactions between actors, and between actors and the environments of their action" [114]. This suggests that when designing technology for the field, it is necessary to carefully examine the actual situations, how all the actors act in practice, and how situational and organizational factors fit into the cognitive process.

This work is framed under a multidisciplinary research project aiming at designing a passive monitoring appliance for wandering management, in order to lighten the

caregiver's burden as well as preserve as much of the patient's autonomy as possible. This paper describes our first findings in understanding the field.

5.2 State of the Art

Most studies on assistive technologies for the dementia sufferers and/or their caregivers stress the massive value tensions that need to be considered in the research and development process [80, 34]. That's why some approaches aim at grasping a holistic knowledge upon attitudes, fears and expectations of familial or professional caregivers – and when possible of the patients themselves – towards ICT adoption and usage, such as GPS locating systems [104, 75, 92]. Others focus on actual usage and reflections of ICT devices and their respective functionalities [34, 118] in their research.

While a branch of research on managing wandering behavior measures in long-term facilities, focuses on “non- or low-tech” measures in different categories, such as medication, environmental manipulation (e.g. camouflage of doors), or activity programs [74]. Other research works tend to support the field with more technical intervention [34].

While there are several research works on new ICT developments for the field, we believe there is still a lack of profound understanding of the current practices of wandering management. And more importantly, what are the intrinsic drive and hesitation of the facilities to create a specific strategy? Not only ICT artefacts incorporate value trade-offs, many other perspectives (e.g. ethical, legal et al.) are weighed against each other to finally consolidate a certain practice. We are especially motivated to verify these perspectives in a study that encompasses different measures and strategies used by care workers from non-, low- to high-tech solutions. By this we are trying to gain a deeper insight into the practical problems of care workers and the strategies they use to balance different value demands in their every-day work.

5.3 Methodological Approach

We have conducted 15 semi-structured interviews and 17 hours of participant observation in three different institutional settings; in care homes, a geriatric ward in a hospital and in assisted living arrangements for people with dementia. Professional

caregivers were care workers on wards, who work directly with those suffering from dementia and also with others in management positions. In addition, we use information of three interviews with relatives of institutionalized persons with dementia, two of them adult children and one wife.

The interviews, lasted from 1,5 to 2 hours, were recorded and transcribed. Field notes were taken during the participant observations. Data analysis largely followed the grounded theory methodology [113] and an analysis was conducted in several steps. We started with open coding, describing loose categories that came up in the interviews. Subsequently, the codes were then organized into higher-level categories. Some of the results of this process are the topics we will describe in this paper.

5.4 Understanding the Field

5.4.1 Constructional Measures

When new dementia care facilities are constructed, constructional measures are taken into consideration as much as possible. In Germany, the entrance for such “open wards” has to be open at all times according to legal regulations. This creates a great challenge for the organization, having to guarantee for the safety of patients with wandering tendencies. During the construction, many doors are intentionally installed in a way that requires much more effort to open them than normal doors. Some doors use opaque material, such as frosted glass, to avoid activities from outside “attracting” the patients inside.

Subsequently, the wards usually camouflage the exits and areas to which wandering patients should not have access. The exits or doors to the fire escapes, which are not to be locked, are sometimes covered with curtains. In one facility they have placed a screen in front of the door to hide it. These measures have received extremely mixed acceptance from the personnel. Supporters consider these measures to be a legitimate expedience without directly restricting the autonomy of the patients. Opposing opinions deem these measures as a detriment to human dignity, as the camouflage creates a false reality and takes advantage of a user group who are not able to tell the difference.

Creating “endless hallways” is another commonly used measure, which was found in a flat shared by sufferers of dementia that we visited. The hallway is built in a

circular form, around a shared activity area in the middle. This lets the patients to take walks through the hallway, but they never reach the exit. However, some interviewees criticized this new constructional principle. They called this measure inhuman, as the patients never see the beginning or the end of the hallway and can then be further confused.

5.4.2 Technical Installations

5.4.2.1 Video Camera

In one facility a video camera was installed on the ceiling of the lounge, which is also used as the dining room for the residents. Although the camera was installed when the building was newly constructed several months ago, it has not been used yet. The ambiguous legal issues need to be clarified before the camera can be put to use. During the past few months the facility management has been researching and negotiating with lawyers and the general staff do not expect a fast solution to this situation. In another nursing home with an affiliated dementia ward, video cameras are installed in the main entrance. The reasoning behind the installation is to provide more safety to the residence from unwanted strangers. As an open ward, there are no fixed visiting times; the relatives of the residents can visit the ward at any time in the day. This openness increases the worries and concerns of the residents about their safety, because suspicious looking strangers have been spotted in front of the main entrance several times. Since then the cameras have been installed, but the residents are still anxious. After receiving the consent of the inhabitants, additionally, the front door is now locked during the night. Feeling like they are doing something illegal, the manager refers to the agreement with the residents and that *“all elderly people would lock their front door at home in the night”*.

5.4.2.2 Door Safety System

Door safety systems can be found in many stationary facilities. We encountered several problems and uncertainties in knowledge of how these doors work.

In the dementia ward of an old people’s home, a sensor system was installed at the main entrance. Five residents wear a special wristband, when they pass the front door an alarm will show on the ward’s phone. However, the sensor is not connected to an alarm system. When we asked whether the ward needed a technical upgrade, the answer was no: *“if you wire up the whole house, it will be like a prison”*. The

major problem, as mentioned by the doorman, was the reliability on the system and its performance. It has happened more than once that the alarm was not triggered even though someone has passed through the front door. Another problem is the battery life: there is no battery indicator on the wristband; the only sign that it needs to be recharged is when it stops working. And the battery only lasts for 3 months if used by active residents, which is much shorter than what the director expected (2 years). Furthermore, the caregiving staff are facing a pragmatic problem: when an alarm appears on the phone display, it will only show “door open”, but does not display the name of the resident. From the alarm there is no clue who has left the ward, e.g. if a “fast” or a “slow” walker has left. This is not a situation caused by technical difficulties, but rather is due to the manager’s decision. He believes that making names transparent will damage the autonomy of the patients, thus an official certificate should be needed.

In a flat shared by dementia patients a specially designed door lock system is installed. To open the door one has to rotate the door knob and press a green button on the wall at the same time to keep an alarm from being triggered. From different care workers we got different answers as to which buttons have to be pushed to open the door. In the end we learned that this system was not activated at all and the staff was not aware of this. A large old people’s home embedded chips into the residents’ shoes. These chips are supposed to trigger an alarm when the residents go through certain exits. These chips are unobtrusive for the residents, as they are hidden in the shoes. One decisive factor for using them is that the caregivers have to make sure that the inhabitants have their shoes on. The caregiving staff has developed according routines to constantly check whether residents are wearing their shoes. Another factor for using the chips is that the system only gives an alert when the patient walks through the official doors and but it does not give an alert when emergency exits are used, which has happened several times.

5.4.2.3 Sensor Mat

In one facility a sensor mat is put in front of beds of patients with a risk of falling. This is used to inform the nurses that the patient has left the bed, especially in the night, so that the nurses can take care of them accordingly. We have discussed this topic with the manager of another facility, where we received a totally opposite attitude towards the sensor mats. The manager perceived the patient’s room to be his/her only private space in the facility. The patients are constantly being watched

when they leave their rooms, so he felt that they should have full freedom in their own rooms. Although we don't have explicit utterances from relatives about the use of sensor mats, we see a tendency of relatives to value safety measures over privacy concerns. This is often grounded in the overwhelming anxiety and excessive demands relatives feel when caring for their spouses/parents at home and which in many cases leads to the patients' transfer to a care home.

5.4.2.4 GPS Location Systems

In one facility the manager told the relatives to look for a "closed facility" as the care workers were not able to manage his heavy wandering behavior. As the sons and wife wanted him to stay, they proposed using a GPS locating system. The manager agreed on the basis that the family would be in charge of operating the system. In general, most facilities are reluctant to use such systems, as they fear litigation problems due to privacy issues: "*We do not know if this would be seen as a freedom-depriving measure*".

5.4.3 Human Strategies

5.4.3.1 Patient Photo for Searches

Normally, when a patient enters a facility for the first time a photo will be taken as a management requirement. In general, these photos have helped caregivers look for the patients that have wandered off. But as a photo is a privacy sensitive medium, how each facility handles patient photos varies considerably. In some facilities photos are a part of the patient record. The patient record can be printed out or sent by email to other caregivers so that they can use the photo to locate the wandering patient. One facility uses photos very cautiously, because of privacy concerns. Here the photos are only saved on the camera itself.

How much the doorman is allowed to access the patients' photos is also not the same among the interviewed facilities. On some wards it's standard measure to send a photo of the wandering patient to the doorman, so that he can easily recognize the patient if he passes by. But on wards where photos are only stored on the camera, it's forbidden to send a photo to the doorman because of privacy concerns.

5.4.3.2 Continuous Observation and Assessment

In many facilities, the caregivers said that they have to constantly keep an eye on the patients' activities and assess the situation. One geriatric hospital ward has a high fluctuation among hospitalized patients and some patient's wandering tendency are not yet known when they arrive. *“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. For example when they put their coat on or take off their pyjamas and put on outdoor clothes, or when they pack a suitcase and move towards the main exit. When this happens, we have to grab them and ask what their plan is.”*

In other “not so busy” facilities, the caregivers still face the big challenge of staying alert to patient's movements in the ward, especially when they are doing care routines in a room. Due to this, the doors are normally kept open, so that they can hear the movements in the hallway. In one facility, the nurses put a barrier in the hallway when they have to enter a patient room. If a patient wants to pass through, he has to move these barriers and the nurses will hear the noise and know what's happening in the hall. Commonly used barriers are e.g. the nursing cart used during the morning and evening rounds, or toilet chairs. This is a compromise for the nurses that they see somewhat ambiguously, because normally they try to have the floors empty so that the residents can walk safely. But they do not know how to solve this practical problem otherwise due to the low number of care workers in one shift.

5.4.3.3 Activity Intervention

For dementia patients, an important intrinsic driving force for wandering is the agitation and the urge to move. Accordingly, caregivers have developed measures to intentionally keep patients busy and distracted. Activities such as reading, chatting with each other, eating together, and going for walks together are the most common ones. In one facility they regularly dance together. Keeping the patients busy during the day also helps them sleep better at night, which reduces the danger of patients wandering off during the night.

5.4.3.4 Cross-area / Cross-ward Cooperation

In facilities with multiple wards or wards where the functions are separated into areas, patients with wandering tendencies are normally monitored collaboratively by care personnel from all wards/areas. *“Normally we call the neighbor stations: ‘XX*

will come to you shortly, can you help bring her back?’ This is how it works.”
“Here the care personnel from the ward opposite ours have always helped keep an eye on our patients. Everyone takes care, also the colleagues from other stations. Our two wanderers always take a walk between the wards, so everyone is involved in the monitoring.”

5.4.3.5 Cooperation with Relatives

The caregivers sometimes call the relatives for help when they feel a strong agitation or wandering urge from the patient, or when the patient has got lost. Talking to a relative on the phone usually helps the patient calm down. Relatives are also willing to involve themselves in the care of the patient when they visit the facility. Sometimes relatives expect the institution to guarantee 100% safety and that they prevent the resident from leaving the house. These strong safety concerns often stem from the relatives’ former experience of taking care of the patients at home and its excessive demands. This wish is in principle against the philosophy of patient-centered care, which supports wandering as a meaningful and soothing activity from the manager’s point of view. But such philosophy often puts a lot of pressure on the nurses who have to constantly balance principles of patient-centered care and risk management (to prevent harm) in their daily work with the residents.

5.5 Discussion

Dealing with wandering in dementia for care facilities is a challenging task. Care workers have to continuously look for a balance between their own and the patients’ risks. Their personal risk is in possible litigation aspects when offending the residents’ rights to autonomy – but they are also responsible of protecting the residents from any harm. However, litigation aspects are far from being clearly defined. That’s why there are attempts to define measures as „normal and usual“, such as the heavy doors or locking the front door at night which, from another point of view, could possibly be defined as a freedom depriving measures. Dahl et al. mention that new care culture and conceptualization of dementia, such as person-centered care [71], has been widely adopted in care facilities – but not in the public so far [34]. Actually, these new care philosophies are regarded as very important in all of the facilities in our sample. But for the care workers it is hard to implement the principles in their daily work. It becomes clear, that to a certain extent, risks are

socially and also culturally constructed [104] and are highly dependent on the organizational structure.

Those who work directly with the residents have to constantly make compromises to meet all requirements set up by different stakeholders, such as management, doctors, IT administration and relatives. The findings of this study thus have several implications for methodological and design related aspects. Our findings have shown that non- and low-tech supportive measures have received controversial reviews from different stakeholders; they also indicate that assistive technologies will almost certainly be controversially perceived. This means that the design process must be deeply grounded in the respective practices of each target group, which can be different even from house to house. Practice-based and participatory design methodologies should therefore be deployed. Linked to this methodological requirement is a need to open up a common discussion sphere for all stakeholders to make the situated and individual practical problems more visible and to find better compromises that serve the practice. The situated character of practical problems also hints at the need for design approaches to allow assistive systems to adapt to individual requirements, such as end-user development. This approach would also allow for future system adaption when discourses and requirements change over time.

5.6 Conclusion

Our study contributes to research on assistive technology for caregivers in long-term dementia care. Examining care workers' non- and low-tech strategies helps understand their concerns towards locating technologies against the background of their every-day practical problems and their needs to balance compromises in the management of wandering in dementia.

6 A HOLISTIC VIEW OF THE RESEARCH³

³ This chapter has been published as a paper in the 32nd annual ACM conference on Human factors in computing systems (CHI), 2014: *Lin Wan, Claudia Müller, Volker Wulf, and David Randall. 2014. Addressing the subtleties in dementia care: pre-study & evaluation of a GPS monitoring system. In Proceedings of the 32nd annual ACM conference on Human factors in computing systems - CHI '14. New York, New York, USA: ACM Press, 3987–3996.*

ABSTRACT

In this work we present a user-centered development process for a GPS-based monitoring system to be used in dementia care. Our research covers a full design process including a qualitative-empirical pre-study, the prototyping process and the investigation of long-term appropriation processes of the stable prototypes in three different practice environments. Specifically, we deal with the problem of ‘wandering’ by persons suffering from late-phase dementia. Although GPS tracking is not a novel technological objective, the usage of those systems in dementia care remains very low. The paper therefore takes a socio-technical stance on development and appropriation of GPS technology in dementia care and assesses the practical and ideological issues surrounding care to understand why. We additionally provide design research in two different settings, familial and institutional care, and report on the design of a GPS-based tracking system reflecting these considerations. What comes to the fore is the need for ICT to reflect complex organizational, ideological and practical issues that form part of a moral universe where sensitivity is crucial.

6.1 Introduction

Recent research work on ICT for dementia care has demonstrated the 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 [33, 34, 103]. The literature demonstrates a picture of the dual nature of surveillance [45], which in the field of dementia care produces value conflicts of awareness against privacy and safety against autonomy [76, 75]. Other authors provide a more nuanced picture on the basis of qualitative research results, such as [33], 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 in theory gives a balance between preserving the autonomy and protecting the safety for them. However, in a first trial of global positioning system (GPS) technology to locate missing persons, Miskelly [86] (though validating the accuracy and performance of the system) found that 5 out of the 11 respondents dropped out of the test. 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 [103]. Our study shows that the take-up of such technologies in this complicated context has been underwhelming, both by familial carers and by institutions.

Brodaty et al. [19] show low take-up in general by caregivers of available services. 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 study of qualitative work which leads to designs of a tracking system for late-phase dementia care, including: 1.) the pre-phase of qualitative investigation into the practices of professional and familial caregivers of sufferers from dementia 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.

Our contributions to the field include: 1.) a more fine-grained understanding of attitudes and practices in GPS-based wandering management in familial and institutional care. 2.) a better understanding of the sheer complexity of the different situations which occasion concern, the heterogeneous nature of organizational and family routines, and the nuances of moral/ideological commitments expressed by different parties, and 3.) Implications for successful assistive technology in such sensitive contexts which include but go beyond technology itself.

6.2 Related Work

There is a general move in studies of healthcare technologies to move towards understanding of sociotechnical problems [10, 47, 69]. Themes in the area of home-based healthcare, for instance, evolve around the communication & cooperation needs of various stakeholders in chronic illness treatment [81, 95, 96, 101].

Research has demonstrated that values and attitudes of each stakeholder play an important role in appropriation and usage of ICT [26].

Other research stresses the social side of healthcare, e.g. research into support for social interaction and the sense of belonging for the elderly [53, 68, 121, 122]. 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 [1, 28, 93, 127] and monitoring [37, 89, 98].

The 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 [33, 56, 76, 75, 92, 103, 118]. 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 [34] and to a claim for more long-term evaluations of developed prototypes in general [47].

While some research alludes to the insufficient acceptance of tracking devices in dementia care [8], 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. [30] 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. 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 [34]. Value sensitive design [51], 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. [103] aim at supporting independent living and involving early-onset dementia patients in the design process. We, however, are dealing with late-stage dementia and frequently in an institutional care setting. The methodological challenges of the two are very different. 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-oriented design research framework of Wulf et al. [131]. Under this framework we approach our research in three phases: 1. Pre-study: empirically analyzing actual practice in specific application context; 2. Development: designing ICT artefacts based on the findings of phase one; 3. Evaluation: examining the appropriation of the technical artefact over a significant period of time. Our work, then, focuses on presenting a whole design process that includes building, deploying and evaluating a system over a long period of time as recommended by Fitzpatrick and Ellingsen [47].

6.3 Pre-Study: Exploring the Field

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.

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 user 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.

6.4 Pre-Study: Findings

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

6.4.1.1 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.

6.4.1.2 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.

6.4.1.3 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.

6.4.1.4 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.

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

6.4.2.1 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).

6.4.2.2 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.

6.4.2.3 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.

6.4.3 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 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.

6.5 Prototype Development

Actual development of the prototype was the responsibility of a software company who formed part of the project 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.

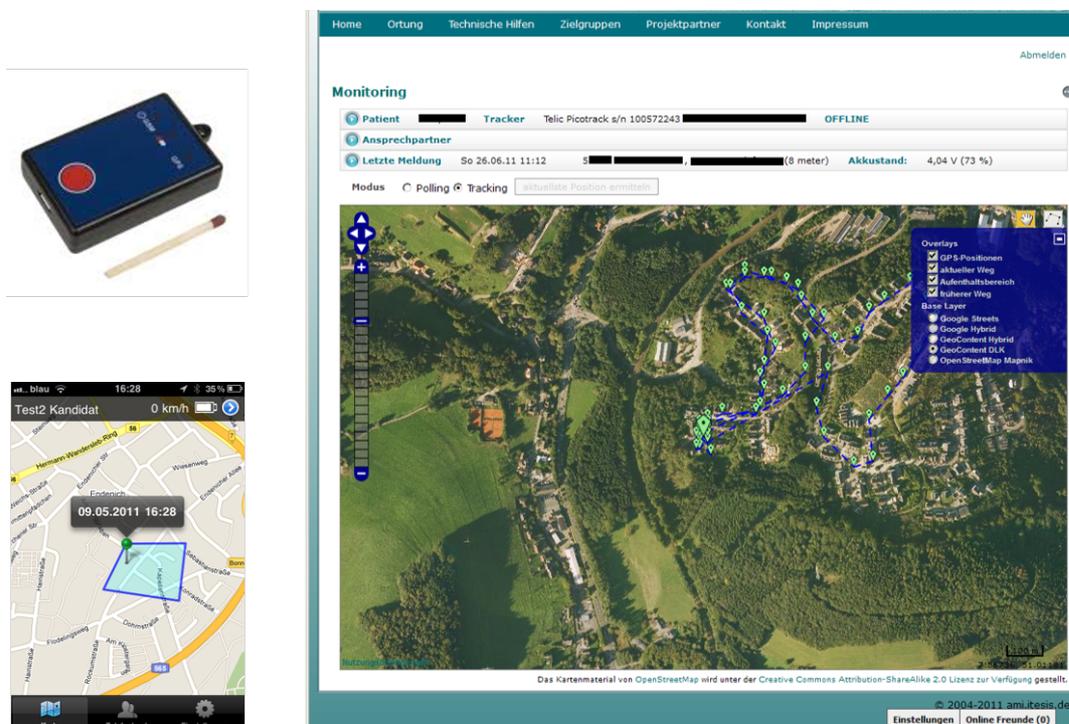


Figure 2. Screenshots of the prototype

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. 2).

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.

6.6 Evaluation: Long-term Field Test

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 serious prototype testing.

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.

6.7 Evaluation: Findings

6.7.1 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.

6.7.2 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.”*

6.7.3 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. Since then 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.

6.7.4 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.

6.7.5 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 artefact 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). (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.

6.8 Discussion & Conclusion

Overall, we are confident that our proposed solutions have a positive effect on the experiences of dementia sufferers, their families and professional caregivers. 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. Tracker design, as one feature of this, is important. And variable shapes, due to the individual preferences and habits of the patient.

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. Solutions, we suggest, are better fitted to selective management of situations rather than to constant monitoring for those reasons.

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.” [105]

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 [33, 34] we see that new care philosophies, such as Person Centered Care [71], are being used in many care institutions. However, the related practices are not clear-cut. Therefore we do – slightly different as [115] 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. It is our view that agile development processes are much more suitable for environments of this kind. 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 [7, 127] and our inability to customize the tracker to cope with ‘indoor’ situations limited perceived value.

In conclusion, we set out to contribute to a better understanding of the subtleties and complexities in familial and institutional dementia of sufferers with wandering tendencies. With a full description of a design case study (investigative pre-study, design & long-term evaluation) we have established, we feel, a fine-grained basis for understanding of how lines of conflicts may occur and how a suitably flexible GPS locating system can aid in their resolution. It is clear to us that technology does not provide a full assistive solution.

Besides technological features, a planned market roll-out requires detailed consideration of support for installation, education, legal matters, after-sales service (counselling, 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. We believe that fixed contact persons with some knowledge of local conditions might better facilitate communication in this challenging context. Finally, the heterogeneity of caregiving contexts means assistive solutions 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.

7 GOING BEYOND RESEARCH: DESIGN PROCESS TAKEN AS A WHOLE⁴

⁴ This chapter has been published as a journal paper in the ACM Transactions on Computer-Human Interaction (TOCHI), 2016: *Lin Wan, Claudia Müller, David Randall, and Volker Wulf. 2016. Design of a GPS Monitoring System for Dementia Care and its Challenges in Academia-Industry Project. In ACM Transactions on Computer-Human Interaction (TOCHI), Vol. 23, Issue 5, Pages 1-36.*

ABSTRACT

We present a user-centered development process for a GPS monitoring system to be used in dementia care to support care for persons with wandering behavior. The usage of GPS systems in dementia care is still very low. The paper takes a socio-technical stance on development and appropriation of GPS technology in dementia care and assesses the practical and ideological issues surrounding care to understand why. The results include: 1) Results from qualitative user studies from which design ideas, implications and requirements for design and redesign were developed. 2) Description of the politics, negotiations, and challenges encountered in the project at hand. These processual matters had a powerful impact on the product that was finally envisaged. The design process was taken as a whole to illuminate the way in which design outcomes are arrived at and to foster discussion about how ‘best practice’ might possibly be achieved.

7.1 Introduction

In Germany there are more than a million people suffering from dementia. Every year more than 250,000 new cases occur. According to one calculation, this number will climb to 2.3 million by the year 2050 [13]. Worldwide, the prevalence of dementia sufferers was estimated at 35.6 million in the year 2009. The projected number of sufferers for the year 2050 will be 115.4 million [3]. Typical symptoms of dementia are progressive memory loss, disorientation in time, loss of spatial orientation, and progressive loss of one’s own personality. The loss of spatial orientation and memory ability means that people with dementia have a significantly greater risk of getting lost [84]. Such situations cause anxiety and even more disorientation, which can lead to life-threatening circumstances [48]. For caregivers as well, this wandering behavior may cause overwhelming stress since dementia patients often need constant company. With the progression of the disease, persons with dementia will become increasingly dependent on help and support. The majority of patients, about 75%, live in the home environment, with the support of family and care services. Approximately 25% live in nursing homes [4].

Dementia patients, as direct sufferers of the disease, are under the spotlight in most research studies dealing with this issue. Nevertheless, family caregivers and relatives also deserve special attention, as they are exposed to high psychosocial and

physical demand. This is especially the case since they themselves are often elderly and suffering from other ailments. A study shows that in the US, the average age of family caregivers is 48 and 51% of them are over age 50 [2]. The physical and psychological stress of both parties can often, in addition, lead to social problems. Research has tended to emphasize medicinal and socio-therapeutic approaches which aim primarily at maintaining independence and vitality of life. This includes support for orientation and safety and the alleviation of co-morbidities such as depression or behavioral change. Recent research work on ICT for dementia care has demonstrated how successful embedding of technology in everyday practices implicates a set of value judgments and attitudes about how best to take care of, and make decisions for, another person [33, 34, 103]. One of the ways in which this plays out is in concern over surveillance [45], which in the field of dementia care has led to consideration of value conflicts such as awareness against privacy and safety against autonomy [75, 76]. Other authors provide a more nuanced picture on the basis of qualitative research results, such as [33], who point at the multi-faceted nature of stakeholders' views on the dilemmas of GPS tracking of patients in professional dementia care. In this paper, we expand on these dilemmas through consideration of different aspects of a GPS-based monitoring measure which we link to distinctive and heterogeneous values that range across settings and roles in both professional contexts and elsewhere.

For clinical diagnosis and therapeutic treatment purposes, different schemes exist which divide the progressive disease into phases. One such international scheme is the Clinical Dementia Rating (CDR) [88]. Phases described are “None”, “questionable”, “mild impairment”, “moderate impairment”, and “severe impairment”. The phases describe the change in the following parameters: memory, orientation, judgment and problem solving, community affairs, home and hobbies and personal affairs.

For dementia sufferers, a tracking system in theory gives a balance between preserving autonomy and protecting safety. However, in a first trial of global positioning system (GPS) technology to locate missing persons, Miskelly [86] (though validating the accuracy and performance of the system) found that 5 out of the 11 respondents dropped out of the test. 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 [103]. Our study shows that the take-up of such technologies in this complicated context has been underwhelming, both by familial caregivers and by institutions. Further, and as we will show, if take-up is limited by experiences of a 'gap' between expectation and reality on the part of caregivers, it is also limited by similar problems with heterogeneous expectations in the design process itself.

Brodaty et al. (2005) showed that caregivers' acceptance of available services is low [19]. Reasons, they suggested, were perceived lack of need and lack of knowledge of related services. The stigma attached to dementia was another reason why many caregivers would not seek assistance. The low uptake of technological aids in dementia care points to the need for 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 we aim to detail this.

This paper reports on a federally funded research project in Germany which aims at design and development of a GPS monitoring system for caregivers of late-phase dementia patients with wandering behavior (mild to moderate impairment). The project consisted of two interdisciplinary partners from industry and academia. It was conducted in the following phases: 1.) a pre-phase of qualitative investigation into the practices of professional and familial caregivers of sufferers from dementia 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 design case study approach advocated by Wulf et al. [131]. It is motivated by a core assumption, that the 'practice turn' in HCI and elsewhere will provide valuable insights into the design and appropriation of computer artefacts. Research in the field of practice-based design [73, 131] calls for attention to the practices of users, of researchers, and of the ways in which they interact. In particular, it considers overall project activities in a broader and dynamic sense rather than the so-called 'clean' design studies which simply reporting on the results of research & development projects. This 'practice turn' in HCI, then, is based on the assumption that all the activities of organizational actors, as well as those they study, in a cooperative project might contribute to the formulation of design goals,

and that the process of investigation needs to be looked at as a set of practices right from the start. There are relatively few examples which demonstrate how the practices of users and the practices of research participants at an organizational level are mutually elaborative in the evolution of a design solution. Specifically, we focus on the potential benefits which may accrue from attention to user practices, and the more problematic issues which may arise when industry and academia collaborate. Such a meta-perspective, we suggest, has seldom been offered in the context of healthcare. This is surprising given that, in the context of Germany and the wider EU, research projects have to conform to certain framing assumptions governing the pairing of research institutes and industry. We argue that, while such collaborations offer considerable potential in relation to the melding of heterogeneous experiences and expertise, they also require careful handling in respect to issues we discuss below. In this paper, then, we show the very complex way in which the field of dementia research is inflected by a series of social, technical and organizational issues which, taken together, may explain why there are relatively few examples of successful large-scale research projects in the history of dementia research literature [47].

Our contributions to the field include:

- A fine-grained understanding of attitudes and practices in GPS-based wandering management in familial and institutional care.
- A better understanding of the sheer complexity of the different situations which raise concern, the heterogeneous nature of organizational and family routines, and the nuances of moral/ideological commitments expressed by different parties.
- Implications for successful assistive technology in such sensitive contexts which include, but go beyond, technology itself.
- Opening up discussion about parameters which may influence successful large-scale research projects in this field.

The paper is structured in the following way. In section 2 we review the related literature. Section 3 provides background information about the project setup and our methodological approach when carrying out the project. In section 4 we describe the first phase of the work: pre-study, including empirical results from the field and meta results of the cooperation process with the project partner. In section 5, design

implications based on the pre-study results are presented and following that, the prototype is described. Section 6 reports on the empirical results of the long-term field evaluation and the corresponding project management reflections on the cooperation process. In section 7, the paper ends with discussion and conclusion on both lines of results: dementia management and project management.

7.2 Literature Review

7.2.1 Healthcare in General

Growing awareness of the demographic shift towards an older population has led to a blossoming of technological development to support healthcare for that group. A large body of work in the field of healthcare has been produced in recent years. Such studies have contributed to our understanding of how healthcare is collaboratively achieved, and to the design of assistive technologies to support this work. Designing assistive technology for healthcare involves subtle yet complex challenges which normally requires comprehensive requirement analysis and tailored methodology [47]. Research under the broad auspices of HCI/CSCW has spanned a wide spectrum of contexts, from professional care centers, e.g. hospitals, to the supporting of individuals suffering from chronic diseases at their homes. ICT development for institutional care has explicitly concerned itself with issues of the coordination of workflow tasks in complex settings like hospitals, as with the introduction of Electronic Patient Record (EPR) [57, 16]. In home context, research has focused more on empowering people so that they can live at home as long as possible (Ageing in Place). Such work increasingly focuses on supporting social interaction and the sense of belonging for the elderly [53, 68, 121, 122] so that older people can continue living, as much as possible, independently even in circumstances where they are experiencing cognitive and/or physical decline.

Recent studies relating to healthcare technology have progressively recognized the that the design, use and management of such technology is a sociotechnical issue [10, 47, 69]. For home-based healthcare, for instance, themes evolve around the communication and cooperation needs of various stakeholders in chronic illness treatment [81, 95, 96, 101]. It has been shown that the values and attitudes of each stakeholder play an important role in appropriation and usage of ICT [26]. Other research work 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 [1, 28, 93, 127] and monitoring [37, 89, 98]. [116] review HCI approaches to assisted navigation and wayfinding support and assess projects aimed at support for outdoor as well as indoor navigation support. Their review comprises different user groups, including not only the elderly but also other age groups suffering from chronic illnesses and cognitive disabilities. [28] argue that, predicated on their user studies, that care for an elderly person is made up of “*uneven distribution of responsibility, miscommunication, misunderstanding, distrust, unmet care needs, and negative impact on the careers and personal needs of the individuals involved*” (p. 22). They describe several usage scenarios for computer-supported coordinated care, but also pinpoint the need for deeper empirical investigation of care circumstances to be able to fully meet the needs by technology.

7.2.2 Dementia Care

In the area of dementia care, a review of commercially available and emerging assistive technologies has shown that most of the technologies were developed for a relatively young population with non-progressive traumatic brain injuries, and that technologies specifically designed for neurodegenerative dementia are actually scarce [12]. [100] have shown that, for early-stage conditions with ‘relatively low’ wandering behavior, GPS-based technology support provides benefits to familial caregivers and the care receivers. However, they also discuss some problems to be further analyzed, such as the interrelation of technical savviness, willingness to adopt a technological system and level of education. Memory-aid technology thus is an important theme for patients whose condition is mild to stable, but it cannot be assumed that design solutions appropriate to that group are also appropriate for people suffering from more progressive or late stage cognitive failures. Systems on offer also include prompting systems such as those to help cognitive disability sufferers carry out everyday tasks that they would not be able to achieve themselves [22], or reminiscence systems for either therapy or providing memory cues [56, 78]. Recognizing the varied nature of the problem, [115] have summarized a technology roadmap for dementia care within Japan.

Wandering is a prevalent behavior of dementia patients. Various strategies have been implemented to intervene in this behavior, such as pharmacological

intervention, behavioral therapy, music therapy, and construction modification. Mobility detection has been already early described as a valuable application for the care domain [110]. Electronic tracking systems enable real-time locating of the patient, thus allowing caregivers to manage crisis situations and reduce anxiety and psychological burden. But, these monitoring technologies do raise serious ethical considerations surrounding the dilemma between safety and autonomy, privacy and awareness. Robinson et al., for instance, have explored the perspectives of different stakeholders on the conflict between prevention of harm and patient's autonomy in the management of wandering in dementia. This study shows that the professional caregivers tended to prioritize safety, while familial caregivers focused more on preserving the autonomy of patients and their quality of life [103]. In Landau et al.'s two related studies, the authors examined the attitudes of professional and family caregivers towards location tracking of persons with dementia, and addressed the issue of who should decide whether a tracking device should be used [75, 76]. Müller et al. focused on the core dilemmas of "safety vs. autonomy" in GPS tracking for persons with dementia and how these were reflected in the care practice in both professional and family situations [92]. Dahl and Holbø similarly addressed the issue of "privacy vs. awareness" with professional stakeholders in the use of GPS tracking for management of wandering and found that the level of details required is intimately linked to the purpose of use and should be carefully balanced [33]. This has further led some researchers to reflect on appropriate research methods, such as the testing of off-the-shelf technologies in real circumstances [34] and to a claim for more long-term evaluation of prototypes in general [47]. Some studies have involved dementia patients in the design process, for gathering precise user requirements [103, 61]. This has been proven to be successful with mild to moderate dementia patients.

In the commercial sector, a handful of available products/services are available. They offer different services, such as a full service support (for a monthly fee [e.g. www.buddy.co.uk]), or simply a tracking device to be used with a mobile or smartphone [e.g. www.trackyour.co.uk]. Others address the knowledge gap associated with many potential users and provide comprehensive learning materials [such as, e.g. www.projectlifesaver.org]. In regard to user acceptance, the solutions provide different devices, such as wristbands or small tracking devices to put in a

pocket [such as the named firms], others provide trackers in shoes [e.g. www.gpssmartsole.com], to increase acceptance of the technology.

While some research alludes to the insufficient acceptance of tracking devices in dementia care [19, 8], we still 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 that compared practices to be found in different care settings and the moral and ideological world they inhabit. A contribution of this study, then, is to show that the differences to be found in different contexts are sometimes striking, and have a direct impact on willingness to deploy technology.

7.2.3 Research Methods in Sensitive Settings

Because of the richly situated, continuously evolving, and collaborative nature of healthcare, studies of this kind in the field of HCI or CSCW often are carried out with qualitative methods. [109] point at the importance of reflecting deployment processes in HCI from a holistic stance, which in the research field at hand is of special relevance. In the case of dementia care – an example of the ‘sensitive setting’ that Crabtree et al. [30] 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 [30]. 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? Studies on this topic exist but are far from sufficient for us to fully understand the current situation [77].

Involving users in the design process is a common practice, associated with “participatory design” [90] and other similar conceptions in HCI/CSCW. However, the specifics of the involvement of elderly persons – and in our research –both those suffering from dementia and their caregivers, who often have little exposure to information and communication technology have only been rarely dealt with so far [94]. Robinson et al., for instance, aim at supporting independent living and involving early-onset dementia patients in the design process [103]. 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 otherwise be unheard [34]. Relevant here would be the notion of value sensitive design [51] as an information system design methodology which emphasizes how values play out in design, and how balancing competing values in various situations plays an important role. This is made more complex by the fact that definitions of key values like autonomy, privacy, or security are highly situated, and are understood differently depending on different contexts or care philosophy [126].

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-oriented design research framework of [131]. Under this framework we approach our research in three phases: 1. Pre-study: empirically analyzing actual practice in specific application context; 2. Development: designing ICT artefacts based on the findings of phase one; 3. Evaluation: examining the appropriation of the technical artefact over a significant period of time [111]. We should perhaps point out here that evaluation here does not refer only to the traditional HCI concerns with robustness, reliability and the user interface but also to the processes by which users do or do not begin to appropriate artefacts in real life circumstances. It is, then, in keeping with the ‘situated evaluation’ perspective described by Twidale et al [119]. Our work, then, focuses on presenting a whole design process that includes building, deploying and evaluating a system over a long period of time as recommended by [47].

7.2.4 Gap in the State-of-the-art

Thus far, we have discussed the existing literature dealing with cognitive impairment on the part of older people, and pointed to the relative paucity of research which deals with interventions in the case of late stage development. We have shown how the literature nevertheless has situated concerns in a sociotechnical universe, increasingly recognizing the related moral and practical issues in the usage of information technology in the context of cognitive impairment. We wish to open up this space further by also reflecting on the process of technology design itself. It is evident that the design of a technology to be used in such challenging moral universes is also strongly influenced by approaches and constraints of the project in which development work is being conducted. Project ethnographies, e.g. from [20] or [97] demonstrate that design of technology is a social process which brings

together professional actors from different backgrounds in a design team (industrial/academia; engineering/social science, etc.) as well as professionals and end-users of the application areas into a common design space of negotiations, specifications, decision discourses and handling of project constraints [20].

Here, we do not attempt to deliver a fully-fledged project ethnography of our design project, but want to examine, at least in outline, the development steps taken and the way in which decision making and negotiation landmarks of the project team moulded design outcomes. This is important because there exist a variety of attitudes and approaches in thinking about a potential technical solution for wanderers in the minds of the designers and engineers as much as in the universe of caregivers. There exist specific beliefs and visions which are shaped by a number of factors, not least how the project has been initially set up. It is our aim to display these manifold interdependencies and how they impact on progress.

There is, of course, no shortage of methodological deliberation in HCI aimed at better involvement of future users, and at recognizing the interests of the full range of possible stakeholders. These include, for obvious mention, PD methods [58, 23, 70]. Even so, a perspective on reconciling the interests of stakeholders in a cooperative project such as the one we discuss has not been extensively worked out. For instance, the emergence of dissonant understandings between diverse stakeholders across academic and commercial backgrounds is more or less foreseeable during project progress due to the different attitudes and goals every project partner brings [32]. Outcomes are seldom wholly clear in advance [32] and partners need to continually negotiate the further progress of the project in order to meet all the different expectations [14, 20, 83]. While the literature attests to the differences between diverse interests, however, we still know little about the concrete decision and negotiation processes during a project's lifetime. Stakeholder management literature provides solutions either from a top-down managerial view [35, 87], in a more process- and tool-oriented stance [136], or in non-participatory approaches [102]. For HCI design research, however, we would suggest that these approaches are not entirely suitable. The knowledge of the different stakeholders involved, the social fabric they inhabit as well as the varied practices that may determine use (or otherwise) will surely shape the consideration of what might turn out to be usable and useful technology. Such knowledge is not given to any particular group within the design process and, just as importantly, how best to

interpret the significance of such knowledge will always be negotiable. The argument for practice-oriented HCI research [73, 131] which recognizes stakeholder interests and performances and how related decisions impact on the final design product has, as yet, produced only a few papers with explicit insights into the social and organizational production of a design outcome [20, 32, 91].

7.3 Project Settings & Research Methodology

7.3.1 Background Information about the Project

The activities we report on in this study are part of a two-year publicly funded interdisciplinary research & development project with the aim of developing a GPS-based monitoring system for caregivers to enable them to cope with the wandering behavior of dementia patients. The project had the philosophy of developing a “passive monitoring” solution for late-stage dementia sufferers, which means that the technology was supposed to be non-obtrusive for patients. The intended user group covers both familial and professional caregivers, and therefore research was conducted in both home and institutional care contexts.

The project consortium consisted of two parties: 1). *DEVLEAD*: an SME (Small and Medium Enterprise) with a software development background, and 2). *UNI*: a university research group with considerable experience in the HCI research field, namely “us” in the context of this paper. The project responsibilities were distributed between both partners in the following way: *DEVLEAD* was the main developer of the system, and *UNI* was responsible for the participatory design processes with end-users during the three design phases. In the next chapter we will elaborate in more detail how cooperation and communication processes evolved during the different project stages.

7.3.2 Methodology in User Study

The pre-study was always intended to be exploratory and used, broadly speaking, a grounded theory-based approach (GTM) [113]. GTM remains controversial insofar as there are disagreements as to what its commitments entail and what its achievements might be (see for instance [117]). Here, we follow the usual initial strategy in GTM to sample for diversity (e.g., [29]), and thus set out to look for interview partners and observation opportunities in contexts of both domestic care

by relatives as well as institutional care in different forms. The results we describe below constitute open coding only, and we have made no attempt to move beyond that.

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 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.

Our ambition initially was to include patients in every context where our field study took place. In all environments we tried to interview patients, but this turned out to be extremely difficult. Severe problems in care at home for persons in mild to moderate – and later severe – stages most often led to the admission of the persons into institutional care homes. Statistics show that, as of 2013, 40% of those with late-stage Alzheimer’s disease live at home, while 60% live in healthcare establishments [39]. In most of our cases, despite our best efforts, we had to work with caregivers, both informal and institutional, to identify with them what the patients would see as appropriate for them in ideologically charged contexts. The same is true for the later evaluation phase in two care homes and a family. In the family, while the husband suffering from dementia participated in every chat and interview, there were evident problems with the depth of his understanding. Unlike Robinson et al. [103], our specific context (late stage, frequently takes place in institutional care) faces very different methodological challenges. We did, nevertheless, manage to invite and have some of the patients present in the interviews and at the workshops together with the caregivers.

Altogether, 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 institutional care

facilities. Each interview lasted about 2 hours. All the interviews were audio recorded with user 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 unclear or ambivalent issues. This has helped minimize diverse interpretations between individual team members.

Based on the results of the pre-study, we held regular meetings with the project partner to outline and discuss design ideas. We also 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 mock-ups 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 enrol 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 significantly harder to find participants for the field evaluation than for the pre-study. The reasons are manifold. 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. The institutions were also very cautious in relation to testing, because of the possible philosophical or legal ramifications associated with technology failure. Furthermore, 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 enrol 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 chapter 7.6.

7.4 First Phase of Design Case Study: Pre-Study

7.4.1 Initial Setup of the Project

The project was conducted in the context of a federally funded two-year industry-academia project in Germany. An SME (*DEVLEAD*) that had previously developed location-based solutions for other application fields (e.g. logistics) initiated the proposal and invited the research group (*UNI*) to submit a joint application for the research grant. The funding scheme had a special focus: research co-funded to support small and medium enterprises in the development of prototypes that would eventually evolve into a marketable product. This funding call required each partner to submit its own part-project proposal and to include its own work plan. All part-projects, it was intended, should work as a whole to achieve the ultimate goal of the joint project. *DEVLEAD* came up with a first draft of its proposal and work plan, which entailed fundamental design decisions (e.g. developing a web interface as frontend UI) and defined the technical development in details. *UNI* was invited to form the consortium. The role of the research group was to add a user-oriented design approach and to validate the practical usefulness of the system by means of user research. The division of project responsibilities was decided with only minor negotiation. It was mainly based on both partners' available resources, different expertise and interests. *DEVLEAD* was responsible solely for the technical development. *UNI* was responsible for work with the users, conducting field studies, delivering user requirements, and in the later stage, testing the prototype in the field

and collecting user feedback. There was, then, right from the start, a clear separation of technical development and user study here, which led, as we discuss below, to difficulties in transferring requirements between the research group and the industrial partner.

We (*UNI*) as researchers had a clear commitment to an exploratory approach associated, as we have intimated, with grounded theory. We began by reviewing the HCI/CSCW literature as well as that of care science and gerontology. We undertook several activities to get in contact with care facilities and families affected. “Door-openers” such as counselors in dementia care and managers of care associations, for example, were the very first contacts that we established. Given a general skepticism towards technical solutions in this context, they were immensely valuable in introducing us to families and care institutions. Finally, after several months, we managed to finish the pre-study with 21 semi-structured interviews and several hours of on-site observation at different locations (private families as well as care homes). We had the chance to talk to people with different roles and backgrounds in dementia care as well as different kinds of family members of persons with dementia.

The engineers from *DEVLEAD* and the researchers from *UNI* held regular meetings every 4 weeks to communicate the latest pre-study results. We (*UNI*) had gathered a large amount of data during the pre-study, and analyzing it would obviously take some time. To keep *DEVLEAD* updated with the progress of the data analysis, the researchers reported on interesting and surprising new insights from the data material (with quotes from the interview transcripts to support the statements) in the form of slides during these sessions. The engineers from *DEVLEAD* showed great interest to the reports, but expressed a preference of clearly defined requirements which could be easily converted to specific development tasks to begin with. The researchers, in the meantime, felt themselves to be constantly suffering from the “Cassandra Syndrome” [79] during the cooperation: the empirical results were perceived as interesting, but doubt was sometimes cast at the same time. One of *DEVLEAD*'s engineers had an elderly relative with dementia at home, and our results were sometimes compared side-by-side with his own care experience. If a result differed from his experience, it was often doubted or objected to. There was a further divergence on the scope of the samples. *DEVLEAD* repeatedly expressed the

view that the number of households/institutions being interviewed was too small for reliable insights and results. Any initial difficulty, then, can be summed as being associated with substantially different epistemological positions.

7.4.2 Empirical Results of the Pre-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.

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

7.4.2.1.1 *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 and biased power distribution in this bilateral selection. Most obviously, it is extremely difficult for families to find a suitable institution for the dementia patient with existing wandering tendencies.

The first issue families have to consider when prioritizing their choices is the distance of the institution from their home. Then relatives are confronted with different care concepts for the ‘wanderers’. Their initial choice pool, that is, rapidly diminishes.

One institution, for instance, noted that they would not accept wandering clients: “*We do not house persons with dementia who wander because we cannot take the responsibility for them*” (care home manager, m.). 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 often have this discussion with the relatives who wish that we take a*

full responsibility for persons who wander. But I always tell them, that we cannot lock the people here because we are an open house” (care home manager, f.). They argued that the doors are open and the inhabitants can leave the house at will. Having said that, some houses 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: *“See for example the new architecture: these round and never-ending floors. This is awful, you never come to an end. We also do not want to hide the doors behind curtains, as some houses do. This is against human dignity.”* (ward nurse, f.).

7.4.2.1.2 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. These are fixed in the German Civil Code (§1906) and are constantly referred to by the care home staff in all interviews. Professionals 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 three 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 allows the patient take walks along the hallway without ever reaching an exit point. 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 been) applied in our samples: video cameras, door safety systems, and sensor mats. The professional caregivers’ attitudes towards monitoring technology are more consistent and are best characterized as a ‘general reluctance’. Their reluctance stemmed from the following concerns: 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 refers to 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*” (ward nurse, f.). 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.

7.4.2.1.3 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 him or her. 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 include the way home, or a personal 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. pretending that "*your daughter has just called. Please come back with me to the house and then you can talk to her on the phone*" (ward nurse, f.). 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 considerable personal understanding of the individual patient so that one can apply such words and phrases appropriately in a challenging situation.

7.4.2.1.4 Attitudes towards GPS monitoring system

None of the institutions we interviewed used a GPS tracking system to monitor patients, however, all managers of the homes were interested to learn from us about possibilities. 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 technologically 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.

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

7.4.2.2.1 Autonomy vs Safety: Two cases

The analysis of the interviews with family carers – husbands, wives, sons and daughters – offers very different perspectives on the evaluation and understanding of the autonomy and freedom needs of the affected family member. The difference can be significant. To illustrate this, we report on two contrasting cases from our empirical investigation. 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 would not allow her to be alone to be on another floor:

“I am feeling safer when she is by my side. I would not allow her to be alone in the first floor, I always want to see where she is and what she is doing. This is because I have experienced several times that she walked off the house – it was a horrible experience for me to look for her with the police and help of neighbors. You cannot imagine how frightening this is. You have all these scenarios in mind, that she might run into a car or lie somewhere in the woods.”

In the interview, he reports that the care situation is for him an overwhelming burden, and how he handles the every-day life of the couple: Being a retired engineer, he developed coping mechanisms for himself to be able to care for his wife at home: he 'engineered' her eating-, sleeping- and bathroom times with medication. For him, the measures which help to maintain the routines of every-day life are more important than autonomy issues: *“I do not see a problem in installing all these measures because my wife is not mentally here anymore. It is only her body.”*

In contrast, the key value of a daughter of a woman with medium-stage dementia, which is basis for all her care-related decisions, is to 'keep her mother's face'. For that reason, she has installed several measures for preserving her mother's life world as far as possible. She has built up a social network of relatives and friends who live locally 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. The members of the network all keep an eye on the lady and call the daughter to inform her when the elderly lady is on her way to the city center and has passed their houses.

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 only up to a certain point. 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:

“I go and clean her house when she leaves for a walk to the city and when she comes back, she proudly pretends that she has cleaned everything herself. She even talks to the neighbors like this. I let her retain this belief,

because for me it is important that she has the feeling of mastery and independence. Even if it is sometimes hard for me to manage this all."

This was an extreme, but illustrative, example of the way the moral universe is constructed, decisions are being taken by familial caregivers, and the value trade-off between safety and autonomy is achieved in a nuanced and contextual manner.

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 family member who acts as a caregiver. So for many relatives, 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).

7.4.2.2 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, of balancing gender roles, and children-parent relationships. 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: "*When he is on his walks, we are in permanent sorrow, but we cannot hold him*" (daughter, 25). 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 his wife, his pre-existing and continuing dominance in the family had actually 'helped' him manage his wife's life with less resistance. In the example above, the daughter who tried to keep 'normality' in her mother's life as much as possible told us that her mother had always been a dominant person. Her care activities were evidently aimed at some preservation of the former mother-daughter relationship.

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.

7.4.2.2.3 *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 well as their general affinity to information and communication technologies and the internet.

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

7.5 Second Phase of Design Case Study: Design Implications & Development

7.5.1 Design Implications and Strategy Steering

DEVLEAD had a clear vision of the prototype development from the beginning: a web interface as the frontend to manage the tracker and monitor real time positions, and its associated server backend. *DEVLEAD* created a spreadsheet of system requirements together with priorities based on the project proposal and their experience at the beginning of the project, and then invited *UNI* to collaborate on it. *UNI* complemented, and commented on, the list with preliminary results from the (still ongoing) pre-study. We stressed that the requirements and priorities were subject to change as the project proceeded, especially when the prototype is tested in the wild. This shared document then became the communication artefact for both partners to exchange opinions and prioritizations of the listed requirements. In follow-up consortium workshops *UNI* and *DEVLEAD* met and discussed on the list

and especially the priorities of each requirement. There was, even so, a noticeable discrepancy between both partners' priorities on many of the features. For instance, *UNI* had set the following features as important: "tracker design as alternative shape (wristband, wrist watch, necklace)", "battery status shown in %", "safety zone should be defined for each user, but not for each tracker". *DEVLEAD* set all of them merely as proposal (least important priority). Another heatedly discussed topic was the targeted platform for the user interface. *DEVLEAD* was dedicated to developing only the web interface. Our field study showed that, however, the institutional care staff are constantly moving and have little time to sit in front the computer to check the website. At least in institutional context, this pre-defined technical offering was unlikely to meet the practical needs. Care practice in institutions turned out to be tightly scheduled and at the same time highly dynamic. Any device for use in the institutional context, it seems obvious, needs to be 'at hand' rather than in a fixed position. As the need for a mobile device became clearer, we asked the users during the interviews whether they would prefer a smartphone or a tablet. The answers were consistently "the smartphone", as that can be carried much more easily than the tablet.

We then communicated this request to *DEVLEAD* and indicated that we need a mobile interface alongside the web interface that was originally planned. *DEVLEAD*, however, refused to add a mobile monitoring application to the development plan as this would bring additional development effort (and therefore cost). It turned out that *DEVLEAD* had limited resources and little motivation to embrace changes to the original plan. *UNI* took the initiative and took over the task of developing the mobile app, although this also required additional resource and cost for *UNI*. Taking this as an example, there was a clear difference in 'worldview' here with traditional perceptions of the requirements process dominating on the commercial side. This became more pronounced the further into the project one went, and as financial and resource constraints became more evident. *DEVLEAD* preferred clear requirements with a technical focus to better entail measurable cost consequences. *UNI* was, however, not able to deliver the well-defined requirements that *DEVLEAD* expected in the early phase of the project due to the complexity of the field and time required to digest the collected data.

Here we summarize the design implications from the empirical results of the pre-study. Clearly, heterogeneous assumptions and practices demand flexible solutions. Tailorability here is of great importance. The system, we felt, should provide as much flexibility as possible to allow for divergent attitudes, ethical/legal concerns, and care routines to find their footing in it:

- *Fine-grained adjustability of privacy and safety settings*: the constant value trade-off between safety and autonomy was a feature of every context we investigated. The specific ways in which these two conflicting values were managed were, however, highly variable. This means, in turn, that a useful system needs to provide options for tailorability according to temporal and spatial features of the particular situation. Not only do we find an individual perception of the balance between autonomy and safety in different settings, we find that even within a given setting the balance fluctuates. Therefore, the system should provide various adjustable means to provide the users with tailorability to suit the technology to individual cases. It should be possible, for instance, to set safety areas (also sometimes called a ‘digital fence’) on the map and prompt notification when the patient leaves those areas. Again, the caregiver should be able to choose between showing or hiding the real time position of the patient, to provide either more safety or more autonomy for the patient. For the general location tracking, the caregiver should be able to configure the tracker to either automatically update the positions or manually (tracking or polling mode). Also the position update interval should be adjustable.
- *Elderly-friendly UI*: Many caregivers are themselves elderly and have difficulty with computers and websites. The provision of a large number of configuration possibilities is potentially confusing. To make the platform more accessible for less expert users, the platform might provide 2 views: a starter view and an expert view. The starter view would only show reduced setting options that allows users to start easily and intuitively with basic tailorability. The expert view should provide user with all setting options and powerful tailorability. The switch between both modes should be easily accessible.
- *History of routes*: almost all caregivers, no matter whether professional or familial, told us that patients have their favorite wandering routes, and are to

a large degree predictable. Keeping a history of the wandering routes in the system could help identify such favorite routes, giving suggestions to searchers. More importantly, provided with the route history, caregivers might be able to identify the patients' motives behind the wandering and their reasons of choosing these routes.

- *Reliability*: reliability/robustness is an important requirement for all IT systems, but is much more critical in such sensitive field. Tolerance of system failure is very low, especially in the institutional context, not least for legal reasons.
- *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 monitoring app, we identified the following additional design implications:

- *Straightforward UI*: reading small screens and understanding smartphone operations are challenging for most of elderly caregivers. The mobile application should, then, have reduced and manageable functions (complexities) and focus mainly on the tracking function of the platform.
- *Navigation function*: It is essential to provide a navigation function in the mobile application to locate the wandering patient and navigate the caregiver to him/her.
- *'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 to provide a combination of web and mobile interfaces allows a distribution of functions. This helps certain functions to be maximized for 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.

7.5.2 Prototype of the Monitoring System

The final prototype consisted of GPS-trackers for the patients to carry, a server backend to receive information from the trackers and remotely configure them, a web portal to manage the trackers and monitor real-time locations, and an iPhone app to monitor the real-time locations on the go.

- *Tracker*: we were using a commercially available tracker as a test device. The tracker is the size of a matchbox, and was equipped with GPS and GSM modules. Locating finding outdoors is very accurate ($< 1\text{m}$). When the GPS signal is out of reach, the tracker roughly calculates its position by triangulation of radio signals, which is not as precise as GPS locating. The tracker communicates with the server backend through mobile data connection (a SIM Card with data tariff is required) and updates its actual position in the system with user defined frequency. The tracker has a configuration interface by a particular format of SMS message, which allows the user to remotely configure the tracker within the web administration interface. Most common configurations include the tracker's reporting interval and reporting mode (active reporting or passive reporting only on-demand). The consortium has gone through a comparison of popular commercial tracking devices to find an appropriate one for the long-term evaluation. Based on its market availability, small size, precise positioning and acceptable battery life, the consortium decided on the Pico Tracker . Obviously, there was a tradeoff between size and battery life here. Going for a smaller size reduces the tracker's obtrusiveness thus reduces the risk of it being rejected. Furthermore, smaller size makes it easier to be integrated into other objects, or hidden somewhere, which allows more possibilities for user appropriation. This specific tracker can last roughly 6 hours with reporting interval set to 1 minute, and it can last maximum 12 hours with reporting interval of 2 minutes. However, even the 1-minute-interval was considered not frequent enough for many of our interviewees.
- *Server backend*: the server takes care of communicating with the trackers and manages all the user data in the background. It can configure the trackers remotely by sending a specific format of SMS to them. More importantly, it receives the real time positions from the trackers and saves them in the database accordingly and securely.

- *Alzheimer Monitoring Web Portal*: *DEVLEAD* chose Liferay⁵ as a technical basis to develop the web interface of the monitoring system. Liferay is an open source, Java-based enterprise portal software, which comes with features commonly required for developing websites or online portals. It has a built-in web content management system so that one can create a website by assembling themes, pages, widgets, and a common navigation (e.g. navigation bar with breadcrumb) even without programming skills. For more advanced use, Liferay can be extended by plugins. Our Alzheimer Monitoring Web Portal is mainly a customized website created using Liferay's built-in web content managements system and extended with a plugin written by *DEVLEAD* to provide the administration and monitoring interface. When entering the web portal after successful login, the user finds his/herself directly in the monitoring interface where the real-time positions of the trackers will be shown. The user has options to hide and show additional information on the map, e.g. the historical routes the tracker has gone through, or the safety zone. The safety zone is like a digital fence, set by the caregiver to provide an alarm when the tracker leaves the safety area. The web portal provides the user with a tool to draw the safety zone directly on the map. The user can enter a phone number to receive SMS alerts when the tracker is detected outside the safety zone. Additionally, if the user is using the mobile monitoring app on an iPhone, alerts will come in the form of iPhone notifications. Besides monitoring, the web portal also provides administrative functions, e.g. the user can create and manage a list of patients he/she is caring for, register trackers and assign them to the patients, remotely configure the trackers, and manage the historical route data. One caregiver can have more than one patient assigned and each patient can have multiple trackers attached in the system.
- *Mobile Monitoring App*: the research group (*UNI*) designed and developed the mobile monitoring app for the iPhone. Its design has been refined in multiple

⁵ Liferay: <http://www.liferay.com/>

cycles based on several PD workshops together with caregivers and, in the limited manner we describe above, with patients. Like the Web Portal, the mobile app opens directly into the monitoring mode, showing a map with the current location(s) of the tracker(s) and the safety zone(s) if any is activated in the Web Portal. It can further show details about the patient, and help the user navigate to the patient. It has a built-in address book to let the user easily call other co-carers to cooperate with each other. Compared to the web interface, the mobile interface provides only limited functions, focusing mainly on the monitoring function. The administrative functions were not included in the mobile app because these were more complicated tasks and were easier to accomplish on a larger screen with mouse/keyboard. The need to run these administrative functions is less important than the monitoring itself. The mobile device is ubiquitous and easy to use and we wanted to utilize this ubiquity to support monitoring above all.

Figure. 3 shows a photo of the tracker together with screenshots of the mobile monitoring app and the web portal.

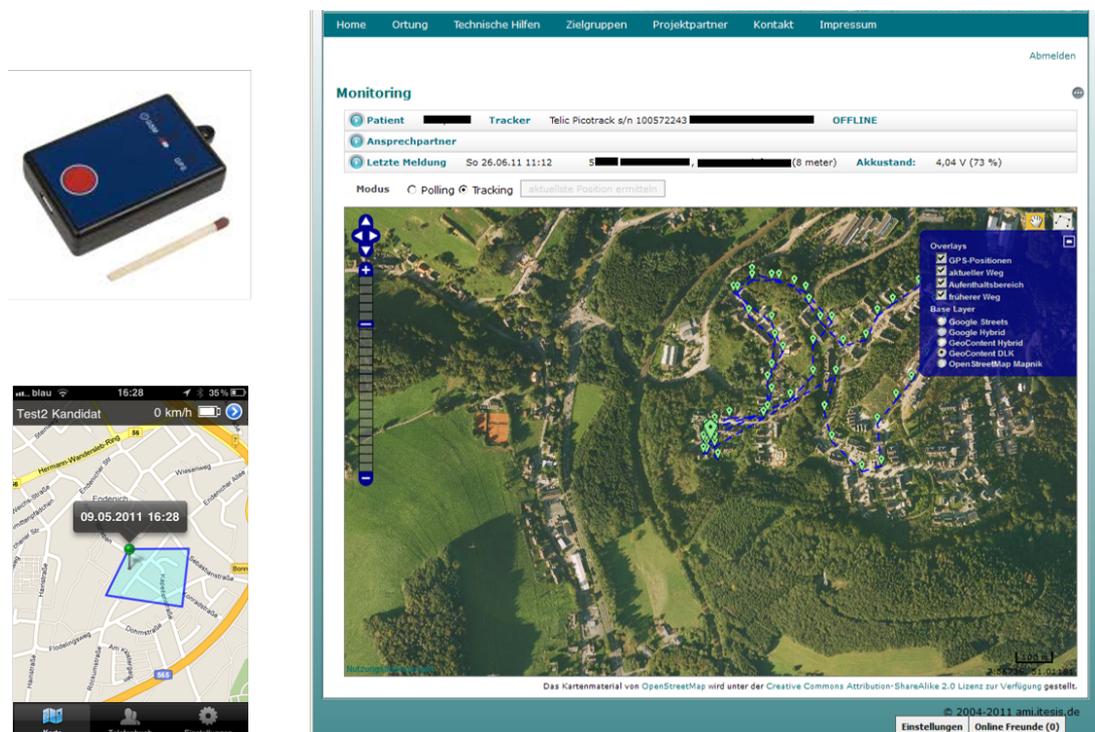


Figure 3. Components of the prototype (Top Left: a photo of the tracker, Bottom Left: a screenshot of the mobile monitoring app, Right: a screenshot of the Alzheimer Monitoring web portal)

We experienced, we should say, significant difficulties in working with commercial interests alongside our own research objectives. The requirements defined from the

pre-study had to be filtered through *DEVLEAD*'s interests. Not all of the requirements had been implemented in the prototype. For example, the cooperative monitoring feature was not included at all. Some of the others, although implemented, hardly fulfilled our expectations. The mismatch of both consortium parties in respect to motivation, design philosophy, and value of user feedback has led to significant differences in how the user requirements were treated. While *UNI* saw the results of the study as essential for the design and development of the system, *DEVLEAD* used them merely as anecdotal confirmation, which had only limited impact in their final design decisions.

7.6 Third Phase of Design Case Study: Evaluation

7.6.1 Evaluation Settings and Results

We rolled out the prototype in three different settings and it was tested in real-life situations over a time span of 3 to 5 months. These included a family in which the husband is suffering from dementia (age 55), a care home with focus on dementia care, and a special ward in a hospital.

The selection of the samples was based on the following considerations: We needed to find a good balance between deployment in a real-life context and an environment and setting safe for the wanderers. In addition, we wished to be able to research into the appropriation of the system in the settings where we had conducted the pre-study. As a result of specific changes in the previously researched settings (as e.g. progress of disease, persons moved to another location), however, we were limited to the hospital in which the special ward nurses participated. Here, and in the other settings, the managers and the wife, respectively, contacted us because they had huge problems with a wandering person/husband. The problematic balance between real-life circumstance and safety of the wanderer using a technological prototype where we couldn't guarantee 100% reliability was acceptable to the caregivers, as all the three settings had a routinized strategy to cope with the wandering behavior and thus didn't solely depend on our prototype to handle the situation.

Deploying the technology was anything but straightforward. Prior to the rollout, we conducted several semi-structured interviews in each setting to gain a detailed overview of their technology infrastructure. Considering each context's specific

conditions and constraints, we made customized deployment plans for each of them. In the institutions we had at least two on-site meetings to inform the management and the staff about the evaluation plan, and to present how the system functioned. The on-site visits were audio-recorded and we took field notes during the sessions.

In the two institutions, we held two training meetings each. The managers, head ward nurses and 1-2 additional ward nurses attended these meetings. We handed out an illustrated hand book, which we had prepared, consisting of screenshots of every single step to be deployed when using the system. In these training sessions we simulated a use case – one of the team members went outside carrying the tracker – and then went through the use case step for step with the staff. In the family setting, the wife and a son attended the training session. Here, we also simulated a test case, handed out the handbook and went through each step. In all three sites we handed over one tracker, to be used with one person.

Despite detailed preparation, we still faced unexpected difficulties during the technology installation in each location. Fine-tuning the prototype so that it could be integrated into daily practice required flexibility and creativity. 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 unsatisfactory.

After the rollout, we visited the family and the institutions regularly every 2 - 4 weeks and were available 24/7 by phone in case of questions and problems. We conducted 12 on-site visits and 6 telephone interviews altogether, with each session typically lasting 1,5 - 2 hours. All the interview sessions were audio recorded with consent and later transcribed. During the evaluation phase 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 media diary was kept very simple, so that caregivers could easily fill in the usage times of the device, mobile or stationary usage, and provide notes about the usage situation for each day (see Fig. 4).

Figure 4. A page of the media diary book (Each page is for one day’s use. The page above is for Monday in the first week. A user records each usage in one row and enters information for the patient, the tracker, the begin and end time, the web and/or mobile usage, and eventually some notes to this usage)

The diary worked as a basis for discussion during the on-site interviews. The data analysis was approached in the same way as in the pre-study. We started with an open coding approach and regularly held internal analysis workshops. A summary of the activities we have taken to engage the deployment can be found in the following Table 1.

Deployment activities	
Before roll-out	During evaluation
Preparatory interviews in each setting (3 environments x 2 interviews each)	Data collection: - regularly in every 2-4 weeks; on-site and telephone interviews (12 on-site + 6 per telephone) - media diary study in each setting
Training sessions in institutions (2 institutions x 2 sessions each)	Additional on-site support sessions: prototype and infrastructural troubleshooting
Training session in family (1x)	Support hotline per telephone and email: available 24/7 throughout the

evaluation phase
IT support sessions in the hospital ward to set up Internet and iPad for the test phase (2x)

Table 1. A summary of activities taken to engage the deployment

7.6.1.1 Environment A: A Dementia Care Home

Environment A is a dementia care institution in the rural area. The care home is committed to new dementia care philosophies which include giving the residents as much free space as possible for them to be mobile on their own. There is a large (and protected) area around the house for the residents to walk freely. There is an alarm system attached to the main entrance of the institution, and patients with a special wristband will trigger a phone call to the care staff when they pass the threshold. 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.

Our contact person was the head nurse (herself an elderly lady) of the care home, with whom we had conducted participatory design workshop in the earlier phase of the project. After she tried out the prototype and found it to be too technically challenging, she delegated it to three young female workers from the federal volunteer service to test the system in house. These young women were familiar with IT and told us that, while they found themselves comfortable using this technology, the other professional caregivers in this care home (who are generally older) might have problem with it. The head nurse shared this view, saying: “*older persons [herself and her colleagues] could not use this system, because in this institution they have too little experience with technology and computers*”. She emphasized this with reference to her team’s general problems with care documentation work on the computer: “*my colleagues already have problems with simply clicking on the right things in our [digital] records.*”

7.6.1.2 Environment B: A Hospital Ward

Environment B is located in a big city and is a large 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. The ward is an open ward, which means that locking the doors is forbidden. Here, location-tracking services were welcomed but worries were also raised because of the high degree of mobility on the part of patients. For example, the patient who was mainly

carrying the tracker during the field test used to be a marathon runner. He suffered from severe dementia as consequence of a car accident. This patient ‘escapes’ from the ward regularly and is very difficult to manage because of his high 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 building. On one occasion he was found in the basement, having spent hours in a disoriented state.

The head ward nurse told us that when the staff were too overwhelmed by attempts to keep him in the house due to his high status of agitation, doctors admitted him to another ward, a “closed ward”. However, this was not regarded as a permanent solution and he was readmitted to the open ward several times, providing constant challenges for the staff. For this reason, the nurse was very interested in getting support through the technological solution: *“Because on the closed ward they are not allowed to keep him so long they permanently send him back to us. It is such a big struggle to care for him because of his extreme agitation.”* (head ward nurse, f.)

On the day we brought our prototype to the ward, we found that the Internet connection in the hospital was too slow for our website to load properly. As an alternative, we then bought an iPad with a 3G data tariff so that the staff could use the iPad to access the web portal. Two days later when we visited the ward again, they told us *“the iPad is safely locked in the cabinet [so that nobody will steal it]”* (head ward nurse, f.). Because of the large flow of people including patients and relatives in the hospital in general, fear of losing the costly device over-rode other considerations.

Recognizing that concern, we 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 ward – telling us that the patient was lost for 20 hours, and had been found the next day 30 kilometers away from the hospital. 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 had proven 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 had died within the safety area, just before the patient left the building. It was apparent that the system needed to send a

notification when the tracker battery is low and that we had to help the caregivers with handling the charging practice. After discussion with the nurse, we deployed another tracker for the patient, so that they could simply exchange the trackers, to make sure that one is always charged. Since then 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, it seems, have grown 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. 5).



Figure 5. A carrying bag for the tracker made by a participant's family

7.6.1.3 Family Smith⁶

Here, the male sufferer is cared for at home by his spouse. He is a former doctor, and lives with his wife and three children aged between 15 and 20. Mr. Smith 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 roughly estimate the time it should take for him to return. Mr. Smith has failed to return home on his own on a number of occasions. For that reason, a volunteer from a local charity organization now comes three times

⁶ Anonymized

a week to take him and the dog for a long walk. Mr. Smith, 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. Smith, 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. Nevertheless, she has 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 felt 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 because, for her, being able to look at the system and knowing that he is safe, already provides sufficient reassurance. *"It is good that I know that I could have a look on the map if I felt a bit anxious. But I do not want to track him all the time, that would be too much."*

7.6.1.4 Cross-case Findings

We have identified some general issues in the acceptance of the trackers. Firstly, the size of the tracker was seen as a problem by the interviewees. Dementia sufferers often dislike unfamiliar devices attached to their body or clothes, and sometimes remove them. The tracker we have used for the field test was already among the smallest we could obtain at that time, but caregivers preferred something even smaller, like a thin bracelet, or in the form of a wristwatch or necklace which - as a known artefact for the sufferers - would be better accepted by them.

"Acceptance of a device to wear is very individual in the persons with dementia. When we tried out the door safety system, the persons were wearing a wristband. One of them cut it off with a knife, because it was not familiar to him. Maybe, if it were kind of hidden in a wristwatch being familiar to him, he would have accepted it. On the other hand, from the principle of newer care philosophies, hiding would mean kidding the people and we are not supposed to do this. We would have to discuss this individually with the relatives." (Manager of Environment B, f).

Considering that smaller size of the tracker will result in sacrifice of battery life, we had to live with the compromise between acceptable battery endurance and tracker size in the duration of the research project. Nevertheless, we could develop design ideas for a casing from the embedding of the project in the real-life circumstances.

Given the high demand for patient autonomy in care institutions, ‘open house’ philosophies mean that professionals negotiate freedom for patients, where possible to maximize it. A ‘Digital fence’ is, in principle, extremely useful in this respect and was indeed extensively used by our professional caregivers. However, for some the fence function was still too intrusive. For that reason, we collaboratively developed the idea for an additional structuring of the feature into three zones, a green one (safety zone), a yellow (be alerted, person has left the safe area) one and a red one (act immediately, he/she is in danger). For the professionals, the digital fence in this shape brought a win-win situation to both the patients and themselves: more autonomy for the patients and reduced burden for the caregivers.

Again, we have observed broadly different attitudes towards patient’s privacy from informal and professional caregivers’ handling of patient information in the system. Familial caregivers assigned the tracker to the care receiver with a real name, which gives the feeling of tracking the person. Most of our professional caregivers ended up only registering the trackers in the system, keeping the mapping between tracker and patient intentionally away from the platform as a further measure to preserve patient’s autonomy/privacy.

Overall, the system was viewed as extremely useful in the institutional context, even with the shortcoming of the imprecise indoor positioning of the tracker. Professionals say, although the indoor positioning is not precise, it still helped them refine search strategies. For instance, in the case of the former marathon runner, although the system could not identify an 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.

The route history function is much appreciated by family caregivers. Mrs. Smith argued that because the system allowed her to retrace the routes, she was able to get a better sense of why her husband deviated from his normal route, thus reducing anxiety. Mr. Smith was once found on a highway (Autobahn) construction site, and was unable to explain how he found himself there. As Mrs. Smith says: “*even today*

we do not know how he had gone to this Autobahn construction site ... Something must have happened that made him leave the normal route. It can drive you crazy that you do not know what has happened.” Now, with the technology, there is the option to at least reflect on possible reasons for, or external factors which prompt, new path choices.

7.6.2 Communication Process in the Interdisciplinary Project Team

During the set-up of the evaluation we experienced several technical problems. To help with these problems, a developer, who proved to be very prompt in tackling problems, from *DEVLEAD* supported us via telephone. In this situation, *DEVLEAD* had a clear understanding of the need to deliver a prototype that was as stable as possible. As it turned out, a stable prototype is pivotal for the initial appropriation process of end users participating in a trial. The technical problems varied to different degrees in different locations. In regard to short-term problem solving and trouble-shooting, *DEVLEAD* acted to ameliorate difficulties where on-site skills were lacking.

The final evaluation phase delivered a number of new insights and implications for redesign. Through the usage of the system in real environments, a thorough understanding of the needs of caregivers and related options for ICT support became apparent. *UNI* documented these suggestions for redesign in a spreadsheet and listed detailed description and empirical data to support the argument. Similarly, as in pre-study, this spreadsheet was sent to *DEVLEAD* and discussed upon during consortium meetings. At this late stage, however, limited resources meant that the firm could allocate very little time and money to this and as a consequence, only a very few minor issues were dealt with.

In retrospect, the initial construction of the work plan and work packages contributed to *DEVLEAD*'s unwillingness to take on another round of prototype redesign. As mentioned, the funding scheme required each partner to have its own part-project and work plan. *DEVLEAD* prepared its plan based on certain assumptions about how user-oriented research could contribute but this didn't reflect the actual investment in terms of time and other resources necessary to fully utilize the results. These were partly epistemological matters, but partly pragmatic as well. It is clear that *DEVLEAD* had little experience of what user-centered design

might look like, and little sense of how qualitative research material might be deployed. It is also the case that *UNI* had little sense of the pragmatic constraints this SME might be working under, notably cost issues and a design schedule that made late alterations difficult. It should be said that in most instances, the problems that arose did not occur because of an obvious failure by either party. Rather, the early structuring of a project proposal in a particular way meant that there was little opportunity to refine *DEVLEAD*'s plan in the light of emerging data.

As the project proceeded, *DEVLEAD* stuck fairly strictly to the time plan and was not able/willing to allocate any resources for redesign. At the same time, and from their point of view, it can be argued that *UNI* showed too little understanding of the need for certainty in resource planning and the sheer organizational difficulty involved in late-stage redesign. This mismatch between 'ideological' commitments and practical realities is a general problem in industry-science cooperation projects: even where industry stakeholders value user-centered and iterative approaches in technology design, the implementation of such a process frequently proves problematic due to the operational business strategies of firms, and may well be a particular difficulty for SMEs. In contrast to scientific partners, for firms it is hard to plan for flexibility in the long-term.

7.7 Discussion

7.7.1 Lessons learned for dementia management

Our experiences can be, for analytic convenience, be described in terms of two discrete relationships. The first is the relationship between researchers and the researched (carers and patients). Our 'design case study' approach was intended to facilitate mutual learning over a period of time. The second involved the relationship between the two project partners, and turned out to be consequential in relation to design outcomes. We report on both here to illustrate how a 'practice based' approach needs to attend to practices on the part of researchers as well as researched, and more specifically needs to attend to organizational features. Overall, our proposed solutions had a positive effect on the experiences of dementia sufferers, their families and professional caregivers, demonstrating, we believe, the value of situated and long term, evaluative procedures. In two of our test environments in particular, the professional and familial caregivers have grown

dependent on the prototype and have used the artefact consistently. 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 at the same time practical to implement. In the organizational care 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. Tracker design, as one feature of this, is important. We had, however, to live with hardware- and technology- constraints for the duration of the project. One can imagine a circumstance where the tracker receives an excellent signal even indoors (e.g. with the EU's Galileo satellite navigation) and a button-sized battery might last for months, with which we may indeed get better results. Regardless, current technological limitations circumscribe what is possible. At the same time, the sheer complexity of the social, legal, and ethical universe in which care is practiced will continue to exist and even more sophisticated technology will or will not be adopted in the light of social as well as technical factors. GPS tracking technology has been explored in research for at least 10 years, and a handful of commercial products can be found in the Internet, but the uptake of the technology in real care situations is still very low. One of our main contributions is to provide a better understanding of why this might be.

One key factor is that 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 constantly high demand on time and a need for caregivers to be available in different locations. We recognized professional care staff's constant high workload in institutional context during the pre-study and this was the main reason that *UNI* spent extra resources in designing and developing the Mobile Monitoring App. In family contexts, demands include the fact that caregivers themselves are sometimes elderly and not tech-savvy, or have other family or work commitments. Even the professionals have problems learning new technologies, especially for the caregivers who are older. This is exemplified in the case of Environment A, where the prototype was not actively

used because of this technology barrier. The relationship between technology acceptance and low IT affinity of caregivers has already been described, e.g. in [100]. Our study augments this problem sphere by describing additional aspects impacting acceptance, such as the high degree of heterogeneity in care concepts and moral and legal standpoints, which also may cause a reluctance in the willingness to use IT in dementia care. Another aspect that our long-term and practice-based study demonstrates is the significance of the shape and size of the tracker as well as compromises that have to be made when deploying a practice-based evaluation study. The study demonstrates a high need for individualization of the tracking devices according to individual familiarity with jewellery, wrist watches, etc. Solutions, we suggest, are better fitted to selective management of situations, rather than to constant monitoring, for those reasons.

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.” [105]

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. It is entirely possible that the strong antipathy in institutional contexts to “freedom depriving measures” is a specifically German feature, reflecting aspects of cultural history. It is certainly true that professional caregivers in institutional contexts express their concerns about such freedom deprivation very strongly, and

expressions of this kind are even more evident at a managerial level where concern for legal liability might be more pronounced. This leads to a certain, understandable, conservatism in respect of technological innovation where it might impose on the patient's autonomy.

The constant renegotiation of care philosophies is another complicating factor. Along with [33, 34] we recognize the way in which new care philosophies, such as Person Centered Care [71, 126], are having a significant effect on practices in many care institutions. However, the related practices are not clear-cut. While we agree in general principle with [115], who promotes Patient Centered Care as “[...] *appropriate for applying the norm of human-centered design*”, we also see a need for careful examination of the way in which new philosophies are actually implemented in different contexts and even why, as in the case of some domestic environments, why they may not be implemented at all.

Thus, autonomy is not a fixed metric. As indicated, this points at the need for flexibility in the design of technologies. Just as importantly, however, it points to ethical issues in respect of how the researcher positions him/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 in a domestic context if we reject them in more institutional contexts? Such issues become even more salient in a research context where the various participants do not share similar understandings or awareness of the kinds of practical constraint that may exist in one organization to a greater degree than another.

There is also no doubt that the design process in this context significantly affected the design product. How to translate our qualitative empirical results for a commercial partner with no prior experience of either iterative design or of qualitative input was a constant difficulty in the project. The discrepancy between the company's waterfall design philosophy (top-down) and our vision of how field work should contribute (bottom-up) limited our success in reflecting certain user requirements in design. Constraints on resources, particularly in the case of late stage redesign, meant that some of what we felt to be our most worthwhile insights were never implemented. There are also other important issues which we were unable to address given the lack of hardware expertise within the consortium. The

ability to customize artefacts, for instance, as well as bring aesthetic aspects into products for the elderly, and especially in dementia care, has been stressed elsewhere [7, 123] and our inability to adequately customize the tracker to cope with indoor situations limited its perceived value.

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 user 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 (counselling, 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.

7.7.2 Lessons learned for project management

The work presented in this paper was carried out through a publicly funded research project, which requires researchers and industry partners to come together and pursue a common goal. As Dachtera has pointed out: *“With regard to the debate on the changing nature of science, our results suggest that within an institutional setting such as a joint research project, there are still epistemological and organizational barriers that are significant.”* [32]. We can summarize the organizational issues we have faced during this project in the following way:

- *Different purposes*: the researchers (*UNI*) had interests mainly in methodological challenges and academic publication. Software production was not a major concern. The researchers spent huge amount of time and expended emotional effort to get access to the real usage context. Their focus was on understanding the care practice of informal and formal caregivers, and thus generating requirements for design based on that. The researchers considered themselves as having ‘privileged’ knowledge about dementia care, knowledge that went beyond the question of technical development, but also shed light on the socio-technical aspects of the problem. The industry partner (*DEVLEAD*), obviously, was primarily motivated by developing a product and bringing it to the market as soon as possible. Due to its financial and resource constraints, *DEVLEAD* could not afford revision to the work plan or extensive redesign, especially late in the process.
- *Problems in translation of requirements*: it became evident that there was a gap between both partners’ conceptions of user requirements, and this problematized the translation from *UNI*’s field findings to *DEVLEAD*’s implementation. The researchers saw the design process as an open-ended activity. They used qualitative methods with a commitment to the illumination of practices across different contexts. Therefore, the researchers gathered user requirements in the sense that they revealed the most significant issues, indicating potential functions, and raising critical concerns. *DEVLEAD*, however, expected user requirements to be clearly defined development tasks to better manage measurable costs. As a compromise, *DEVLEAD* structured a list of pre-defined functions and asked *UNI* to prioritize them according to the results from the user study. While this was a helpful move, it nevertheless did not solve the issue of late stage changes.
- *Parallel working – different priorities in practice*: Although *UNI* and *DEVLEAD* shared a common framing of the project lifespan in the broad view, their actual practices in prioritization of work, perception of efficiency, and project management varied. For example, during the pre-study *UNI* had expected *DEVLEAD* to wait until the results from the field became more explicit to start the exact software development. *DEVLEAD* had, however, put heavy focus on the software development from early on. This left very

limited room for design to adapt to an evolving understanding of user requirements. There are several reasons that led to this mismatching. 1). *DEVLEAD* started development early, and did not see starting earlier than planned as in any way problematic. 2). *UNI* did not manage to deliver pre-study results on time due to unexpected difficulties in the field. The work plans for both partners did not provide enough flexibility to foresee this possibility and did not provide for this contingency. 3). Different values of pre-study: *DEVLEAD* treated the pre-study as anecdotal confirmation and did not expect any significant impact from it. *UNI*, in contrast, took the field study very seriously. However, the complexity of the field was much higher than expected. To get access to, and develop an adequate understanding of, the field took much longer time than originally planned in the proposal. The negative effects included not only the delayed transfer of results to *DEVLEAD*, but also the fact that *UNI*'s analysis remained, for them, unconvincing at a generic level. We should stress here that in writing this paper, we are not engaged in blame allocation. Both partners were constrained by assumptions built into the project call and neither was in a position in respect of time and resources to compensate for that fact. Nevertheless, taking this project as a lesson, we would suggest a radical rethink of funding strategies aimed at near market development, if the products in question are to reflect real need. And we hope that, by addressing meta-problems in an open way, we might eventually bring insights to the funding parties that might result in a better synergy of the different project management practices between academia/industry partners. For example, flexible start- and end-date for the partners would help bridge the gap where intensive field work is still being conducted but specific user requirements are yet to surface. HCI researchers should be able to start the project at first and have the time to understand the field. Industrial partners should be able to start the project from a later phase, when user requirements are (almost) identified. This should also reserve more resource for the industrial partners for redesign cycles in the later phase.

- *Different philosophies of software development*: *UNI* conducted its field study according to the practice-based design paradigm and devoted itself to a bottom-up design philosophy based on profound knowledge of the real usage

context. *DEVLEAD* has taken a typical Waterfall approach to develop the prototype, driving the development from the top down. The lesson is obvious. The two paradigms fit uneasily together. More importantly, however, we need to ask why this potential friction was not anticipated. Clearly, judgements about the relative expertise of project partners are difficult to make. While it seems obvious to us, post hoc, that a company with agile development expertise would have been the best suitable partner for us, given our commitment to a design case study approach. The development might, then, have been function-oriented, rapid, iterative, user- and test-driven. The reality is, however, that at a very early stage, neither partner showed adequate interest in, or knowledge of, their different design philosophies before forming a consortium.

Below (Fig. 6 and 7) we try to depict the different conceptions of the cooperation process from both parties. Figure 4 was created entirely from our own view of *DEVLEAD*'s approach. We were unable to validate it with the company as it ceased to exist shortly after project end. The company was going through a difficult and ultimately fatal financial situation. This financial constraint became more evident in the late project phase and the company went bankrupt after the project end. The conception is, nevertheless, based on the company's work plans.

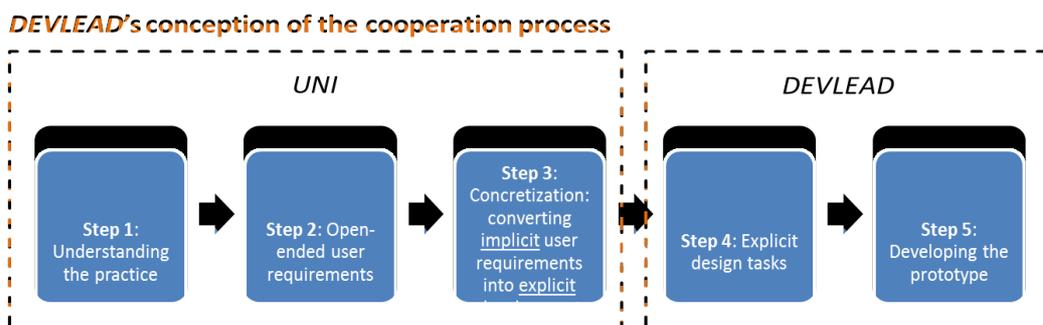


Figure 6. *DEVLEAD*'s conception of the cooperation process

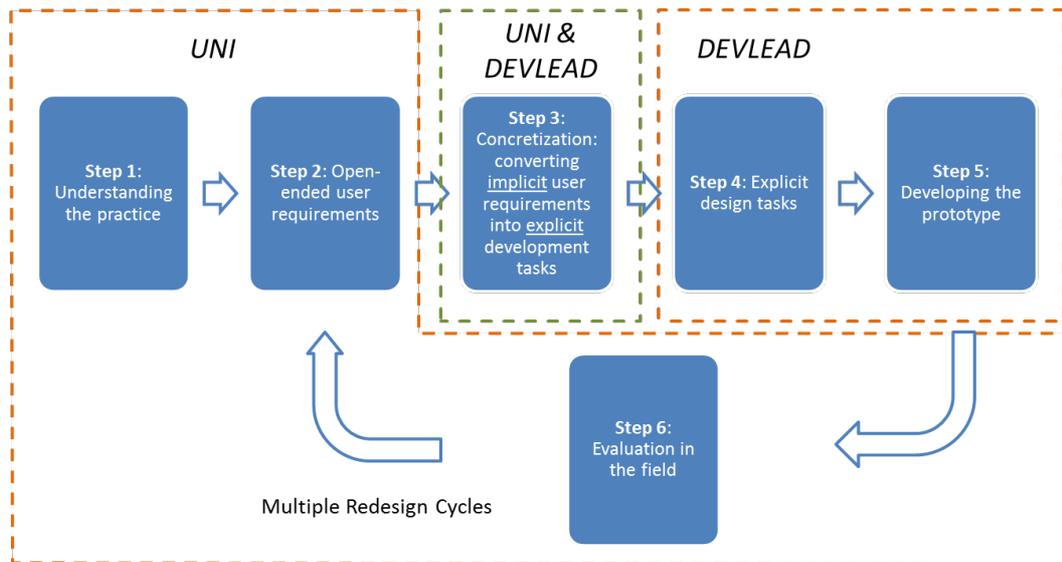
UNI's conception of the cooperation process

Figure 7. UNI's conception of the cooperation process

7.7.3 Reflections on a “messy” field of assistive technology development in the context of an academia – industry partnership

Pot et al. 2012 indicate that it is of high importance for IT support in dementia care to define the specific problem of the specific person with dementia and his or her caregiver and to search for the most appropriate solution for the problems of this particular dyad [100]. Our study confirms this claim and it furthermore shows that this is not an easy endeavor in many cases. In dementia care, as well as more broadly in assistive technology development, it is often not possible to find “clear-cut” solutions.

The systems to be developed in this highly loaded moral, social and legal complex universe imply the need for a nuanced viewpoint on both the process and the product of development. By displaying the qualitative-empirical data, we would like to illustrate this way of reflection on what scholars of health sociology and science and technology studies (STS) have identified as the different ways health problems are being conceptualized and articulated by different groups of stakeholders. Depending on the perspective, methods of diagnosis and therapy may have very different outcomes. In the field of dementia care especially, one is confronted with varying discourses among physicians, professional and family carers and social and medical organizations [31, 67]. This means for IT research that it is important to look more closely at the practices out of which dementia care “is constructed”. Different discourses may appear contradictory, but make perfect contextual sense

(e.g. that personnel in care homes reports to us that they take prohibitions concerning locked doors seriously, but tell us about different measures to hide and camouflage the doors at the same time). Looking at these contradictory, and often not clearly or explicitly articulated issues helps us better understand obstacles and challenges in care practices - a perspective which has not been taken up very widely in research on assistive technologies.

Programming a system ultimately needs clear-cut, distinct, complete and unambiguous requirements. This is the bridge to be built between academic research and industrial development: Handling unfamiliar empirical research results as well as the tolerance for discrepancies is very difficult for work contexts in industry. Conflicts and contradictions may be highly interesting results in the context of academic research and open up new scientific perspectives and reflections, such as from the viewpoint of STS on dementia care [67]. However, they are problematic in regard to operationalization and feasibility for design purposes.

Overall, we are not able to share complete solutions in this paper, but we have highlighted some contradictions and discrepancies which affect development process and product. Hopefully, both kinds of reflection will impact on future projects with similar research aims.

From a long-term perspective, with this paper, we would like to contribute to the building-up of a more realistic and practice-based research in assistive technology design, which - undoubtedly - is both uncomfortable and complicated at times. The need for careful and consistent communication, furthermore, extends to relations with caregivers and the cared-for. They have an undoubted interest in assistive technology but are uncertain about how it might be deployed in practice without considerable help from project members. Moreover, the great uncertainty in respect of differing care concepts and if and how these are compatible with technological aids demonstrates the need for regular ongoing exchange between different stakeholder groups such as information scientists, IT developers, geriatrics, social workers, etc., in order to develop a common ground.

7.8 Conclusion

Research in the field of practice-based design [73, 131] calls for attention to overall project activities, investigatory and otherwise, in a broader sense rather than simply

reporting on the results of enquiry or the final results of research & development projects. This ‘practice turn’ in HCI is based on the assumption that all the activities of organizational actors, as well as those they study, in a cooperative project might contribute to the formulation of design goals, and that the process of investigation needs to be looked at as a set of practices right from the start. The study at hand, dealing with the user-centered development of a GPS-based system to support caregivers of wanderers in the field of dementia care tries to explicate and bring together two lines of the project: how it is that understanding the practices of potential users can be viewed as contributions to design, and how it is that the practices of participants to the research can and will mediate possible contributions. Accordingly, we have tried in the above to link the two together in such a way as to provide for a better understanding of how ‘practice’ might include the activities of designers and developers as well as those of subjects and, more importantly, how they ramify. First, we offered results from the qualitative user studies and the generation of design ideas, implications and requirements for design and redesign grounded in the practices of the end-users involved. Second, we reported on the interaction and communication processes between the project partners which framed the user research and the development of the system and which ultimately compromised the evolution of a design solution. We conclude with the observation that there are relatively few examples which demonstrate how the practices of users and the practices of research participants at an organizational level are mutually elaborative in the evolution of a design solution. In our case, the development of the final design product suffered from different paradigms that were brought in by the project partners. Nevertheless, the project has succeeded from each stakeholder’s view:

- Academy (*UNI*) has invested emotions/time/resource in the project, and has fulfilled its responsibilities to the project and its target group. Its input has even gone beyond the planned assignment and resulted in a mobile app, which was viewed by a heterogeneous group of users as both useful and usable.
- Company (*DEVLEAD*) saw project outcomes as successful insofar as the work done satisfied the basic purposes they envisaged for it.
- The end users in the pre-study found both process and product to be beneficial. The users from the evaluation particularly appreciated the working

technology that they were able to use and demonstrated its value by continued use.

We see our paper as a contribution to the development of a practice-oriented perspective in which the study of user practices and the study of organizational practices taken together can further illuminate the way in which design outcomes are arrived at and to foster discussion about how 'best practice' might possibly be achieved.

8 GOING FROM HERE

In this thesis, we have revisited the whole developmental story of the design and evaluation of a GPS-based monitoring system for caregivers to deal with the wandering behavior of dementia sufferers. The 4 case studies revealed the whole process of an interdisciplinary and collaborative research project in a progressive way. Here, we focused on a specific sub-group of dementia patients: the late-phase dementia sufferers, who are no longer independent and requires extensive and permanent care from informal or formal caregivers. The technology assistance we chose to offer was then meant to be a passive monitoring system, meaning that the technological artefact remained transparent (unobtrusive) or minimal obtrusive for the patients. According to the three types of users (*primary, secondary, and tertiary*) identified by Eason [40]: “*primary users are those who actually use the artefact. Secondary users are those who will occasionally use the artefact or those who use it through an intermediary. Tertiary users are persons who will be affected by the use of the artefact, or make decisions about its purchase*”. In this passive monitoring case, the patients are secondary users and the caregivers are primary users. In the ideal case, successful design should take all stakeholders’ views into consideration. In our work, we had to make a compromise and didn’t manage to integrate the patients into the design process. This was a limitation, albeit a necessary one, of the work, given by the developing conditions of the participants and the relatively long-term nature of our study. The first trials of having late-phase dementia patients in design sessions (interviews and workshops) as reported were not successful because of the cognitive and communicative constraints of the patients which made the

communication with them difficult, and in many cases not possible at all. Nevertheless, the effect of the artefact on all stakeholders was carefully considered. The fact that not all stakeholders were represented at the design team was then not an issue [106].

But it shouldn't stop here. The deterioration of dementia patients is normally a slow and fluctuating progress and there are no clear boundaries between the different "phases" of the disease and therefore assistive technologies for the other facets of the disease lifespan are just as important as the work presented in this dissertation. This means assistive technologies for the early and medium phase of the disease are also important. And in this section, I would like to provide a brief outlook into the other potential areas where assistive technology could play an important role in the dementia care through a holistic lens.

8.1 Indoor Navigation Technology

An obvious weakness of using GPS as tracking technology is the imprecision of such systems when indoors. GPS signals are not strong enough to penetrate, for instance, concrete walls and thus will not reliably work when the tracker is indoors. The tracker, as used in this work, falls back on using the triangulation of mobile signals to roughly determine location, but the result is normally not satisfactory. This is a limitation of this work. A deeper look into the indoor navigation realm and integration of it to the existing tracking solution would arguably bring a huge benefit to users.

Wireless indoor navigation has been successfully used in many application areas such as asset tracking and inventory management. As wireless technology keeps evolving, indoor navigation should see a consistent improvement in precision and feasibility in the foreseeable future.

For indoor navigation, there are mainly 4 types of location information that could be used by different application: physical location, symbolic location, absolute location, and relative location [63]. Physical location is a coordinate in a 2D/3D world to present a specific location. Symbolic location is a naturally expressed way that requires common sense, such as in the office, in the living room, etc. A relative location expresses a transformation from an absolute position. Designer of an indoor

navigation system needs to take good consideration of how to integrate these 4 types of information to suit different use cases.

It is out of the scope of this thesis to go deep into the algorithms of indoor navigation technologies so, instead, I will give a technological outline of available technological approaches that may be utilized in future assistive technologies:

- *GPS-based*: due to poor coverage of satellite signal for indoor environments, GPS is unsuitable for indoor location estimation. Assisted GPS (A-GPS) is a variant of GPS that uses cell tower data to augment signal quality when satellite signal is poor, or too few satellites are available. This not only greatly reduces the initialization time of the localization service, but also provides an acceptable accuracy (normally 5–50 m) in most indoor environments. The downside is that an assisted GPS system depends on external data that is usually retrieved from internet connection, which incurs data access and corresponding expense.
- *RFID*: Radio-frequency identification (RFID) is an electronic device that serves the purpose of a unique identifier. An RFID tag is normally small enough to be attached to other objects, and there are basically 2 types of RFID tags: passive and active. Passive tags don't need a battery, they collect energy from a nearby RFID reader's interrogating radio waves. The typical reading range of a passive RFID tag is 1–2 m. Active tags require a battery to actively transmit their ID to an RFID reader. Active tags can operate in a much longer range (tens of meters). One advantage of RFID tags in comparison with barcode is that they don't have to be within sight range of the reader, so that it can be attached to cash, clothing, and possessions, or even implanted in animals and people. Of course, this raises privacy concerns of personal information being compromised by unauthorized reading of the data.
- *Cellular-based*: This approach uses the existing infrastructure of mobile cellular network to estimate the location of a mobile client. The location is estimated by multilateration of radio signals to the next nearby antenna towers, the process does not require an active call. Generally speaking, the accuracy is higher (50m) in densely covered areas (e.g, urban places) and much lower in rural environments. The advantage of the cellular-based

technique is that the service providers can non-intrusively reuse their current network infrastructure.

- *Ultra-wideband*: UWB is a communication technology to utilize high bandwidth to transmit data at high speed over short distance. Its application area is mainly in personal area networks and peripherals. Compared to RFID technology, UWB consumes less power and can transmit over multiple bands of frequency simultaneously. Thus, UWB is more tolerant to interference and in general a better penetration of signal through walls.
- *Wi-Fi positioning system*: another multilateration-based positioning technology based on measuring the intensity of the received signals from different access points. Similar to cellular-based approach, the accuracy of Wi-Fi positioning techniques depends on the density of access points and the locations of the access points need to be known beforehand.
- *Bluetooth Low Energy*: Bluetooth beacons are a class of *Bluetooth low energy* (Bluetooth LE) devices that broadcast their identifier to nearby portable electronic devices. The technology enables Bluetooth LE-enabled devices to be notified when need a beacon to trigger follow-up actions. The beacon technology transmits a specific format of data using the Bluetooth channel. The Apple iBeacon⁷, e.g. sends out a pre-defined format of data and the client (such as a mobile phone) needs to interpret the data with a specific software to determine the distance between itself and the beacon. To determine the position of a mobile device, it will require that the device can detect at least 3 beacons.
- *Google Tango*: Google Tango⁸ is a collection of technologies, including depth perception, area learning, and motion tracking. The key technology that enables Google Tango is the depth sensing using a depth sensor, which can “learn” the indoor environment through the lens, depicting the nearby

⁷ <https://developer.apple.com/ibeacon/>

⁸ <http://get.google.com/tango/>

environment in 3D. It is similar, it is argued, to how we use our eyes to identify feature points in a room setting, remember them, and navigate with the help of them. These physical relationships are an essential part of how we move through our daily lives, and Google Tango utilizes this information to enhance the indoor navigation experience, such as showing the routing information indoors in an augmented reality mode.

8.2 Social Innovations

Recent studies relating to healthcare technology have progressively recognized the that the design, use and management of such technology is a sociotechnical issue. In this developmental story of an assistive technology for dementia management we have shown that, technology itself will not solve all problems. The social aspects of assistive technologies in healthcare face great challenges in real situations. But social innovation in this field also has great potential.

The dementia care community has long been a relative closed community, consisting of the patients, familial caregivers, and professional caregivers. The rest of the society knows little about this user group and solutions through which broader society could be implicated in helping the dementia community are rarely seen. Dementia village⁹ and the 8 pillars model of community support¹⁰ concept are approaches which aim at providing integrated and comprehensive support for dementia care. We are strong advocates of the need to promote awareness for and of the dementia affected user group and how to engage more people (such as the volunteers) to provide help to dementia management. The ultimate goal is to establish important steps towards a modern community care of people with dementia.

At the present time, different approaches and explorative projects have been carried out for the care of people with dementia based on the assessment that the increase of dementia affected community in the context of the ageing society requires new

⁹ e.g. <http://www.dementiavillage.com/>

¹⁰ http://www.alzscot.org/campaigning/eight_pillars_model_of_community_support

community-based approaches. A major initiative of the German Alzheimer's Society, supported by the Robert Bosch Stiftung, develops, for example, concepts and training courses for municipal actors. The aim is to raise awareness of the needs of people living alone with dementia, and to promote social inclusion and informal support structures in the neighborhood through education and information for a wide range of local actors (e.g. professional groups, associations, organizations, citizens).

A further focus in current approaches of neighborhood-based dementia care is to improve cooperation between professionals, informal caregivers and volunteers. There are already pilot projects that pursue, for example, the improvement of communication interfaces between medical and care professionals and familial caregivers, or between hospital and ambulant care service. It is, however, pointed out that the interface to an important social resource, namely volunteers in the field, has been neglected and requires more structured access. In particular, it is still necessary to formulate and systematize municipal structures in this respect [64]. Hilse et al. suggest a heuristic of a co-production workgroup, which helps to make the work of volunteers and their chances and potentials visible and searchable. The prospect of volunteering is thus also extended to differentiations, e.g. From informal neighborhood assistance to differentiated care structures, such as senior citizens' cooperatives or associations.

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10 APPENDICES

APPENDIX 1 LIST OF PUBLICATIONS 142

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Part of this dissertation has already been published as conference or journal papers.

This appendix lists the accepted versions of these publications:

- **Chapter 4:** This chapter has been published as a paper in the GROUP conference, 2010, November 7–10, 2010, Sanibel Island, Florida, USA: *Claudia Müller, Lin Wan, and Dalibor Hrg. 2010. Dealing with wandering: a case study on caregivers' attitudes towards privacy and autonomy when reflecting the use of LBS. In Proceedings of the 16th ACM international conference on Supporting group work - GROUP '10. New York, New York, USA: ACM Press, 75–84.*
- **Chapter 5:** This chapter has been published as a paper in the 7th International Conference on Pervasive Computing Technologies for Healthcare (Pervasive Health), 2013: *Claudia Mueller, Lin Wan, and Volker Wulf. 2013. Dealing with Wandering in Institutional Care: Exploring the Field. In Proceedings of the 7th International Conference on Pervasive Computing Technologies for Healthcare. IEEE, 101–104.*
- **Chapter 6:** This chapter has been published as a paper in the 32nd annual ACM conference on Human factors in computing systems (CHI), 2014: *Lin Wan, Claudia Müller, Volker Wulf, and David Randall. 2014. Addressing the subtleties in dementia care: pre-study & evaluation of a GPS monitoring system. In Proceedings of the 32nd annual ACM conference on Human factors in computing systems - CHI '14. New York, New York, USA: ACM Press, 3987–3996.*
- **Chapter 7:** This chapter has been published as a journal paper in the ACM Transactions on Computer-Human Interaction (TOCHI), 2016: *Lin Wan, Claudia Müller, David Randall, and Volker Wulf. 2016. Design of a GPS Monitoring System for Dementia Care and its Challenges in Academia-Industry Project. In ACM Transactions on Computer-Human Interaction (TOCHI), Vol. 23, Issue 5, Pages 1-36.*