Enabling a Mobile and Independent Way of Life for People with Dementia – Needs-oriented Technology Development

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> "I run around in the corridors of my memory and feverishly trying to understand what's going on. Sometimes the search makes me even more confused, as I forget what confuses me."
> Taylor 2008: 6

1. Introduction

Life expectancy will increase over the next 50 years, and demographic change over the coming decades appears to alter Germany's population structure. These developments offer the opportunity to integrate older people in their neighbourhood[1] as long as possible, but they also raise questions around how people are cared for and looked after in the future. In 2011 2.5 million people (83% aged 65 or over) were in need of care in Germany; 754,000 people were cared for in 12,400 licensed nursing homes (Federal Statistical Office 2015). Furthermore, given the rapid growth of people suffering from dementia (Bachman et al. 1993) and the parallel decrease in the number of people entering the care profession, the unmet needs of people with dementia will grow to an even greater extent (Meiland et al. 2010: 80). In Germany, more than 1.4 million people suffer from moderate to severe dementia (German Alzheimer Society 2014); two-thirds of them are affected

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[1] | The term 'neighbourhood' denotes here and hereafter a defined, public and social space around a residential care facility.

by Alzheimer's. Every year nearly 300,000 new cases occur. Unless there is a breakthrough in prevention and therapy the number of people with dementia will increase to about 3 million by 2050, according to projections of population development. This corresponds to an average increase in the number of sufferers of around 40,000 per year, or more than 100 per day (ibid). It is already assumed that 69% of residents in nursing homes suffer from dementia-related mental illnesses (BMFSFJ 2007). Based on these demographic and social developments shortages in and pressure on the provision of care are expected. Affordable and high quality care must be guaranteed for the expanding population of those who need it.

An increasing number of scholars propose technological solutions like assisted living strategies to address this challenge, as they have the potential to enhance the efficiency and effectiveness of formal health care services. These technologies could improve and extend the quality of life for people with dementia by helping them lead fuller and more independent lives. In this context, various types of services and several devices are discussed and are available (see, inter alia, Lenker et al. 2013; Salminen et al. 2009; Löfqvist et al. 2005). Currently there are relatively simple products on the market such as automatic pill dispensers, as well as more complex and complete products such as tracking devices using Global Positioning Systems (GPS) that assist in locating people. In addition, internet-based applications designed to provide carers with clinical, decision-making, and emotional support have been evaluated in field trials and the initial results have shown the systems to be beneficial both to carers and to people with dementia (Lauriks et al. 2007). Nonetheless, at present there are just a limited number of systems on the market which are capable of offering help and solutions with respect to movement for people with dementia in long-term care. This could be because the movement needs of people with dementia are very different. In general, it must be noted that currently available applications or devices for people with dementia have been designed with little involvement of the end-user (see in this regard Encarnação, et al. 2013; Orpwood et al. 2005). Where there was involvement of the end-user, this occurred after the decision had already been made as to which kind of device or service would go forward for technology development. It is our view that integrating and respecting the perspectives of the whole care arrangement[2] (people with dementia, their

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2 | The authors support the use of the term 'care arrangement' (Blinkert und Klie 2004) which has been further developed by their organisation, the Institute for

relatives and formal carers) in the development process has a decisive impact on the development of technologies for care and support to become successful innovations. Technologies are developed for specific, everyday situations, according to the social context of the technology and the living environment of the potential user.

2. MOVEMENT IN PEOPLE WITH DEMENTIA

Dementia is an umbrella term used for one of the most common mental health problems amongst elderly people; it is progressive and characterised by serious losses in cognitive functioning, particularly memory, thought processes, orientation, aptitude for learning, language, as well as the ability to judge. Along with these cognitive losses, emotional and behavioural changes occur, which can develop into depression, hallucinations and extreme agitation (Schäufele 2008: 169). As the dementia progresses so does the loss of mental ability, including the capacity to solve everyday problems, with the effect that people with dementia experience an increasing loss of independence and rely ever more on support. This deterioration can express itself in a great variety of ways and differs greatly between individuals. A relatively common form of expression is extreme agitation amongst people with dementia, which can manifest itself as a strong urge to move (known as 'wandering'). This, in combination with the impairments described, can lead to elderly people potentially endangering themselves, as their orientation ability is limited or non-existent. In addition, people with dementia displaying these symptoms may walk themselves to exhaustion, and fail to adequately perceive their own physical limitations or bodily signals, such as hunger or thirst. Other people with dementia display so-called 'running away tendencies', leaving their neighbourhood and wandering in search of previous environs (a house they lived in, perhaps), or wander because they sense the need to complete a chore (look after their mother, for example).

At the same time, movement is recommended as an intervention to activate brain function and thereby slow down the development of symptoms, and

Technology Assessment and Systems Analysis at the Karlsruher Institute of Technology (KIT) (Krings et al. 2013). The term captures the relationship between care needs and care activities. The care arrangement concept analyses how and to what extent various actors are involved in shaping care in real situations.

is recognised as countering gradual immobilisation (becoming bed-bound) (Schrank 2013; Abt-Zegelin/Reuther 2011; World Health Organization 2010; Zegelin 2010). The authors of the S3-Guidelines 'Dementia' by the German Society for Psychiatry and Neurology (Deutsche Gesellschaft für Psychiatrie, Psychotherapie und Nervenheilkunde) and the German Association of Neurology (Deutsche Gesellschaft für Neurologie) reach the following conclusions regarding movement facilitation as a psychosocial intervention: "Regular physical movement and an active mental and social life should be recommended" (DGPPN/DGN 2013: 91). The authors refer here to studies which evaluate an active lifestyle with physical movement, sporting, social and mental activity as protective with regards to the development of dementia (ibid: 91). Another supporting argument is that falls are one of the major health risks in our rapidly ageing population. Falls frequently result in moderate to severe injuries and when added to the fear of falling, they can limit the activity of the people with dementia (Baldewijns et al. 2013); the mobility and balance of the person already at risk thus further declines, subsequently increasing the risk of future falls (Fleming/Brayne 2008; Milisen et al. 2004).

Movement can therefore be considered an effective and supplementary key component in the care and support of people with dementia. Movement is associated with motor, sensory and social activation, which can have an effect on the quality of life and functional status of people with dementia, and can help avoid contractures and bed sores. In addition, the development of dementia in older people often occurs in association with signs of ageing, and according to Kangas et al. (2009), about one-third of all people over the age of 65 fall once a year. In many residential care facilities efforts are made to reduce the number of falls by strengthening 'body resources', as there is so much scientific evidence that exercise itself is important for the body's physical well-being, but no "vision-zero concept" will ever be reached in relation to falls. Movement, physical activation and inspiring physical strength also fulfil basic psychological and emotional needs. Individuals' own capacity to move may be tested and developed autonomously. Through the experience of this capacity to move, the daily routine can be designed to be vital and stimulating in order to maintain existing capabilities for as long as possible and thereby delay the need for a high level of care.

Enabling movement, in particular outside the care facility, poses a difficult situation for care providers, residents and their relatives, as well as for the inhabitants of the neighbourhood: on the one hand, independence for people with dementia is to be sought and promoted, whilst on the other,

depending on the individual's cognitive abilities and their condition, carers and relatives seek safety for the elderly person, which often correlates with a withdrawal of freedoms. This leads to a situation in which the desired autonomy and independence is restricted by safety considerations and a fear of self-endangerment. All of these issues considered, the care facility itself often has regulations to ensure its duty of care, which don't allow for movement in the open air. As a result, legal reasons dictate that the elderly person's safety is given a greater weight than their entitlement to movement. The frequent shortage of sufficient personnel in these facilities often contributes to the fact that individually-designed movement facilities cannot be provided.

As a result of the situation in residential care a number of conflict areas can be identified, namely the aforementioned conflict between freedom to move and self-determination versus safety.

Upon this backdrop, the question is whether and how technological devices yet-to-be-developed can support (in various ways) individuals' ability to participate and carry out daily life as independently as possible, and thereby maintain and develop the basic need for movement within care contexts (see, inter alia, Skymne et al. 2012; Pape et al. 2002; Daley/Spinks 2000). This question includes the intention to incorporate danger-free access to individual social areas in the neighbourhood outside of the care facility. This means that, using technically-possible devices, models are to be investigated which offer people with dementia the opportunity to (once again) take walks unaccompanied, go shopping or make visits within the social neighbourhood in which their care facility is embedded. In order to achieve this, innovations which strive to combine technical solutions with social interventions in neighbourhoods should be sought. Finally, steps should be taken so that people with dementia, as members of the neighbourhood, encounter a dementia-friendly environment and an age-friendly infrastructure. In this situation, technical aids could provide a reliable basis upon which people with dementia are able once again to manage the external world. Moreover, other technical systems which offer elderly people numerous options for reliable orientation are conceivable: these could help reduce feelings of fear, doubt or lack of orientation and, in the short-term, help encourage steps out into the neighbourhood. In this context, technical options should be initiated and launched which enable the basic requirement for movement to be implemented in a range of management strategies. In the same way that there are great differences in the ability to learn new technologies during one's lifetime, the necessary adaptations and systems transferability in technical implementation will reflect changing

abilities as the dementia progresses. Whether or not this will be successful, and the requirements potential users in care management will have of the technologies, must be verified in a demand-oriented analysis.

3. INVESTIGATING THE NEED FOR MOBILITY: THE IMPERATIVE OF NEEDS-ORIENTATION

Mobility plays a pivotal role in modern Western societies, and a survey revealed it to be the impairment-related issue of greatest personal importance (Roentgen et al. 2013: 571). For this reason, the motto for the care and support of people with dementia must be 'As much freedom as possible, whilst providing as much protection as possible'. As discussed above and according to experts, technical support to help in this area of conflict suggests itself and is already being developed, e.g. localisation devices. Despite the fact that various scientific disciplines emphasise the importance of user-oriented development of products and services and that according to surveys manufacturers rank usability as 'high' or 'very high' in relation to market success, in practice implementation is typically technology-oriented. This means the integration of a potential user occurs in order to optimise a technology's usability. However, these development processes remain technology-focused, as they only take into account the needs of the potential user in relation to an already specified technology (cf. Cooper 2002; Reichwald et al. 2004; Bias/ Mayhew 2005). As a result, only traditional market research was carried out until the start of the buying process, or during product utilisation (e.g. complaint management). User tests are only carried out once the product is almost completely developed and, therefore, only minor modifications remain possible. With this 'technology-push' approach, a technology is suggested, which, from a technical perspective, fulfils care and therapeutic needs. This is particularly relevant for assistive technologies and services, given that these are still very new areas of research (Nygard/Starkhammar 2007).

Reasons for this are, on the one hand, a lack of anthropometric data or human models for the very heterogeneous target group of elderly people with dementia and, on the other, the lack of life experience and the knowledge gap e.g. for gerontological aspects and specific user demands in many product developers. This shortcoming hinders the developers' ability to put themselves in the position of elderly people, in particular those with dementia, and stops them relating empathetically to their requirements. In this case, knowledge

of individual disease symptoms and progression would be crucial in the development of user-oriented technology. In order that assistive technologies are successful on the market and aren't obstructed by use-related innovation issues, they must be acceptable to the user, that is, products must be user-friendly (i.e. fit for purpose) (e.g. Grunwald 2011; Schlick et al. 2010; Glende et al. 2009; Blythe et al. 2005). Moreover, the solution potential fails more profoundly the more specifically the relevant context is analysed. Increasing numbers of studies indicate that all 'users', (i.e. those with dementia), the care providers (several aspects of the changes in care work are focused on) and the relatives of those in care should be included (Weinberger et al. 2014).

4. IMPLEMENTATION OF A NEEDS ANALYSIS: THE MOVEMENZ PROJECT

Against the observations and reflections mentioned above, the project "Mobile, self-determined living for people with dementia in neighbourhoods" (Movemenz), funded by the German Federal Ministry of Research and Development (BMBF; 01/2013-12/2015), currently explores technical requirements – expressed as needs by potential users – for mobile technologies, primarily to provide the infrastructural preconditions and conceptual standards to allow people with dementia to move as autonomously as possible around their neighbourhood. Taking this into consideration, the course of this project follows a needs-oriented technology development and thus, analyses the 'desires' of potential users for technical support. Potential user, in this context, means the respective stakeholders in the care process, such as dementia patients, relatives, care professionals and service providers (the so-called care arrangement defined in Krings et al. 2013).

In particular, using a participatory design[3] of technologies, those with dementia are considered experts. The technological solution will not itself be assessed, but rather it will be regarded as just one component, with its on-going interdependencies with the stakeholders in the complete care arran-

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3 | Participatory Design is the name given to certain design principles and practices which aim to create products and systems that are more receptive to human needs (Clement/Van den Besselaar 2004). Sanders (2002) differentiates it from the more commonly used term "user-centered design" (UCD) by describing UCD as design for users and PD as design with users.

gement. In addition, problems, expectations, feelings of security and accessibility (Gimskär/Hjalmarson 2013) or failings in the status quo (in short, the participating stakeholders' wishes) are to be included for consideration. Furthermore, these wishes must be explained to all stakeholders, potential conflicting wishes discussed and the expectations of the parties involved in the technology usage must be reconciled. In parallel, a methodological overview of subjective parameters, such as well-being and happiness, security, privacy as well as a clarification of the meaning of autonomy and quality of life will be undertaken. Quality of life implies, here, the involvement of the physical and social environment, quality of support, behaviour, medical and cognitive status, psychopathology and behavioural traits as well as experiences and emotional sensitivity in support providers. Drawing attention on these issues it becomes essential to identify the environmental, social and functionality contexts in which the technology is to be introduced and to analyse the socio-structural background of the care 'environment' in which the investigation is to be carried out. This approach implements the idea of social innovation[4]. Here the technical innovation is analysed in its use context. In this case, the use context of the technological development consists of the care arrangement and the neighbourhood. This is where the stakeholders' expectations as well as their 'unrealistic demands' meet: People with dementia may not recognise their failing capacities and will expect their relatives to allow them to live an autonomous life. Relatives form expectations of the people with dementia and the care personnel, whom they expect to be concerned with the security of the dementia sufferer and provide stimulating care for as long as possible. Finally, the care personnel expect support from the relatives and have a realistic expectation of the intensity of care and support.

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4 | Up until now scientific and political interest was very much concentrated on technical innovation. Social innovation is a complex process that profoundly changes the basic routines, resource and authority flows, or the beliefs of the social system in which it occurs (Wesley/Antadze 2010: 2; Blättel-Mink 2006). Social innovation does not necessarily involve a commercial interest, though it does not preclude such interest. More definitively, social innovation is oriented towards making a change at the systemic level. As Phills et al. (2008: 37) explain, "Social innovation transcends sectors, levels of analysis, and methods to discover the processes – the strategies, tactics, and theories of change – that produce lasting impact."

In addition, social changes which accompany each technical innovation must be considered, thereby increasing the chances of the technical innovation's successful implementation, based on its acceptability. This means that all stakeholders in the care arrangement will be studied and assessed during the context-specific needs analysis. The user needs analysis is especially important, with a focus on the mobility of people with dementia, as effects like cognitive difficulties, physical disabilities and changes in emotions and behaviour vary from person to person. Therefore, the issues around people with dementia being mobile are person-specific. One person may need just a little balancing support whilst standing, while another may need intensive support or a technical device e.g. a walking stick, four-wheel walker or wheelchair (simple, low-tech). Not only does the need for support vary greatly between users, but technology offering similar functionality may have different actual uses. In addition to this, each individual's technological competence as learned over a lifetime must be taken into account as well as the continuous decrease of this competence in progress of dementia.

The methodological implementation of the user needs assessment should therefore clarify the conditions under which the support system would be attractive to all participating stakeholders. The starting point for the research should be an open needs assessment.

Starting with the identification of the empirical setting, determining the regional location of the home for people with dementia and gaining access to the field was challenging. The same applies to selecting which scientific methodology to use to provide an insight into the daily routines both of the people with dementia and all "care givers" (in the broad sense) around them. Coming from this perspective it seemed important to accompany and to simply observe the daily routines in the home. This included analysis of the institutionalised structure of the home on the one side, and on the other, it included an observation of how walks and shopping trips by the elderly people are conducted in long-term care settings, the environment in which their everyday life is embedded and which areas of need can be identified. Observation of technical aids within these routines was also a focus of attention.

Taking the challenges of a demand-analysis into account, the approach to the empirical field was developed into a two-phase process. In the first phase, sensitive involvement of the research team in the home as well as careful observation of the daily lives of the people with dementia was prioritised. In the second phase, individual as well as group interviews were conducted in order to hear the voices and opinions of *all* social groups involved.

In addition, the needs assessment is accompanied by an interdisciplinary and transdisciplinary research process. In this reflection process aspects of ethics, law, economy, technology, society and care science are observed based on empirical analysis. The aim is to consider not only technical but all relevant aspects, especially ethical and social ones but also, for example, aspects like who is liable for damages that might occur during the use of technical aids and what is the cost-benefit ratio of technological and social innovations.[5]

5. Approach to the Empirical Field and Initial Results

In order to get closer to the field of residential care of people with dementia and to learn something about health care and mobility relating to dementia in everyday care, the field was firstly considered from the perspective of the qualitative method of Grounded Theory.[6]

According to the ‚all is data’ concept (Glaser in: Przyborski/Wohlrab-Sahr 2010: 198), materials and information such as the website of the residence, documents, statistics and informal talks etc. were included in the process of collecting data. However, explicit preference is given to observation, which is reflected within the observation protocols of each team member. These protocols are based on two two-week observation periods. This stage investigated how care is organised in these contexts, and which needs and challenges those participating have around the concept of movement. This specific method highlights that the 'field', being an essential pre-condition, is to be determined in an unbiased way. Unbiased here means that no technical options are presented which would affect the structure of the 'field' in advance. Instead, first and foremost, the intention is to open up the 'field of residential care' as the basis

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5 | The entire project process is described elsewhere (see inter alia Weinberger et al. 2014).

6 | The process of Grounded Theory was developed by Anselm Strauss and Barney Glaser in the USA in the 1950's and 1960's. The basis of this qualitative applied method is to bring empirical research and theory-building closer together from the start. No specific surveys were developed within the scope of this method: "Important, here, is the interwoven process of sampling and theory generation according to the principle of theoretical sampling." (Przyborski/Wohlrab-Sahr 2010: 189)

of this exploratory project, as well as for general further questioning. Based on this, this phase was conducted in a care home in a neighbourhood with approximately 5,000 inhabitants in Baden-Wuerttemberg. The denominational, diocesan-supported, non-profit home for people with dementia is located in the redeveloped town centre, surrounded by historical buildings and shops of all kinds. "You can linger in cafes, or buy daily provisions in various specialist shops or markets. Churches, the town hall and the station are all easily accessible on foot" (care home's website, translated by authors). In this care home live 49 people aged between 76 and 98 (and one 66-year-old) spread over two floors (24 residents on first floor, 25 on the second floor). The residents suffer from moderate to severe dementia.

Based on these comprehensive observations and impressions, structured interviews were conducted, as mentioned above, to prioritise the areas of need according to the dementia sufferer's abilities. Targeted exploratory focus groups of relatives, carers as well as inhabitants of the neighbourhood were established in order to reasonably determine their motivations, expectations and fears. Not before the end of the process of needs assessment, questions were posed to the potential users regarding technical solutions with regard to possible technologies in the immediate future. The questions didn't focus, at this stage, on specific ideas for technological options. Instead, the questions were kept open e.g.: In what areas of care and support for people with dementia are technical aids needed for supporting everyday care?' and ‚what demands would be made of these technologies and how might they look?'.

Although the results of these two phases of data collection have not yet been systematically evaluated, the following chapter will provide some insights, as preliminary results. This preview will offer an idea as to how multifaceted the implementation of a needs-analysis could be. This is particularly the case when technical options are adjusted to the different social needs of dementia sufferers' care.

6. HYPOTHESES BASED ON OBSERVATION OF THE EMPIRICAL FIELD

As mentioned above, the data resulting from implementing Grounded Theory as a methodological approach, including observations protocols, discussion notes, photographic material as well as complete interview materials, was systematically evaluated. In the first stage of analysis, the subjective per-

ceptions and observations were gathered and considered by the project team on the bases of the varying perceptions, in order to objectify them through a lengthy communications process. A common perspective of varying observations phenomenon was hereby developed, and a selection of themes was made which appeared, from an external perspective, to be relevant to this social context as well as the questions underpinning the project. This evaluation process resulted in a total of 14 hypotheses which provide a thematic insight into the field of residential care for people with dementia. These are presented in this book chapter as examples only. Therefore, in addition to the selected *theses (indicated by italics)*, the underlying situational descriptions as well as an evaluation of discussions[7] with residents (B), community service volunteers (E), relatives and nursing staff (P) was illustrated. The following are introduced as examples of the themes: a) the discrepancy between care and support, b) training requirements for supporting people with dementia and c) neighbourhoods as social spaces for people with dementia.

The Discrepancy between Care and Support

A series of situations in the residential area of the home led observers to the conclusion that due to time restrictions and institutional guidelines, such as the categorisation of task fields into so-called 'care stages', little or no support can be given or adapted to the individual person and their individual personality. The nursing staffs' tasks focus predominantly on straight forward care activities.

Situation (exemplarily, observations protocol 2): a B screams "Let me go, damn it. I haven't broken anything, have I. I'm not in prison. Ordered onto the toilet. What nonsense. How much longer do I have to sit here?' Another B comes out of her room without a Zimmer frame, therefore uses the handrail, care trolley and plate trolley instead. "I can't go any further!" P walks past. B is in a wheelchair by the window but can't see out, and due to her physical condition is unable to move herself in the wheelchair. When asked if she wants to attend the programme, she responds with a definitive no, but is taken there in her wheelchair, regardless.

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7 | In relation to this, it should be noted that the discussions were not initiated by the observers, rather contact between the residents of the care home and the observers was actively sought by the residents.

There is general consensus that the daily routine in the care homes that were investigated follows a set pattern which determines the activities of both the care providers and those receiving the care. Getting up in the morning, washing and meals as well as the activities on offer provide a certain amount of structure to the care providers' work flow. A legally stipulated ratio determines the number of registered nursing staff to those in need of care, and the care provision may only be provided by this nursing staff, whilst housekeeping activities may be carried out by porters. Under normal circumstances, this process operates smoothly. However, when incidents occur, for example if a resident wets their bed, falls over or is in a depressed state of mind, and other demands are being made, great strains are placed on this process. The entire nursing staff identified time pressures and stress as shortcomings, as well as the feeling that they were able to tend to the physical needs of the elderly people whilst conversation or support activities were not recognised. From the point of view of those receiving care, this shortcoming was expressed predominantly by the relatives. The people with dementia had few opportunities to comment, having to comply as part of the process. Extraordinary nervousness or an apathetic demeanour was observed most probably as a reaction to these pressures. Thus a distinctive discrepancy was identified between physical care and emotional/mentally stimulating care.

This conflict is highlighted by an example of two quotes taken from conversations (community service volunteers group interview):

E1: "The residents are still spending too much time sitting around their rooms, alone. The bed-bound are provided for, but that's it." E2: "You can't put people in their wheelchairs at 8am, and not take them eat until midday."

These quotes indicate that despite a distinct sense of responsibility as well as a high level of competence among the nursing staff, the structural framework leaves little room for the provision of holistic care for people with dementia.

Training Requirements for supporting People with Dementia

Despite deepening research and medical understanding of the progressive stages of the disease dementia, this understanding was barely transferred into care in the residential unit investigated. This was established as a shortcoming within the framework of the observation, and provided a thesis which characterised many subsequent situations: *Professionalization within*

the framework of the dementia syndrome is shaped, to a certain degree, by training such as building a biography, or acquiring a deeper understanding of the dementia sufferer's life story. This additional learning is necessary in order to sufficiently understand on the one side the dementia sufferer's behaviours, and on the other, in order to adequately handle and react to these behaviours. It was found that despite an overwhelming majority of residents suffering from dementia, only the registered nursing staff had taken the opportunity for further study in relation to the care of people with dementia (biography building). This nursing staff was, however, engaged in 1:1 day care support in the facility, and not present in either residence. Thus it emerged that due to a lack of training amongst the nursing staff regarding the syndrome dementia, specific situations in the everyday care were either unresolved, or unresolved in the long term.

Situation (exemplarily, observations protocol 2): B comes out of her room and drops her key off with a P. "I'm going home". She then walks in the direction of the lift and leaves the care home. In the residence there is great consternation, as it is not known that the resident is only going to her son's house, a couple of streets away, and is then coming back alone. The son is informed. A member of the nursing staff reports that in such situations the police are also informed.

Situations (exemplarily, observations protocol 1 and 2): There is a resident who continually screams:

B: "Mother, Mother, Mummy, Mummy. Who's saying that?" Rolls back and forth in the wheelchair. Appears agitated. "It's too much for me. Come here. Come here. Mummy."

B is collected by P. P begins to feed her straight away. B screams and so is taken immediately to another lounge.

B screams "Lunch. Meat. Meat. Please. I shouldn't say it. Please (ten times). Don't tell anyone. Mummy. Cheating. Coffee cup. It's a cheat. Uncovered."

P thereupon says definitively "Right, that's enough!" and takes B to her room

Situation (exemplarily, observations protocol 4). A resident sings constantly. B comes out of her room singing and puts the chairs in the eating area in order. She sings 'Little Hans', a nursery rhyme. Her singing gets louder. Other residents tell the observers, "She sings all day. Has done for years."

These two behaviours led in a large number of cases during the observations to a significant disturbance among the other residents, some of whom

asked vociferously for quiet. In many cases, the thought and action processes of the dementia sufferers conflicted on the one hand with the facility's structural processes. On the other hand, the dementia sufferers' statements and phrasing were often met with incomprehension, and were not taken in a wider context. It appeared however, that the dementia sufferers' diverse styles of expression could translate into biographical knowledge, leading to less incomprehension on the part of the nursing staff as well as the residents. Thus an adequate biographical study could provide solutions for such challenging situations.

Neighbourhoods as Social Spaces for People with Dementia

Within the framework of the observation, the residents were also observed on walks, and whilst shopping. This was of great interest as, ideally, the integration of people with dementia in neighbourhoods fits parallel to increased mobility. Technological access should create scope for enablement in the long term, in order that the neighbourhoods may be used both more and in an individual way. On the basis of observations, the notions of mobility, and thus neighbourhoods as a social space to be used by people with dementia must be revised. The thesis developed in this context frames the following observation: *The notion of neighbourhoods, within the framework of the research question, is a very individual social space. It consists of no more than a radius of 150m around the care home. Furthermore, amongst people with dementia, the desire for mobility does not seem to incorporate a desire to be outside. These residents identify the home as the social space. Thus the theoretical expectations of being outside and mobility were vastly different from the reality in the care home investigated.*

Although many residents make use of the home's open door policy and it's good location next to a park with a stream, only one in 50 residents goes on walks alone, taking responsibility for themselves. The length of the walk depends on their condition on the day, and the weather. On a good day the resident takes the longer route of about 500m; on less good days, and when it's raining or cold, the shorter route of around 250m was selected. In addition there was only one other resident who left the home alone and independently during our observation. She made use of the shopping options which were between 60m (the first shop) and 160m (the last shop) away. She takes a direct route from the care home to the shop or shops, does her shopping, and returns immediately, using the direct route. Her leaving the home to go

shopping, however, was based on compulsive shopping caused by neurosis, as the nursing staff informed us.

Situation (exemplarily, observations protocol 2): B sets off with a shopping basket, in the bakery asks other customers for 1 euro. Sales assistant comes out: "Leave my customers alone immediately – go away!" The sales assistant ejects B from the shop.

The notion of integrating people with dementia into the neighbourhoods more, and making use of attractions in the neighbourhood in order to mobilise people presented itself as complex within the unit investigated. This is due in large part to the fact that the residents are mentally and physically no longer in a position to decide upon and carry out excursions in the neighbourhood. In addition, the social integration of people with dementia into the neighbourhood as a social space is also very complicated and it would have to be prepared and promoted using targeted strategies and publicity work. Although this objective was one of the main concerns when the facility was established, the expectations, according to the former head of the facility, are largely unfulfilled. Targeted political and social efforts must be made to promote the integration of people with dementia into neighbourhoods. This is, however, currently widely lacking.

7. KEEP MOVING!

The three example theses form only a fragment of the on-going research process presented, however they do clearly reveal two aspects. Firstly, there are huge areas of conflict between the expectation that residential care-providing organisations have an institutional structure and the expectation that care-provision includes the nurturing of people with dementia in the care facility's daily routine. These areas of conflict are widely known and have been debated within the field for a long time. Due to economic considerations, obvious solutions in residential care such as, for example, increasing the ratio of support workers or the comprehensive promotion of professionalization strategies within the care sector seem unlikely.

Secondly, technologies and visions for the implementation of technologies in care are, in the project presented, not necessarily at the forefront in the minds of the nursing staff, the people with dementia or their relatives.

However, the needs-oriented approach to technology development, particularly in care, has been promoted for a considerable time now, and user involvement in the development of innovative technologies in care are increasingly required. Most importantly, against a backdrop of increased use of Responsible Research and Innovation (RRI)[8], responsible technology development should also be translated into practice.

The case presented, however, shows that with the user group encountered (people with dementia) this approach could and was only applied in a limited way. This was due to the fact that very elderly residents lived in the care home selected, up to the age of 96, and that the majority of these, with few exceptions, were in the later stages of dementia. An initial and provisional conclusion can be drawn from the approach, that the method of assessing need must be adjusted for each individual and the syndrome. How the method is to be adjusted to the group of people with dementia requires further research and discussion. Adequate technologies for care and support, as well as danger-free access to individual social spaces in neighbourhoods as well a social life for people with dementia as 'protected participants' can only be developed with an optimal needs analysis.

Nevertheless, based on observations, it can also be determined that the multiple areas of tension in residential care may not be resolved just by the use of technology alone. It would surely be helpful to think here of social innovations, which would frame the future demographic transition in terms of social and communal functions.

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8 | "Responsible research and innovation is an approach that anticipates and assesses potential implications and societal expectations with regard to research and innovation, with the aim to foster the design of inclusive and sustainable research and innovation. Responsible Research and Innovation (RRI) implies that societal actors (researchers, citizens, policy makers, business, third sector organizations, etc.) work together during the whole research and innovation process in order to better align both the process and its outcomes with the values, needs and expectations of society. In practice, RRI is implemented as a package that includes multi-actor and public engagement in research and innovation, enabling easier access to scientific results, the take up of gender and ethics in the research and innovation content and process, and formal and informal science education." (European Union 2015)

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