



Matching values to technology: a value sensitive design approach to identify values and use cases of an assistive system for people with dementia in institutional care

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Abstract

The number of people with dementia is increasing worldwide. At the same time, family and professional caregivers' resources are limited. A promising approach to relieve these carers' burden and assist people with dementia is assistive technology. In order to be useful and accepted, such technologies need to respect the values and needs of their intended users. We applied the value sensitive design approach to identify values and needs of patients with dementia and family and professional caregivers in respect to assistive technologies to assist people with dementia in institutionalized care. Based on semi-structured interviews of residents/patients with cognitive impairment, relatives, and healthcare professionals (10 each), we identified 44 values summarized by 18 core values. From these values, we created a values' network to demonstrate the interplay between the values. The core of this network was caring and empathy as most strongly interacting value. Furthermore, we found 36 needs for assistance belonging to the four action fields of activity, care, management/administration, and nursing. Based on these values and needs for assistance, we created possible use cases for assistive technologies in each of the identified four action fields. All these use cases already are technologically feasible today but are not currently being used in healthcare facilities. This underlines the need for development of value-based technologies to ensure not only technological feasibility but also acceptance and implementation of assistive technologies. Our results help balance conflicting values and provide concrete suggestions for how engineers and designers can incorporate values into assistive technologies.

Keywords Assistive technology · Delivery of health care · Self-help devices · User-centered design · Value sensitive design

Introduction

Dementia is a key risk factor for admission to nursing home facilities (Miller et al., 2011) and hospitals (Bickel et al., 2018; Sommerlad et al., 2019). In Germany, the shortage of medical staff increases as well as the number of medical treatments and patients with need for care (Brücher & Deufert, 2019). Consequently, unskilled workers or those with only a short training in nursing are working as nursing assistants in hospitals or nursing homes and take over basic nursing tasks such as dressing, body care, and cleaning up resident's or patient's room. In nursing home facilities, more than a half of the residents are living with dementia (Hoffmann et al., 2014). In hospitals, people with dementia are often challenged by an unfamiliar environment. People with dementia may exhibit challenging behaviors due to disorientation and confusion (Digby et al., 2017). This leads to high burden for patients and caregivers and increased demands on time for caregiving (Digby et al., 2017). Staff needs to

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provide surveillance and practical assistance and has to cope with challenging behaviors of patients with dementia (Lorenzo-López et al., 2017; Misplon et al., 2004). These increasing needs meet decreasing numbers of trained medical staff in many countries. Assistive technologies (ATs) have the potential to support people with dementia in their daily life and may be able to take over some routine care activities (e.g. food preparation and intake) from professional caregivers in nursing homes and hospitals (Astell et al., 2019; Hoenig et al., 2003). Therefore, these technological solutions may help saving nursing care resources and maintaining person-centered care for people with dementia in institutionalized care.

“Zero effort technologies” (ZET) provide assistance with little need of active user input (Boger et al., 2018). They are particularly relevant for people with dementia who have limited ability to handle a technological device (Malinowsky et al., 2010). Additionally, ZET may be tuned towards delivering situation-aware assistance, i.e. only in automatically detected instances of need for help (Boger et al., 2018; Teipel et al., 2016). Thus, a situation-aware ZET device may help to maintain or even enhance the users’ autonomy and self-efficacy (Boger et al., 2018).

The process of technological development has to identify and integrate needs and values of future users in order to create useful and accepted technological solutions (Scherer & Craddock, 2002). User-centered development approaches such as value sensitive design (VSD) collect users’ needs and values systematically to integrate them into technology development (Friedman et al., 2008). Recently, research interest in values for the development of ATs for people with dementia has intensified (Dahl & Holbø, 2012; Ienca et al., 2018; Teipel et al., 2016). However, more proactive and patient-centered ATs for institutional care settings are needed (Koumakis et al., 2019). Our study aimed for collecting values and identifying use cases of an AT for and with people with cognitive impairment or dementia in institutionalized care using the VSD approach. The majority of studies listed values in the context of care as single items or pairs (Al-Banna, 2017; Ienca et al., 2018; McNeese-Smith & Crook, 2003; McWhinney, 1998; Rassin, 2008; Rider et al., 2014; Teipel et al., 2016; Toop, 1998; Zwetsloot et al.,

2013). Our study aimed at a comprehensive network of values as well as an in-depth investigation of their conflicting and reinforcing interplay. This interplay is important to balance possibly conflicting needs and values in regard to the development of AT (Ienca et al., 2018). From this network we created use cases for the integration of values into AT for people with dementia in institutional care (hospital or nursing home) in a user-centered way.

Method

Following the iterative VSD approach (Friedman et al., 2008), in the first phase, we identified the relevant stakeholders. In the second phase, we elicited values within a qualitative research approach. By semi-structured interviews with key stakeholders, we ascertained need for assistance, values, and potential use cases. In the third phase, we created technological use cases based on the results of the first and second phase. The implementation of a technological device covering these use cases will be part of subsequent research.

Identification of stakeholder groups

Following the first phase of the VSD approach, we identified the following three stakeholder groups based on the review of Richardson et al. (2019): people with cognitive impairment, their relatives, and healthcare professionals. Table 1 shows the inclusion criteria for each group.

Elicitation of stakeholders’ values and needs

Participants

We interviewed ten persons per group (in total 30 persons, see Table 2). All people with cognitive impairment received a mini mental status examination (MMSE) before the interview to check if they met the inclusion criteria. The majority of these people were in mild to moderate stages of dementia. The mean age of the people with

Table 1 Inclusion criteria for the three Stakeholder groups

| | |
|----------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| People with cognitive impairment | Mini-mental-status-examination (15–29) and clinically documented diagnosis of mild cognitive impairment (MCI) or dementia Age \geq 65 years Resident in a nursing home and/or experiences with hospital admission within the past 2 years |
| Relatives | Related to a person living with dementia or MCI residing in a nursing home and/or experienced hospital admission within the past 2 years Degree of relation: spouse or son/daughter (in law) |
| Healthcare professionals | Experiences in the treatment of people with dementia in their work life Occupational groups working in medical care such as physicians, nurses, therapists, and related occupations |

Table 2 Characterization of participants

| Patients or residents living with dementia | | | | | | |
|--------------------------------------------|---------------------------------|-----------------------------------|-------------|-----------------|--------------------------------------------|----------------------------|
| ID | Duration audi- ofile (hours) | Group of interviewees | Age (years) | Sex | Former occupation | MMSE |
| Inpat01 | 00:18:14 | Inpatient | 77 | Female | No response | 19 |
| Inpa02 | 00:25:07 | Inpatient | 92 | Female | No response | 29 |
| Inpa03 | 00:15:50 | Inpatient | 88 | Female | No response | 26 |
| Res04 | 00:27:02 | Resident | 98 | Female | Post office clerk | 27 |
| Res05 | 00:32:06 | Resident | 83 | Female | Factory worker | 15 |
| Res06 | 00:14:31 | Resident | 98 | Female | Foreign language correspondent | 23 |
| Res07 | 00:41:32 | Resident | 82 | Female | Healthcare employees | 22 |
| Res08 | 00:42:46 | Resident | 78 | Female | Sales woman and train conductor | 26 |
| Pat09 | 00:22:46 | Former patient | 69 | Male | Engineer | 27 |
| Pat10 | 00:15:29 | Former patient | 79 | Male | Bricklayer | 22 |
| Mean | 00:25:32 | 5 residents/5 in-/former patients | 84.4 | 2 male/8 female | | 23.6 |
| Relatives | | | | | | |
| ID | Duration audiofile (hours) | Group of interviewees | Age (years) | Sex | Former occupation | Employment status |
| Rel01 | 00:30:12 | Child | 64 | Female | No response | employed |
| Rel 02 | 00:33:00 | Spouse | 76 | Female | Physician | retired |
| Rel 03 | 00:33:08 | Child | 55 | Male | Engineer | employed |
| Rel 04 | 00:38:14 | Spouse | 81 | Female | Farmer (academic) | retired |
| Rel05 | 01:04:23 | Spouse | 84 | Male | Medical professor | retired |
| Rel06 | 00:22:16 | Child | 56 | Male | Managing director | employed |
| Rel07 | 01:16:18 | Spouse | 68 | Female | Economist and rehabilitation manager | retired |
| Rel08 | 00:37:51 | Spouse | 71 | Male | Engineer | retired |
| Rel09 | 01:13:51 | Spouse | 80 | Female | Office clerk | retired |
| Rel10 | 01:05:52 | Spouse | 64 | Female | Sales woman | retired |
| Mean: | 00:47:30 | 7 spouses/3 children | 69.9 | 4 male/6 female | | 7 retired/3 working |
| Healthcare professionals | | | | | | |
| ID | Duration audiofile (hours) | Group of interviewees | Age (years) | Sex | Occupation | Work experience (years) |
| HcpHo01 | 00:21:55 | Healthcare Hospital | 26 | Male | Nursing assistant | 9 |
| HcpHo02 | 00:18:06 | Healthcare Hospital | 39 | Female | Nurse | 19 |
| HcpHo03 | 00:19:54 | Healthcare Hospital | 32 | Female | Occupational therapist | 12 |
| HcpHo04 | 00:29:51 | Healthcare Hospital | 44 | Female | Occupational therapist | 19 |
| HcpHo05 | 00:48:22 | Healthcare Hospital | 54 | Female | Physiotherapist | 24 |
| HcpNh01 | 00:24:47 | Healthcare Nursing Home | 36 | Female | Nurse | 15 |
| HcpNh02 | 00:12:43 | Healthcare Nursing Home | 33 | Female | Nurse | 17 |
| HcpNh03 | 00:50:13 | Healthcare Nursing Home | 32 | Male | Occupational therapist assistant | 5 |
| HcpNh04 | 00:46:35 | Healthcare Nursing Home | 56 | Female | Occupational therapist | 20 |
| HcpNh05 | 00:35:52 | Healthcare Nursing Home | 36 | Female | Nursing assistant | 9 |
| Mean | 00:30:50 | 5 hospital/5 nursing home | 38.8 | 2 male/8female | 5 therapists/5 nurses (nursing assistants) | 14.9 |

cognitive impairment was 84.4 years (range: 69–98) and the mean MMSE was 23.6 points (range: 15–29).

The relatives' group consists of seven spouses and three children with a mean age of 69.9 (range: 55–84) years. The healthcare professionals had on average 14.9 (range: 5–24) years of work experience and were 38.8 years (range: 26–56) old.

Creation of the interview guideline

Following the second phase of VSD, we created an interview guideline for each stakeholder group to focus on specific needs, perspectives, and roles.

Besides socio-demographic data, the interview guidelines covered three further categories (see Table 3).

Socio-demographic and personal data contained age, sex, recent or previous occupational activity, details of illness, and living or working situation.

Category 2 focused on daily routines, leisure activity, working routines, and need for help.

We asked the following questions to people with cognitive impairment:

1. How does your everyday life look like?
2. What do you like to do?
3. Do you need assistance in your everyday life?
 - (a) If yes, in which activities?
 - (b) If yes, who provides assistance?

Category 3 covered challenging behaviors (e.g., disorientation during hospitalization), coping strategies for these behaviors and their consequences. We asked people with cognitive impairment and their relatives about difficulties in unfamiliar environments during their stay in institutional care:

1. Where did you/your relative have to adjust the most?
2. What problems did the hospitalization/admission to the nursing home cause?

Category 4 concentrated on experiences with modern technologies, expectations from technologies as well as concrete situations of need, kind of assistance provided, and design ideas of a conceivable AT. The questions were based on the technology acceptance model (Davis, 1985) and technology usage inventory (Kothgassner et al., 2013) and aimed to identify predictors for technology use. We asked for previous experiences with novel technologies, resources, and obstacles during use and barriers to access for technology use as well as desired functions and design ideas for an AT. Due to the large amount of collected data in category 4, we concentrated on the evaluation of the categories *everyday living & need for assistance* and *behavior on inpatient admission*.

All questions were openly formulated and tried to avoid any suggestions. If applicable, questions were supplemented by further in-depth sub-questions.

Procedure

The recruitment took place in the memory clinic of the University Medical Center Rostock, in the geriatric ward of a regional hospital and in a nursing home. In addition, relatives were recruited by the network of the German Alzheimer's Association.

All participants or their legal representatives provided written informed consent. Interviewers ensured ongoing consent during questioning. The study was approved by the responsible ethics committee of the University Medical Center Rostock (A 2018–0109) and conducted in accordance with the Declaration of Helsinki (WMA, 2018).

Two female dementia-educated researchers (SK, DG) from the University Medical Center conducted the interviews in rooms of the institutions, in a patients' day care facility, or at relatives' home. All thirty interviews were audio taped, transcribed verbatim, and pseudonymized.

Analysis

The analysis was divided into two parts. First, we applied qualitative content analysis according to Mayring to analyze

Table 3 Main categories of the semi-structured interview guideline

| Category | Domain | People with dementia | Relatives | Healthcare professionals |
|----------|-------------------------------|---------------------------------------------------------------------------------------------------------------------|-----------|--------------------------|
| 1 | Socio-demographic data | Socio-demographic and personal data | | |
| 2 | Daily activities | Daily living Need for assistance | | Daily work |
| 3 | Behavior | Behavior on inpatient admission | | Challenging behaviors |
| 4 | Characteristics of technology | Potential areas of application of technological assistance Design ideas Acceptance and adoption of technology | | |

the transcribed material in respect to the daily living/work, situations of need, and potential use cases for an AT (Mayring, 2000). Secondly, we identified values and their interplay in the categories of daily living/work of the stakeholders within a grounded theory approach. To achieve this, we interpreted the data following the logical analysis method (Patton, 2015).

In line with Mayring’s qualitative content analysis approach, we defined the evaluation units (all transcripts), context units (sense section/paragraph), and coding unit (individual words/word groups/sentences) (Mayring, 2014). After identifying the coding unit, we categorized and reduced it in three steps: paraphrasing the coding unit, generalizing the paraphrase and reducing the generalization (see Fig. 1 for an example) (Mayring, 2014).

The main categories were built from the interview guideline and deductively filled with coding units and their reduction, respectively. If necessary, coding units were assigned to multiple categories. Deductively built categories were supplemented stepwise during the evaluation process by inductively creating new sub-categories from the interview material (Mayring, 2000). A coding guideline served to ensure an unambiguous assignment to the categories (see Table 4).

Further, we conducted intra- and intercoder-reliability checks (Mayring, 2014). In sum, three researchers contributed to the research process: two drew up the interview guidelines and conducted the interviews (SK, DG). The same researchers analyzed the data together with a third researcher (AK) to perform the intercoder-check. Within a grounded theory approach, we inductively extracted values from the interviewees’ answers coded in the categories *everyday living & need for assistance*, *challenging behavior*, and *behavior on inpatient admission*. Further, we conducted an intercoder-check (DG) and compared our results to the literature.

In accord to the logical analysis method (Patton, 2015), we extracted the values’ relations to each other by crossing the quotations. Logical analysis is an interpretative method which visualizes patterns and cross-classification matrices (Patton, 2015). Therefore, the analyst moves iteratively through the material to find and validate his/her findings until he/she achieves meaningful patterns (Patton, 2015). Figure 2 illustrates the analysis process. Instead of a matrix, we created a values’ network from the derived relations.

We used the evaluation software MAXQDA 2018, release 18.2.4 (VERBI software, Consult. Sozialforschung GmbH,

Fig. 1 Process of reduction according to Mayring (2000, 2014), created with power user

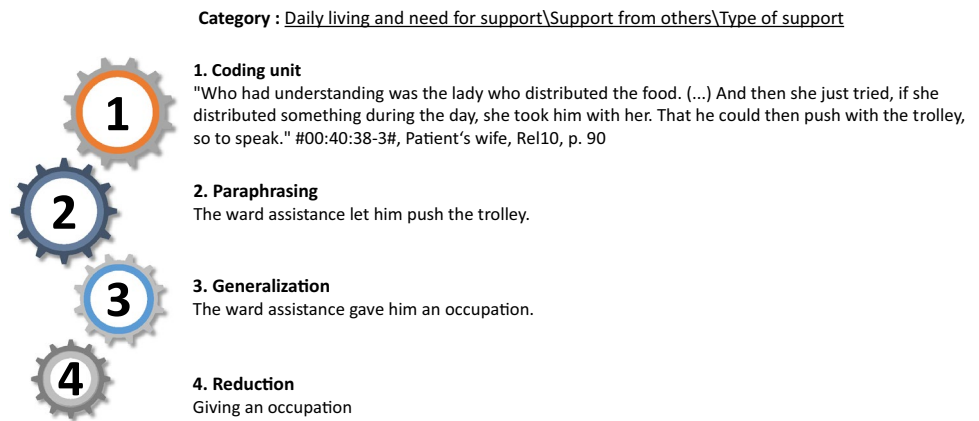
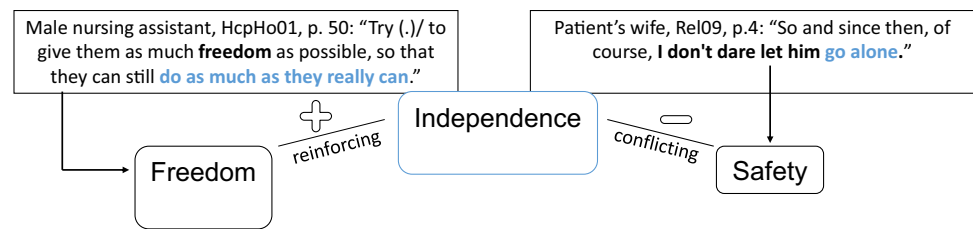


Table 4 Extract from the coding guideline

| |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Main category: behavior during hospitalization/in nursing home |
| Sub-category 1 |
| Behavior during stay\Problems with adaptation of people with cognitive impairment |
| Definition |
| Describes the adaptation to the unfamiliar environment from the perspective of the people with cognitive impairment or relatives |
| Anchor example |
| “Yeah, some things are different, for example it’s [the place] so small. It’s 2×4 m and I had a whole house.” Female participant, Res6 #00:04:07-4# |
| Coding rules |
| Barriers and difficulties due to admission as well as resources for a successful adaptation of people with cognitive impairment to unfamiliar environments are captured (e.g. multi-bedroom, day structure, lifestyle) |

Fig. 2 Example for extracting reinforcing and conflicting connections between values using the logical analysis (Patton, 2015) approach



Berlin, Germany) and Microsoft Excel for data management and analysis (Please contact corresponding author to obtain supplementary materials, e.g. transcribed interviews or MAXQDA-data written in German).

Results

General data

In total we collected 17:19 h audio-material, ranging from 13 to 76 min for each participant.

In sum 4.228 codes were found in text material and assigned to 232 categories. The intracoder-reliability yielded 88.00 percent, the intercoder-reliability 83.72 percent for presence of the same codes in the document (evaluate unassigned codes as a match). We checked 23.30 percent of the interview material (7 Interviews).

Everyday living and need for assistance and potential action fields for an AT

In case of need, the persons living with dementia received assistance by a range of different caregivers. In the interviews, spouses, children, grandchildren, nieces, neighbors, colleagues, roommates, nursing service personnel, legal guardians, facility managers, ward assistance, and nurses were named as caregivers. Subsequently, we asked the participants, for which activities they needed assistance. The answers were summarized in four inductively built action fields: activity, management/administration, care, and nursing. These action fields were further divided according to the stakeholder groups (see Table 5). Table 5 broke down the widespread field of using AT in dementia care which was often only illustrated by few examples or generally as ADLs (Burmeister, 2016; Cahilla et al., 2007; Hoenig et al., 2003; Ienca et al., 2017).

Values associated with caring for people with dementia

In total we extracted 44 values from 167 extracts with an interpretative grounded theory approach. The quotes were screened by a second researcher (DG) and reached

concordance of 90.74 percent for identifying the same 44 values in the selected extracts. The interrater-team (SK, DG, AK) discussed values' translation from German (SK) into English and compared them to dementia and healthcare literature to ensure best possible translation. In result, we renamed some values, e.g. "charity" into "altruism", "openness" into "broadminded", and "integration" into "social inclusion". The literature check also pointed out that ten of our 44 values had not been reported before.

We structured the values according to the "analytic process for determining key design values" (Burmeister, 2016; Burmeister et al., 2011). In line with this process we searched for value categories and reduced them to themes. Finally, we defined key values within each theme (Burmeister, 2016; Burmeister et al., 2011). We identified key values by summarizing values which positively influenced each other or were semantically related with each other (see Table 6). After collecting the key values (further named as value/s), we analyzed their relationship. The majority of values was interacting, while some of them were not strongly related with others.

Figure 3 proposes a concept of a network of values derived from the interviewees' answers.

Caring & empathy was the most frequently connected value and built the core of the network. Besides many reinforcing connections, *caring & empathy* can contradict *autonomy* due to overprotection or admission to nursing home without consent in the context of *care* and *responsibility*. Also, *authenticity* can conflict with *caring & empathy* or *peace* because relatives lied to their relative living with dementia for example about the real circumstances [rehab instead of nursing home, (resident's wife, Rel07), p. 98] or they disguised their feelings [pretending to be happy to show strength, (resident's daughter, Rel01), p. 40] to avoid conflicts with their loved ones. The following extract shows how *justice* and *caring & empathy* are competing. The interviewee told us that she had many residents to care for but few residents demanded the majority of her time. If she wants to take care of these residents as they demand it, she would not be able to do justice to the other residents. This brings her into conflict with herself:

"So, it [the work] is always very focused on this one resident or on these two residents. That is often diffi-

Table 5 Need for assistance of people with dementia extracted from the interviews. Items named by all stakeholder groups are written in bold. Items in normal font were reported by only one or two stakeholders additionally labeled with Pwd (=people with dementia), Rel (relative), or Hcp (Healthcare professional)

| Action field | Need for assistance |
|---------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Activity | Activation/sports (Rel, Hcp) Assisting /initializing activity (puzzles, gaming, handcraft, music, celebrating, singing, dancing, and reading out) Bringing patient/resident visitors or things to the hospital/nursing home (such as visitors, the patient’s dog, or favorite things) (Rel) Practicing ways together (Rel) Conversation (including in low German) |
| Care | (Permanent) Accompaniment (meal, activity, toilet, or bed) (Rel, Hcp) Being a contact person Pushing someone with a wheelchair (Rel) Excursion/go for a walk (city, fair, dancing, café, group meetings for people with dementia) Interrupting wandering tendencies, searching for residents (Hcp) Mediating between nursing home and residents (Rel, Pwd) Picking up dropped things (Pwd) Promoting residents’/patients’ independence (Rel, Hcp) Supplying individualized or group-based interventions (Hcp) Keep company (incl. assistance settling in and explaining the new living-situation) (Rel, Pwd) Wayfinding outdoor (Rel) |
| Management/administration | Banking/dealing with authorities (Rel, Pwd) Cleaning up operations (reporting cleaning needs, house cleaning) (Hcp, Pwd) Dissolution or furnishing of the apartment (Rel, Pwd) Driving service (to emergency room, group care, physiotherapy, game afternoon) (Rel) Organization (appointments, treatments, nursing home places/moves/aids) (Rel, Hcp) Reminder (appointments, dates, drinking, washing) (Hcp) Shopping (Rel, Pwd) Taking over the correspondence (including making or assisting calls) (Rel, Pwd) Visiting a doctor (discussion of findings and medical treatments) (Rel, Pwd) |
| Nursing | At night: putting on fresh bed linen, dressing, waking up someone to getting him to toilet (Rel) Checking on residents (Hcp) Doing laundry Dressing (shoes, compression stockings) Food intake/processing (Rel, Pwd) Guiding at ADLs (verbal instruction) (Rel, Hcp) Help with medication intake (Rel, Hcp) Patient positioning and mobilization (Hcp) Personal hygiene Prepare items for clothing (Rel) Assisting healthcare professionals (Rel) |

cult (...) to find a middle ground.” (female occupational therapist, HcpNh04, p. 30)

Privacy in institutional care can contradict *community*, especially due to roommates (resident’s wife, Rel04, p. 78) and disorientation of other residents (resident’s daughter, Rel01, p. 10). But also *caring & empathy* as well as *safety* encroaches on *privacy* due to nursing activities (female nurse, HcpNh01, p. 46) or *surveillance* (core value *safety*) (patient’s wife, Rel10, p. 50 & 66). *Adaptability* and *individuality* are limited through fixed *management* structures

(female occupational therapist, HcpNh04, p. 40 & female nursing assistant, HcpNh05 p. 48).

But *individuality* is also reinforced by *knowledge* as the following extract underlines:

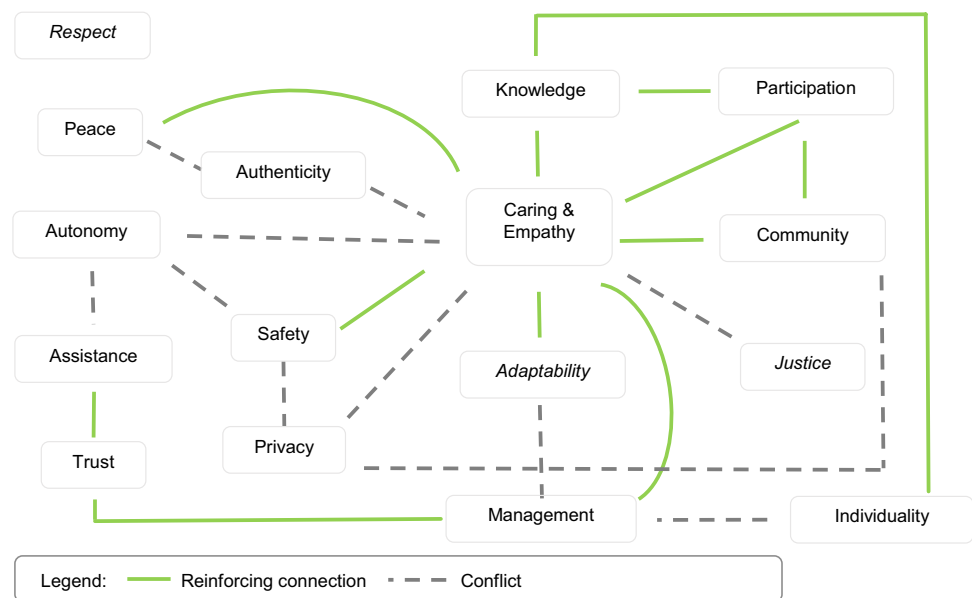
“Because every personality is different, you have to get to know people for a day or two to know how to deal with them.” (male nursing assistant, HcpHo01, p. 12).

Acting in accordance with these values is endangered by dementia symptoms, shortage of staff and time, and the infrastructure of institutional care. Challenging behavior (aggression, affective disorders), cognitive impairment

Table 6 Extracted values from all interviews and their assignment to core values. Values written in italics were not found in the literature (developed for these study)

| | |
|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>Adaptability Adaptability (Zwetsloot et al., 2013, p. 191)</p> | <p>Authenticity Authenticity and Honesty (Rassin, 2008, p. 619; Rider et al., 2014; Starr, 2008, p. 56)</p> |
| <p>Autonomy Autonomy, freedom, independence, autonomy in decision-making, and being useful/giving meaning to life (Al-Banna, 2017; Rider et al., 2014; Rassin, 2008, p. 619; Teipel et al., 2016, p. 697; van der Roest et al. 2007, p. 577; Zwetsloot et al., 2013, p. 191)</p> | <p>Caring and empathy Broadmindedness, empathy, tolerance/acceptance, <i>familiarity</i>, altruism, responsibility, patience/calm, <i>solicitude</i>, and <i>devotion</i> (Al-Banna, 2017; McNeese-Smith & Crook, 2003, p. 262; Rassin, 2008, p. 619–620; Rider et al., 2014; Toop, 1998; Zwetsloot et al., 2013, p. 192)</p> |
| <p>Community Community (Zwetsloot et al., 2013, p. 189)</p> | <p>Individuality Individuality, adapted care, and <i>tradition</i> (Al-Banna, 2017; Toop, 1998)</p> |
| <p>Justice/fairness Justice/fairness (Al-Banna, 2017; Bolmsjö et al., 2006, p. 345; Rider et al., 2014; Zwetsloot et al., 2013, p. 187)</p> | <p>Knowledge Knowledge, expertise/reflective practice, <i>understanding</i>, and personal development (Bolmsjö et al., 2006, p. 345; Rassin, 2008, p. 620; Toop, 1998; Zwetsloot et al., 2013, p. 193)</p> |
| <p>Management <i>Structure and continuity</i> (McNeese-Smith & Crook, 2003, p. 262)</p> | <p>Participation Social inclusion, integration, and participation (Ienca et al., 2018, p. 1047; Teipel et al., 2016, p. 697; Zwetsloot et al., 2013, p. 192)</p> |
| <p>Peace <i>Harmony</i>, companionship, and <i>contentment</i> (Rassin, 2008, p. 619)</p> | <p>Privacy Mature love and privacy (Ienca et al., 2018, p. 1041; Rassin, 2008, p. 620; Rider et al., 2014; Teipel et al., 2016, p. 697)</p> |
| <p>Respect Respect, <i>credibility</i>, and human dignity (Al-Banna, 2017; Rassin, 2008, p. 620; Zwetsloot et al., 2013, p. 192)</p> | <p>Safety Safety and surveillance (Rassin, 2008, p. 620; Teipel et al., 2016, p. 697; Zwetsloot et al., 2013, p. 187)</p> |
| <p>Assistance Assistance and cleanness (Rassin, 2008, p. 619; Zwetsloot et al., 2013, p. 193)</p> | <p>Trust Trust (Al-Banna, 2017; Rassin, 2008, p. 620; Rider et al., 2014; Toop, 1998; Teipel et al., 2016, p. 697)</p> |

Fig. 3 Reinforcing and competing connections between the values derived from the interviews (developed for these study)



(disorientation, reduced sense for reality, memory decline), or neuropsychiatric symptoms (hallucination) lead to conflicts with *responsibility* (core value *caring & empathy*) and *self-efficacy* (core value *autonomy*):

“And then you think “yes”, you can do it. You can do it, as a doctor you have to manage to look after your own husband until the end of life, no matter when/. That is/the theory and in practice, it is completely different.” (resident’s wife, Rel02, p. 12).

Shortage of time and staff was named as challenging for practicing the values *continuity, trust, knowledge, responsibility, and self-efficacy*:

“(…) and now we get a lot of unskilled workers, always only assistants, so that tomorrow we don't even know who is responsible (.) for us or who is coming, that we sometimes have to wait a long time until someone comes.” (female resident, Res08, p. 76) or
 “We also have our workload, the other patients also want to be looked after, other things also have to be done. And we only have a certain amount of time available. And that then puts us under pressure.” (female physiotherapist, HcpHo05, p. 36).

Knowledge and *social inclusion* were endangered due to missing access to informative media in institutional care for inpatients or residents:

“We don't even know what's going on in the world. Every now and then we steal a newspaper so that we know whether the Federal Chancellor still exists.” (female resident, Res06, p. 113).

Additionally, *community* and *integration* are reduced due to “*coercive community*” (male occupational therapist assistant, HcpNh03, p. 30) and lack of *understanding* or *acceptance*:

“The integration of demented residents with non-demented residents, cognitively clear residents. I also find creating acceptance very difficult.” (female nurse, HcpNh02, p. 4).

Especially, *familiarity* gets lost due to admission to hospital or institutional care:

“I: Was that also a change factor? Female resident: Yes, at first yes. First of all, having meals, with strangers” (female resident, Res08, p. 86)
 “Yes, but they are in a completely new environment and if you imagine being torn out of, at home they could (...). These were processes that are stored in memory and everything is new in the hospital, whether it's the noises (...) And that scares them and then they become aggressive, not always, but they are scared.” (female physiotherapist, HcpHo05, p. 20)

These extracts show the vulnerability of values and how they are affected by dementia symptoms, shortage of staff, or/and admission to institutional care. Our results agree with the findings of an integrative review of (Digby et al., 2017) which point out the threat to values due to the conflict between time-consuming care of people with dementia and the need to finish caring tasks in time. The authors also show the stigmatization of people with dementia in institutional care expressed by less empathy, attention, and value-guided

care (Digby et al., 2017). Our interviewees reflected this stigma and showed empathy and understanding, but were bound by institutional guidelines and workload.

Derivation of use cases

In conclusion of the analysis of needs, of ideas from the stakeholders and the underlying values, we conceptualized four use cases for technological assistance. Due to the large amount of data, we created one use case for each of the four inductively found action fields expanding on everyday living and need for assistance (see Table 5).

In the first step, we created realistic use cases by filtering the situations and personal conditions that were described by the participants. Subsequently, we assigned the use cases to AT. In the third step, we identified the values that were touched by the use cases and the related AT. Hence, the following use cases represent a fusion of all stakeholder views, based on all analyzed categories.

From the stakeholders' perspective, the AT should mainly take the values *respect, adaptability, individuality, trust, and assistance* into account. *Respect* was understood as polite and calm communication which is adapted to the degree of impairment. *Adaptability* was understood as flexibility in interacting with the person concerned and adapting the assistance to the users' needs. This is strongly related to *individuality* which includes preferences, rituals, and daily structure. *Trust* should be realized by devices' reliability such as giving assistance if needed, being pervasive and always ready to use. *Assistance* was understood as giving useful and tailored assistance to the person of need. The following four figures show use cases derived from the interviewees' answers independently from feasibility and practicability criteria.

The first example covers sleep-disturbances at night (see Fig. 4). The resident or patient wakes up desoriented at night. The smartwatch on his/her wrist recognizes his/her awakening and his/her standing up. The smartwatch tells him/her the time and that it is time to sleep. Instead of lying down, the user starts walking so that the smartwatch infers -based on daily routines- that he/she needs to go to the toilet. It switches on nightlights and navigates him/her to the bathroom. Simultaneously, it informs the nurse who communicates by intercom with the patient/resident. Depending on the success of the communication he/she decides whether to check on him/her personally or not. In that way AT promotes *autonomy* and *safety* and support *privacy* to a large degree.

The second use case focusses on getting lost behavior (see Fig. 5).

The AT in this use case would promote the values *autonomy, participation, and safety*.

Example 3 illustrates the need for instructing ADLs due to impaired planning skills (see Fig. 6). Integrated fall

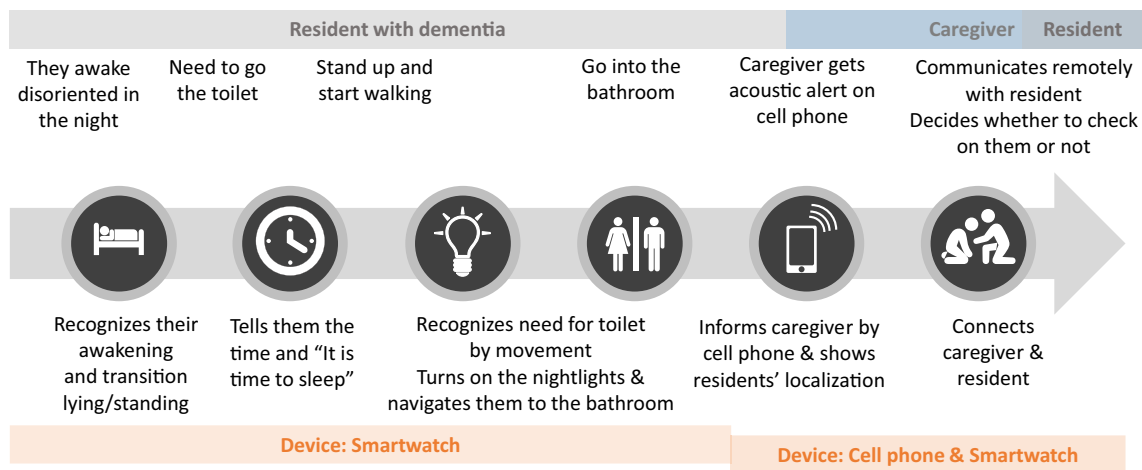


Fig. 4 Action field “Care”: Flow diagram of an AT intervention providing accompaniment in case of sleep-disturbances (developed for these study with power user)

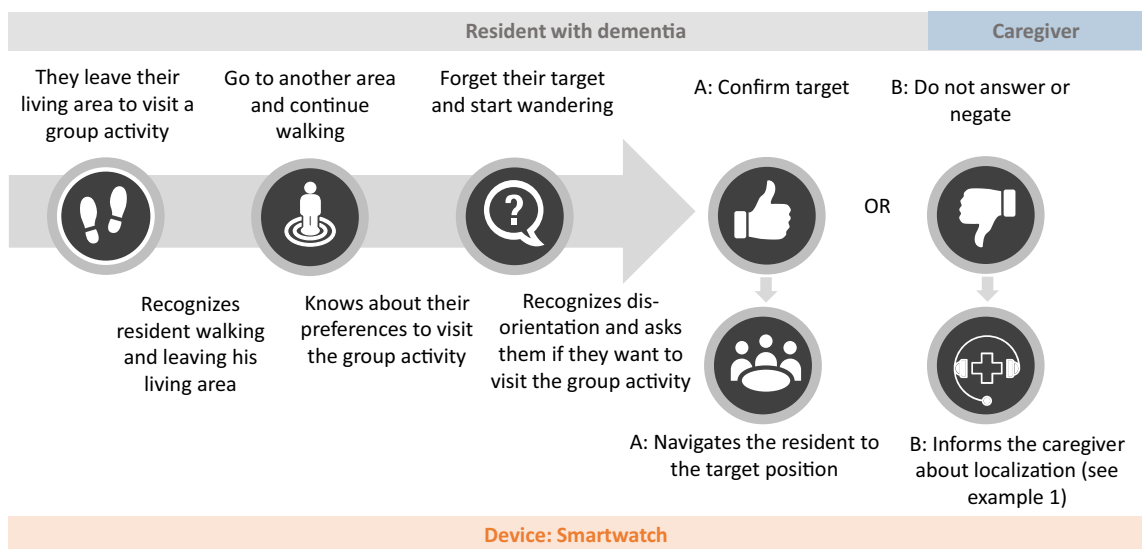


Fig. 5 Action field “Management”: Flow diagram of an AT intervention in case of wandering tendencies and getting lost (developed for these study with power user)

detection would enhance *safety*. Other values promoted by this AT are *autonomy* and *privacy*.

The fourth example (see Fig. 7) takes the desire for activity and knowledge into account. This AT promotes *autonomy*, *community*, *participation*, *management*, and *knowledge*.

These examples of use cases show the widespread field of possible applications for AT. 14 of the 18 identified values were supported by or integrated in the presented AT. The values *peace*, *authenticity*, *caring & empathy* as well as *justice* are missing in our examples. Other use cases can be imagined that may address these values as

well. Although, values are context-sensitive (Burmeister, 2016; van Wynsberghe, 2013), our interviewees define the values *respect*, *adaptability*, *individuality*, *trust*, and *assistance* as fundamental for using ATs. Furthermore, our use cases underline the need for individuality and adoption to the user’s current situation, which were also found in other studies (Boger et al., 2018; Cahilla et al., 2007). As different devices interact in our use cases, interoperability of technological solutions to deliver context sensitive and individual assistance needs to be ensured (Boger et al., 2018; Thorpe et al., 2016).

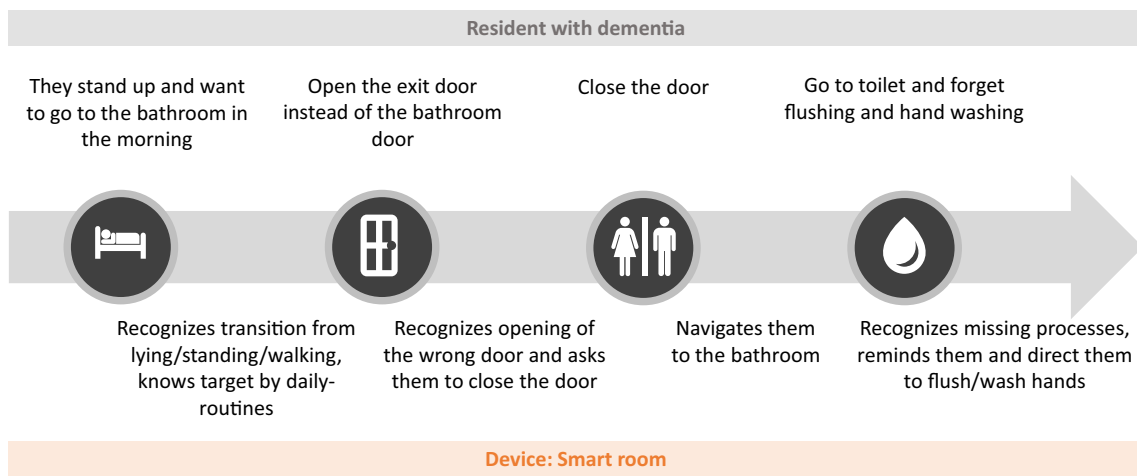


Fig. 6 Action field “Nursing”: Flow diagram of an AT intervention in case of impaired planning of ADLs (developed for these study with power user)

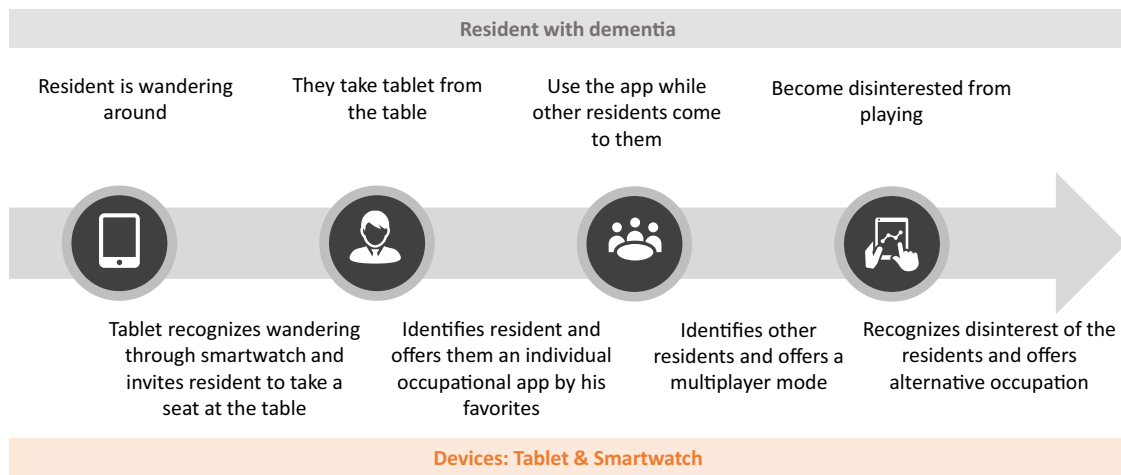


Fig. 7 Action field “Activity”: Flow diagram of an AT intervention to provide activity and knowledge (developed for these study with power user)

Discussion

Here, we identified values and needs of people with dementia, their family, and professional caregivers in institutionalized care. We constructed a value network from the reported values that allowed identifying both reinforcing and conflicting value interactions. On this basis, we constructed four use cases from the material provided by the stakeholders that illustrated how digital

ZET may promote values and contribute to resolving value conflicts.

Need for assistance

The stakeholders’ responses on need for assistance identified four action fields, including activity, care, management/administration, and nursing. The mentioned items in the action fields management/administration and nursing

agreed with the domains of the I-ADLs of Lawton and Brody which covered ability to use telephone, shopping, food preparation, housekeeping, laundry, mode of transportation, responsibility for own medication, and ability to handle finances (Lawton & Brody, 1969). Additionally, we identified caregiver needs concerning activity and care, such as conversation, being a contact person, assisting or initializing activities (e.g. puzzles, singing, handcraft), conflict mediation, and interrupting wandering tendencies or searching for residents. These results from the caregivers' perspective match the findings of a systematic review (Cadieux et al., 2013) and a cross-sectional survey (Miranda-Castillo et al., 2013) which identified from the patient perspective that daytime activities and company are the most frequently unmet needs of people with dementia. Current AT are mostly concentrated on assisting ADLs and house maintenance (Ienca et al., 2017; Lawton & Brody, 1969). If these technologies are well adapted to the needs of people with dementia, healthcare professionals and family caregivers could be relieved from routine tasks to provide socially salient support such as accompaniment, and social activities and interaction.

Values' network

We found a large range of values ($n = 44$) embedded in a complex system of interaction. Values play a guiding role in human interaction, health care, decision making, and in being authentic (Al-Banna, 2017; Rassin, 2008; Rider et al., 2014; Starr, 2008). According to our interviewees, conflicts between the identified values mostly emerged due to a lack of medical staff and its shortage of time, challenging behavior, and missing information.

Curse and blessing of management

Few conflicts were mapped in the values' network by the value *management*. On the one hand, *management* (*continuity* and *structure*) endangers *adaptability* and *individuality*. Our findings agree with findings in a previous study which reflected ethical problems in dementia care (Bolmsjö et al., 2006). This study identified organizational structures as obstacles for integrating values if routines prevail over individualized care (Bolmsjö et al., 2006). On the other hand, *management* leads to *trust*. As trust in nursing arises if someone behaves as expected (Hupcey et al., 2001), structure can give a framework for expectations. Further, continuity is necessary to build and maintain trust because trust in nursing is not transferable from one person to another (Hupcey et al., 2001). Regarding the development of an AT, *trust* and *management* should be incorporated by devices' reliability of functioning and well-structured procedures. Subsequently, adaptive assistance (*adaptability*) for the individual

needs (*individuality*) of the target group should be provided. Therefore, *knowledge* about daily routines, biography, and preferences of the person at need is necessary (Toop, 1998). Consequently, future AT in health care should be context sensitive and adaptive (Alirezaie et al., 2017).

Hazards for privacy, autonomy, and authenticity

Our values' network showed *privacy* (*privacy* and *mature love*), *autonomy* (*autonomy*, *freedom*, *independence*, *autonomy in decision-making*, and *being useful/giving meaning to life*), and *authenticity* (*authenticity* and *honesty*) as most endangered values. This endangerment arises from many conflicts, for instance with *caring & empathy* or *safety*, and a lack of supporting values. *Privacy*, *autonomy*, and *honesty* are central values in caregiving (Rassin, 2008; Rider et al., 2014) as reflected in the International Charta For Human Values In Healthcare (Rider et al., 2014). Nevertheless, our interviewees complained about difficulties in respecting these values in healthcare. Reasons were multi-bedrooms, challenging behavior and disorientation, nursing activities, prevention of conflicts, overprotecting, surveillance, or lack of consent of the people with dementia. In a previous study (Scerri et al., 2020), people with dementia in hospital were asked about their perceived needs. They also identified privacy as often unmet. Another need was being involved in decision making. An integrative review (Digby et al., 2017) which focused on the experiences of people with dementia and nurses in hospitals found that risk management by physical or chemical restraints was preferred to patients' dignity. Our data showed conflicts between *autonomy* and *safety* as well. Besides aspects of challenging behavior, our interviewees named infrastructural prerequisites and lack of staff as obstacles for acting in accordance with values. These results are similar to previous studies (Bolmsjö et al., 2006; Digby et al., 2017). Consequently, AT may be usefully employed if they leverage time and staff resources (Hoening et al., 2003) and free time for value oriented instead of routine-oriented care (Digby et al., 2017).

Bringing justice into care

Our interviewees reported problems in justice in care due to the different demands of residents with and without cognitive impairments. This leads to conflicts as other residents feel or are disadvantaged. An integrative review also described such conflicts of allocation based on time-consuming care and challenging behavior of people with dementia (Digby et al., 2017). However, cooperative people with dementia are endangered to receive less attention (Digby et al., 2017). In times of staff shortage, justice can be realised if basic needs of all residents/patients receive priority over less basic ones of individual residents/patients (Bolmsjö et al., 2006). But

this prioritisation endangers individual and need-oriented care (Digby et al., 2017). AT can undertake basic care tasks as assisting food preparation and delivery, leisure activities, in- and outdoor-mobility, toileting, and bathing (Astell et al., 2019; Hoenig et al., 2003; Ienca et al., 2017). Consequently, the use of AT reduces or solves conflicts of justice in care and lead to more need-oriented care and well-being of all parties involved.

In summary, our values' network underlined the complex relationships between values. Current literature on ethics and AT in healthcare presented values separately with little regard on conflicts or reinforcing connections (Al-Banna, 2017; Ienca et al., 2018; McNeese-Smith & Crook, 2003; Rassin, 2008; Rider et al., 2014; Teipel et al., 2016; Zwetsloot et al., 2013). Being aware of possible value conflicts and synergies will help in the creation of AT that avoid supporting one value at the cost of another. It also underscores that an individual user's values should drive the decision if a given AT should be used or not. Further, values' connection can be used for strengthening many values at the same time. For instance, if *knowledge* about preferences in daily activities will be increased, *participation* and in line with this *community* will also be promoted. These interplays can be used for enhancing benefit of AT.

Use cases

Technological feasibility

Our use cases showed scenarios for the application of AT addressing sleep-disturbances, getting lost behavior, instructions of ADLs, and activity. In the interviewees' opinions, AT should be aligned to give information, reduce possible value conflicts, and enhance self-efficacy by simple communication, localization, and individual assistance. In principle, all the use cases can be realized with currently available technologies such as detection of movements and body position by accelerometry (Fanchamps et al., 2018; Ge & Xu, 2014), ambient sensors like door-sensors or remote light switches (Alirezaie et al., 2017; Pirzada et al., 2018), indoor localization (van Haute et al., 2016), and remote communication. However, these technologies have not yet been implemented in institutional care facilities although they are technologically and in parts financially accessible (van Haute et al., 2016) and evaluated to be helpful by our interviewees. This points to a lack of specific adaptation of current technologies to the needs of the users. Currently, still an estimated 60 percent of AT are developed without an user-centered design approach (Ienca et al., 2018). Our data support the implementation of methods for participatory technology development following the VSD approach (Friedman et al., 2008).

Consideration of values

We identified privacy and autonomy as the most vulnerable values. Our use cases were based on personal data such as daily routines, localization, sensor data, personal preferences, and biography. A systematic review (Yusif et al., 2016) as well as several studies on values and AT reported concerns about privacy (Brewster & Dunlop, 2004; Dahl & Holbø, 2012; Ienca et al., 2018; Teipel et al., 2016). Privacy can be divided into personal privacy (being alone and unobserved) and data privacy (possibility to control own data) (Yusif et al., 2016). Providing adaptive and individual assistance requires access to data worth protecting. Therefore, the principle of data parsimony must be respected, i.e., collect only the minimally necessary data.

Autonomy is a driving value in our and previous studies (Ienca et al., 2018; Teipel et al., 2016) and people are even willing to exchange privacy for autonomy (Townsend et al., 2011). In contrast, autonomy is often restricted by safety (Scerri et al., 2020; Teipel et al., 2016). Consequently, providing autonomy should be an overarching goal of AT to justify restrictions of privacy. Automatic detection of endangering situations or need for personal assistance as shown in the first and second use case should be integrated in AT for ensuring safety and autonomy simultaneously. Additionally, little is known about the limits of the willingness to exchange privacy for autonomy. Future investigations should aim to identify user types and their individuality in need for privacy.

We found *peace* (*harmony, companionship, and contentment*), *authenticity, caring & empathy* (*broadminded, empathy, tolerance/acceptance, familiarity, altruism, responsibility, patience/calm, solicitude, and devotion*), and *justice* not covered by our use cases. *Authenticity* and *justice* were already discussed in the paragraph "**Bringing justice into care**". Furthermore, our results showed *caring & empathy* as most important value for our interviewees. Therefore, AT should be programmed on acting empathically and with care.

Strengths and limitations

Qualitative user surveys allow eliciting the users' perspective beyond limited predefined answer possibilities (Aspers & Corte, 2019; Patton, 2015). Qualitative surveys if conducted with an open mind have the potential not only to confirm already predefined answer options, but eventually to find different views on a topic (Patton, 2015). Here, we wanted to give the patients and caregivers a voice in how future technologies for assisting people with dementia should look like.

Our results demonstrated the ability of people with dementia to make valuable contributions to scientific research and underlined their expertise in expressing

their values, needs, and daily challenges. We linked their responses with those of healthcare professionals and relatives to validate the answers given by participants with dementia (Nygård, 2006). Although we consulted people with dementia in our project, involvement with decision power (Arnstein, 1969) of these people is missing. In future projects, we aim for a closer collaboration oriented on the needs and abilities of our target group.

The intercoder-reliability was high at different stages of the evaluation process. We applied a rule-guided, transparent evaluation method which we discussed and developed during the process of evaluation. Inductively built categories allowed us to gain further information across given categories. However, Mayring's content analysis is focused on the spoken words and neglects words' emphasis and non-verbal expression (Mayring, 2014). This may lead to incompleteness and different understanding during the reduction process although the intercoder-reliability was high. As the meaning of values differ between German and English, the translation could be improved by translating for- and backwards.

We showed a wide range of different values and emerging conflicts in nursing practice. Also, we proposed a concept of interactions of values. Due to the fact that values are very individual and depend on culture, society, and demographic data (Al-Banna, 2017; Rassin, 2008), our results must be understood as benchmark for other studies. Further, values in nursing are mostly investigated from the healthcare professionals view (Al-Banna, 2017; McNeese-Smith & Crook, 2003; McWhinney, 1998; Rassin, 2008; Rider et al., 2014; Toop, 1998; Zwetsloot et al., 2013). We presented a multi-perspective view on values without distinguishing between the stakeholder groups. Future investigations on values should aim on the values' prioritization for each stakeholder group to better understand which values are most important and to identify intersections. At least, these intersections should be integrated in technology.

Our results are mainly focused on the situation in hospitals and nursing homes. Therefore, transferability of our results to other care concepts (e.g., rehabilitation, daily care facilities or care at home) is unclear and requires further investigations.

Conclusion

Little is known about the interaction between values in the context of care. Our results provide a deeper understanding of values and use cases for AT from different stakeholders' views. Ienca et al. (2018) demand balancing conflicting values in the design of AT. Our network shows value chains in the literal sense which provides ideas on how negative impacts on values can be balanced. For example,

trust fosters management whereas *management* strengthens *caring and empathy*. *Caring and empathy* can balance the negative impact of *safety* on *privacy* and *autonomy*.

Our use cases, the values network and the needs for assistance in particular may help designers and engineers to tailor ATs to the users' needs and to enhance users' acceptance, perceived usefulness, and motivation to use (Boger et al., 2018; Cahilla et al., 2007; Ienca et al., 2018). Of course, this is just one example for such an approach that needs to be replicated and extended by future studies. Furthermore, we demonstrated a practical implementation of the value sensitive design in the context of institutional care. Our use cases demonstrated the need for interaction between different devices and sensors (for example, tablet, smartwatch, and/or smartphone each with integrated move and/or face recognition sensors) and access to multi-dimensional data (daily routines, sensor data, and biographic data). The need for interoperable devices emphasizes data security as well as the importance of compatibility between different (medical) devices and (medical) software (Iroju et al., 2013).

As existing technology seems unsuitable for the people with dementia in institutional care, researchers and engineers should continuously involve people with dementia and their caregivers in technology development. Thereby, VSD is a beneficial and realizable approach for iterative involvement of people with dementia and their stakeholders in technology development.

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Author contributions All authors contributed to the study conception and design. Material preparation, data collection, and analysis were performed by SK, DG and AK. The first draft of the manuscript was written by SK and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

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Data availability All transcribed interviews, MAXQDA-files, and the interview guidelines are available in German. Please contact corresponding author to obtain materials written in German.

Declarations

Conflict of interest Stefanie Köhler is a lecturer at the Europäischen Fachhochschule Rostock, Germany and for the German Alzheimer's Association, regional group Mecklenburg-Western Pomerania. An-

tonia Kowe is fellow of the program “Freies Wissen” by Wikimedia Deutschland. Doreen Görß declares to have no conflict of interest. Stefan Teipel has done the listed works below (all in Germany): MSD Sharp & Dohme GmbH, Lindenplatz 1, 85540 Haar: 11/09/2018—Quality circle for physicians in Kühlungsborn, Talk: “Dementia and Diabetes—current report”; 14/11/2018—MSD Expert-forum: NAB Alzheimer in Munich, participator as consultant & 13/08/2019—Event “Diabetes and Dementia” in Rostock, Talk: “Dementia and Diabetes—current report.” ROCHE Pharma AG, Emil-Barell-Str. 1, 79639 Grenzach-Wyhlen: 12/09/2019—3. Nationales Advisory-Board in Frankfurt am Main, participator as consultant & 27/09/2019—ROCHE Symposium at the DGN Congress in Stuttgart, Talk: “Amyloid as target for diagnosis and treatment in Alzheimer’s disease”. Biogen GmbH, Riederburger Straße 7, 81677 München: 23/04/2020—Biogen Advisory Board Session.

Ethical approval The study was approved by the responsible ethics committee of the University Medical Center Rostock (A 2018–0109) and conducted in accordance with the Declaration of Helsinki (WMA, 2018). All participants or their legal representatives provided written informed consent. Interviewers ensured ongoing consent during questioning.

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