Technology as an Area of Conflict between Autonomy and Safety
Acceptance and Attitudes of Family Caregivers in Regard to Technical Assistance to Ensure Safe Areas of Movement for People with Dementia Diseases

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Abstract: Family caregivers take on a responsible task when caring for people with dementia showing the phenomenon of wandering. Technical systems like Global Positioning Systems (GPS) could support them in this respect. So far, there are no empirical studies in the German-speaking area that illustrate the attitude and acceptance of family caregivers on this subject. The subjective perspective of the family caregivers has now been ascertained after a systematic literature review and the selection of a qualitative research design based on n=14 problem-centered interviews. As a result, family caregivers endorse the use of technical devices to ensure safe areas of movement for people with dementia in cases where the benefit is recognizable and the handling is uncomplicated. Ethical questions are a major challenge for family caregivers as they have to make decisions for people with dementia that conflicts with autonomy and safety.

1 INTRODUCTION

The utilization of technical devices for domestic use as information and communication systems or for entertainment and occupation represents a daily routine for most people. Technical devices are also entering the caregiving and nursing field of people with dementia, who have the symptom of wandering. For this group of people, wandering is associated with maintaining their own identity, with the reduction of negative emotions, with self-determination and autonomy, as well as physical exercise. At the same time wandering is connected with several risks and dangers, e.g. getting lost, and accidents. Family caregivers, who take care of about 75% of people with dementia, are confronted with many decisions and challenges. In the present study the apparent logical consequence to the use of technical devices to create safe areas of movement was investigated from the perspective of family caregivers.

2 THEORETICAL BACKGROUND

2.1 Dementia and Wandering

The adaptability of people with dementia to their environment is reduced due to disorders of their cortical functions like memory, orientation, speech, and judgment (International Classification of Diseases, 2016; Marquardt and Schmieg, 2009). As a consequence, people with dementia experience an increasing threat to personal identity (Bunn et al., 2012). They struggle to meet central needs, such as the continuation of their lifestyle habits, the maintenance of their own identity, and the management of an autonomous life (Sütterlin, Hoßmann and Klingholz, 2011; Robinson et al., 2007a). Apart from symptoms, such as word-finding disorders, difficulties with everyday planning, and problems with the short-term memory, the symptom of wandering occurs in 15% to 60% of people with dementia. In literature, where different causes and manifestations are discussed, up to now no consistent definition of the phenomenon of wandering exists (Graham, 2015; Halek and Bartholomeyczick, 2012; Houston

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et al., 2011). In this study we follow the definition of wandering by Algase (2007):

'A syndrome of dementia-related locomotion behaviour having a frequent, repetitive, temporally disordered and/or spatially disoriented nature is manifested in lapping, random and/or pacing patterns, some of which are associated with eloping, eloping attempts or getting lost unless accompanied' (p. 696).

Although walking in everyday language describes a kind of movement, the phenomenon of wandering in combination with the disease of dementia gets a risk-occupied and pathological connotation. Often, interventions are aimed at avoiding wandering, for instance by closing the doors or by medicalization. However, these approaches are considered as restrictive and counterproductive (Graham, 2015; Wigg, 2010; Robinson et al., 2007a; Furuta et al., 2004). Therefore, a redefinition of the term wandering appears to be necessary in order to discuss how the living spaces of people with dementia could be designed safer, and to provide them with self-determination, autonomy, and quality of life (Kitwood, 2013).

2.2 Technical Devices and Family Caregivers

For family caregivers, the care of people with dementia is a time-consuming task, since with the progress of the disease and the presence of the phenomenon of wandering, immediate proximity and permanent availability become necessary. In order to meet these requirements, 70% of family caregivers live in the same house together with the person with dementia (Schneekloth and Wahl, 2005).

Often, family caregivers find themselves in situations where they have to balance the risks on one side, and the right or the desire for autonomy on the other side against each other (Bunn et al., 2012; Robinson et al., 2007b). Various studies show that daily challenges, the recurring conflicts, and time-consuming care entail negative consequences for family caregivers. Emotional distress (Robinson et al., 2007b), sleep disorders (Schäufele et al., 2005), reduction of their own social contacts (Moise et al., 2004), and a deterioration in their quality of life (Spring, Rowe and Kelly, 2009) are only few of the burdens of family caregivers described in the literature.

The use of technical devices supporting people with dementia to lead to an autonomous life in familiar surroundings, to preserve cognitive skills, and to maintain social contacts, becomes increasingly important for a need-oriented individual handling the phenomenon (Wigg, 2010; Heeg et al., 2007). High-tech systems that use electronics and micro-electronics as well as Ambient Assisted Living provide various technical devices for this purpose (AAL Germany, 2016; Heeg et al., 2007). From an ethical and data protection perspective it is very demanding for family caregivers to establish a balanced relationship between personal freedom on one side and the necessity to control activities and behaviour to a certain extent on the other side. Currently, only a few studies from England, Ireland, the Netherlands and the U.S.A. are available that take -with regard to the application of technical devices- the users´ perspective of family caregivers, and consider ethical issues. It remains unclear under which conditions, in which situations, and with what ethical attitude family caregivers would use the support of technical devices in Germany.

2.3 An Overview of Technical Support Systems

Technical devices developed on the basis of Global Positioning System (GPS), Global Mobile System (GSM), and Radio-Frequency Identification (RFID) are mainly used to identify the location of people with dementia, and to protect them from accidents (Mahoney and Mahoney, 2010; Wigg, 2010; Rasquin, 2007). In the study by Rialle et al. (2009) especially younger and female interviewees consider the tracking system as advantageous because safety is increased for people with dementia, fear and worry of family caregivers are reduced, and family caregivers can again take up their own social contacts in the long run.

Apart from the GPS-systems the literature mentions, numerous other technical devices are used to support the care of people with dementia. These include video surveillance, passive alarms (Mental Welfare Commission, 2002), actometers (Dietz, 2012), night-time monitoring systems (NMS) (Spring et al., 2009), and the iWander system (Sposaro, 2010). However, no valid studies could be found on these technical systems.

2.4 Acceptance of Technology

The acceptance of technical devices is a result of different influencing factors as described in the *Technic Acceptance Model* (TAM) (Davis, 1991) and its further developments TAM2 (Venkatesh and Davis, 2000) and TAM3 (Venkatesh and Bala, 2008). The model has been developed to explain the acceptance of individual users. The model was modified by Claßen (2012) with the result that it is now also valid for older people (TAM3a). In this study the TAM3a was used for two reasons. First, family caregivers are often older persons, second, in advanced stages of dementia family caregivers make decisions about the use of technology. In this model, the predictors *Perceived Usefulness* and *Perceived Ease of Use* directly influence the intention of a person to use a technical device. *Perceived Usefulness* is defined as 'the degree to which a person believes that using a particular system would enhance his or her job performance' (Davis, 1989:p.320) while *Perceived Ease of Use* is described as 'the degree to which a person believes that using a particular system would be free of effort' (Davis, 1989:p.320).

From a psychological perspective the formative phase between the ages of ten and twenty five is imprinting for the attitude to technology (Claßen, 2012). Each generation could collect different experiences in their formative phase depending on which role technology occupied in their time, to what extent technology was used, and which devices were available to the population (Claßen, 2012; Sackmann and Weymann, 1994).

3 AIMS OF THE STUDY

In order to take a closer look at the acceptance and attitudes of family caregivers regarding the use of technical devices in caring for people with dementia, two research objectives were formulated:

1. Collecting data from family caregivers on their attitude to wandering.
2. Investigating the acceptance of family caregivers concerning technical support systems in order to ensure safe areas of movement.

4 METHODS

Qualitative research strategies were used to investigate the subjective perspectives of family caregivers caring for people with dementia. Throughout the research process ethical principles have been strictly adhered to. The interviewees were informed in detail about the research aims, the procedure, their rights during and after the interview, and the anonymization of the data (Schnell and Heinritz, 2006; DGPs, 2004; BDSG, 1990). Each interviewee was asked to give written informed consent to participate in the study.

The research process is described in three phases as follows.

4.1 Phase 1

To get an overview about the object of research a systematic literature review was carried out in the databases CINAHL, The Cochrane Library, DIMDI, and the US National Library of Medicine. The results were evaluated after the subsequent completion of a freehand search in national libraries. Consideration was given to publications which

- were carried out as meta-analysis, randomized controlled trials, outcome studies, case-control studies, individual case studies, or qualitative studies,
- provided sufficient information on study design, the assessment instruments, and the methods of evaluation,
- were published during the search period from 1990 to 2016.

Subsequently the selected sources were excerpted and used as basis for the further research process.

4.2 Phase 2

Based on the findings from the literature and in compliance with the TAM3a (Claßen, 2012), a semi-structured interview guide was developed and structured according to the recommendations by Helfferich (2011). The following inclusion criteria were set for the problem-centered interviews according to Witzel (2000):

- The interviewee is or was the family caregiver (relative, friend, acquaintance, neighbour) of the person with dementia,

- the interviewee will take over or took over the responsibility for the care of the person with dementia,
- the patient was diagnosed with dementia and showed the symptom of wandering.

4.3 Phase 3

After submitting an informed consent, n=14 problem-centered interviews with family caregivers were carried out. As an example, illustrations of technological devices (e.g., GPS tracking system integrated into a watch, a sensor mat) were shown to the family caregivers during the interview to give them an overview about existing technical opportunities. A qualitative content analysis was carried out after complete interview transcription following Mayring (2008). The data material was repeatedly checked by the authors. In order to consider the ethical perspective, further categories were formed in conformity with the *Model for Ethical Evaluation of Socio-Technical Arrangements (MEESTAR)* according to Manzeschke et al. (2013). The developed categories were continuously reflected and adjusted during the data evaluation.

5 RESULTS AND DISCUSSION

Four male and ten female caregivers between the ages of 21 and 85 were included in the study. Half of the family caregivers (n=7) were older than 60. N=13 family caregivers lived or live in the same house with the person with dementia. At the time of the interviews n=6 interviewees gave accounts from the retrospective, because the care situation had changed due to the fact that the person with dementia had moved into a long-term care facility, or that the person with dementia had died. According to Robinson et al. (2009), these family caregivers brought in experiences which they could reflect critically due to the temporal distance.

5.1 Attitudes of Family Caregivers Towards the Phenomenon of Wandering

The phenomenon of wandering is omnipresent for all of the family caregivers (n=14) in everyday life. They are confronted with this behaviour both during daytime and nighttime. All interviewees stressed that they are not able to distinguish comprehensible causes but they are convinced of the fact, that wan-

dering serves a purpose for the person with dementia:

'It does make sense for her, but not for us.' (FC08:176)

'He´ll do it for some reason. But it is a mystery to me. So I take it as it is. ' (FC06:22)

The family caregivers observed a kind of restlessness in people with dementia. They describe people with dementia as 'very driven and unsatisfied' (FC10:136) and wandering is 'like a fixed idea' (FC05:60). According to the statements of family caregivers, wandering directly influences the mood of people with dementia. Four family caregivers noticed a beneficial change in mood during wandering. This change was either caused by walking alone or by being accompanied by an intimate person:

'Sometimes he is in a bad mood. Then he goes for a walk.' (FC06:112)

These results correspond with the findings of Robinson et al. (2007a). The people with dementia felt, that walking was enjoyable, kept them fit, relieved tension, and facilitated independence. Autonomy and self-determination are for family caregivers in the forefront of the early to middle stages of dementia, when the symptoms often occur only for a short time and in a moderate form. Only when they occur more frequently and get more severe, safety for the person with dementia gains priority (Sifton, 2011). The interviewed family caregivers realized the importance of wandering for the person with dementia, and were trying to fulfill their needs in this respect.

In our study the majority of the family caregivers (n=11) stated that the person with dementia no longer recognized well-known places, ways and persons anymore. Additionally half of the family caregivers had already experienced situations in which the person with dementia was getting lost. Therefore the risks of falls, losing their way, and accidents which were subjectively felt by the interviewed family caregivers increased:

'She has also fallen several times. And now we are confronted with the risk, that she doesn´t find her home anymore.' (FC13:30)

These experiences of family caregivers are affirmed in the literature. Approximately 60 - 80% of people with dementia fall at least once per year (Lord et al., 2007; van Doorn et al., 2003). Eight family caregivers said that they were constantly looking for suita-

ble measures that would provide support for handling the symptom of wandering in order to minimize the risks and to improve their own wellbeing. Due to these situations, they are in a caregiving dilemma. On one side they are aware of the risks and dangers, on the other side, they try to offer autonomy for the person with dementia. However, they feel insecure on how to balance both issues:

> 'I´m still not finished with answering this question. I´m asking myself again and yet again. Is it better to do what we want or is it better to look what´s good for her? That is difficult.' (FC13:59)

5.2 Acceptance of Technical Support Systems by Family Caregivers

The family caregivers see positive effects in the use of technical devices in two respects, which are also followed by the approach of Ambient Assisted Living (AAL Germany, 2016). On one side they are connecting safe-guarding of autonomy and self-determination for the person with dementia with the use of technical devices, on the other side they derive possibilities of easing their own burden by using technical devices:

> 'I´m not the technology freak. But if it´s necessary, I would deal with it. If it makes sense, then I say yes.' (FC10:223)

According to the findings of Rialle et al. (2009) more than 50% of the family caregivers were in favour of GPS-systems. As a result they expected safety for the person with dementia to a higher degree, and a reduction of their own anxiety and preoccupation.

With regard to financial aspects some of the family caregivers raised concern in relation to the acceptance of the technical devices by the person with dementia:

> 'Where does he get the money from when he is already on welfare?' (FC11:109)

Furthermore, due to the lack of insight into their illness and deterioration of their cognitive skills, the person with dementia could reject the technical devices or could cause errors due to incorrect handling. This findings correlate with the results of Faucounau et al. (2009) and Robinson et al. (2009).

Additionally, some family caregivers raised doubts that the devices comply with the aesthetic ideas of the person with dementia:

> 'I personally wish for small devices without attracting attention.' (FC04:198)

These findings are concordant with the results of other authors. The appearance of a technical device which could indicate a handicap and therefore stigmatize the person with dementia will be rejected (Robinson et al., 2009; Mental Welfare Commission, 2002). Furthermore the interviewed family caregivers expressed concern about the dangers of susceptibility to errors, malfunctions, breakdowns and exposure to radiation, especially when using GPS-based tracking systems:

> 'It´s possible that devices can be a source of malfunction or fire, which could be life-threatening.' (FC11:109)

> 'One says that they send radiation or things like that.' (FC02:167)

Additionally, the issue of unwanted and undetected transfer of data to third parties was raised several times in the interviews:

> 'It provides the opportunity of manipulation or changing the software. I think this is a risk' (FC11:101)

As many of the interviewed family caregivers use smartphones or navigation systems with GPS-functions themselves, the risks connected with the use of these systems were regarded as a matter of rather minor importance:

> 'Well, that is dealing with surveillance, with control […] but from that point of view, I couldn´t use my smartphone anymore.' (FC13:165)

However, it has to be considered, that both, the person with dementia and the family caregiver received comprehensive information concerning privacy and performance of the technical devices. Based on this information they were enabled to give informed consent (Manzeschke et al., 2013).

6 CONCLUSION

Wandering is a frequent symptom of people with dementia, that is associated with a high degree of burden for family caregivers. Additionally, it is entailed with different risks and dangers for the person with dementia. Family caregivers want to give people with dementia a realistic chance to experience safe, self-determined wandering.

The TAM3a according to Claßen (2012) was used to determinate the acceptance of technical support systems by the family caregivers in order to ensure safe movement spaces.

In reference to *Perceived Usefulness*, technical devices such as household appliances but also electronic information and communication systems have become indispensable in everyday life according to the opinion of family caregivers. The comprehensibility of the benefits, the anticipated results as well as the simple handling are of great importance. Only after gaining this knowledge the family caregivers would consider a possible use. None of the family caregivers generally rejected the use of technical support systems. They would use such systems themselves in the future, provided the mentioned conditions are fulfilled, because they expect positive results relating to the improvement of safety for the person with dementia.

With regard to *Perceived Ease of Use* each interviewed family caregiver was willing to deal with a new technical device, and attempt to put it into operation. Most of the relatives considered it as a positive challenge apart from a certain fun factor. Should they be faced with problems before and during the use of the device they would get help from other family members, specialists, and providers. They would consider comprehensive explanations and instructions when they purchase a device as very helpful:

> 'Yes, I would need support and instruction because I wouldn´t be able to learn it by myself.' (FC08:288)

About 50% of the interviewed family caregivers were 60 years old or older at the time of the study. It can, therefore, be assumed that they gained experience with mechanical devices during their formative phase rather than with electronic devices. They were in full agreement with the use of electronic devices such as a GPS based tracking system in the form of a watch or a bracelet.

Caring for persons with dementia is associated with a high burden for family caregivers. Poor health of the family caregivers is one of the most important predictors for nursing home placement (Joling et al., 2012). Based on our findings, electronic devices might be an opportunity to reduce the mentioned burden of the family caregivers. To support the acceptance of these devices, they should be small without attracting attention to avoid stigmatization, and they should be affordable for family caregivers.

In the course of the survey, it became obvious that ethical questions were of utmost importance for family caregivers. Based on the seven ethical dimensions according to Manzeschke et al. (2013) - care, autonomy, safety, justice, privacy, participation, and self-image - it could be ascertained that the question of safety for people with dementia is the central issue. It influences the further six ethical dimensions and restricts them sometimes. This statement will be illustrated by two examples.

Care vs. safety
Family caregivers see it as a caring act to let people with dementia wander. In order to ensure safety, it is necessary to restrict the areas of movement required for wandering.

Privacy vs. safety
The family caregivers want to give people with dementia a high degree of privacy. They accept a reduction of privacy for example due to use of GPS-systems provided that the safety is increased.

In the interviews, it turned out that the decision to improve safety at the expense of other ethical dimensions was associated with strong doubts. Many of the family caregivers were asking themselves if they were entitled to make this decision without the knowledge of the person with dementia and at which point in time the person with dementia should have been involved in this decision. The step which should have relieved their burden to a certain extent turned into an ethical distress. All interviewees felt left alone with the ethical dilemma as advisory services neither considered the use of technical devices nor the solution of ethical conflicts. Therefore training possibilities and advisory services should be expanded to explain the functions and applications of technical devices and to support the process of ethical decision-making (e.g., decision coaching).

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