Towards designing a long-term assistive environment for people with dementia

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Abstract
We report on the analyses of two interview studies conducted with people with dementia and their carers in the UK and in Germany. Results show that technological solutions alone would not be successful, if they did not take individual and social contexts into account.

We develop a number of recommendations one of which is that we should focus more on the world as it is perceived by people with dementia instead of how it really is. We propose the concept of “benevolent manipulation” which, although assistive, helps to subtly remove at least some of the limitations people with dementia experience.

We further found that the principal aim should be to develop assistive technology that can be adapted / tailored, intuitively used, does not feel intrusive, and at best disappears as any device, tool or aid that need to be operated or learned. To ensure consistent functioning across all supportive entities and to guarantee optimal support, we argue that we need a larger framing in the sense of an intelligent assistive environment. We provide detailed conceptual considerations regarding architecture and behaviour of such a long-term support system.

Keywords
Long-term assistance, assistive environment, assistive technology, people with dementia, user-centred design, inclusive design, survey methods, holistic approach

Introduction
One of the most important challenges of demographic change is dealing with the growing number of people suffering from dementia. In the majority of cases, symptoms aggravate progressively, thus imposing heavy constraints, even on everyday routine tasks. The consequences are a reduced quality of life, inferiority complex, anxiety, and
social isolation [1]. Dementia primarily affects cognitive functions such as memory, attention, language, and problem solving, but also disperses into other bodily processes. The most common type is Alzheimer's disease (about 27 million patients worldwide [2]) – one of the most costly diseases to healthcare in developed countries [3].

Researchers of different domains have begun to tackle the multitude of issues associated with dementia in various joint efforts. We are combining methods from Psychology and Computer Science to study and address the needs of people with dementia by taking all key members of the concerned ecosystem into account (also including families, caregivers, doctors, and health staff). In particular, we build on the user-centred framework proposed in [4] that aims at an intelligent approach to adaptive aid selection where control and interaction facilities, as well as supportive stimuli are offered to the recipient dependent on her or his current state and context. Assistance is optimal, when it keeps the people with dementia in (subjective) control of situations, and ensures utility while minimising potential side-effects of the assistance itself. We further base our work on the data and insights from an interview study carried out with people with dementia and their caregivers [5]. First results clearly highlight the need for social interaction as the main concern. Carers confirm this view and argue that technology for supporting social interaction should be much more promoted and focussed on in the future, and made easier to use for people with dementia. The data as well as related work also show that, however impaired they may be, people with dementia relish their independence and value social contact while either not being interested, reluctant, or no longer able to use complicated technology [1, 5, 6].

Although systems exist that help people with dementia perform task sequences in the right order, remind them of their medication, offer orientation aids, help to cope with everyday task scheduling, facilitate social interaction [1, 5-8], and so to improve quality of life [9], we believe that a more holistic thinking is necessary to arrive at a long-term assistive environment that meets their (constantly changing) individual needs, no matter whether at their homes or at a residential facility. Approaches to adaptive real-time assistance, e.g. during hand washing [10, 8], offer means to react to changes in the current situation and guide persons in their activities (for an overview, see also [11, 12]). Working towards a more general assistive environment is what we aim at in this paper. We continue to analyse earlier interview data [5] and acquire further first-hand qualitative feedback to nurture the conceptual work we have begun in [4].

**Interview studies**

**Methods**

Extending the methodology presented in [5], we base our requirements analysis and design process on information about a person's background, the day and life structures of people with dementia, their cognitive and physical condition, medication, contacts to family members, friends, doctors and medical staff, the general affinity to technology, the barriers found during everyday activities, as well as organisational matters at different interpersonal and institutional levels. We use semi-structured interview and observation techniques that are inspired by [5] and [13]. We further employ standardised self-report questionnaires to gather data about mental and emotional strain. These questionnaires
will be administered by caregivers who also accompany most of the interviewees with dementia in order to keep barriers low, “break the ice”, and to be able to validate answers in a retrospective session.

Study 1
This previous study, conducted at a British day centre, has been part of the work described in [5]. Eight people at an age of 76 to 86 years, with early to moderate dementia participated in the study. They either lived at home, with their spouse or at an elderly residence. The topics covered by the interview included:

- Use of music (listening, playing)
- Social participation (keeping contact with families, friends and carers)
- Community relationships (activities in the local community)
- Assessing outdoor space (going out alone or in company)
- Daily activities / household tasks (dressing, household, gardening)
- Exercises / physical activity (types of activities, motivation)
- Creative activities (hobbies, carried out alone or with someone else)
- General questions (day organisation, ideas about assistive technology)

Further, two members of the day centre staff were interviewed and asked about ideas on technology supporting people with dementia in their independent living. All participants have been voice-recorded. Transcribed recordings have been revisited for additional analyses in the context of the current work.

Study 2
Four people at an age of 78 to 95 with early to severe dementia have been interviewed at two fulltime care facilities in Germany. Two interviewees still spend some time at home, but all are dependent on regular professional care. The methodology has largely been adopted from the above study, slightly been modified and extended to address the particular circumstances at a care facility, and to gain further insights into the needs and problems of people with dementia. Added questions focussed at:

- Personal background (profession, family, day organisation, hobbies, desires)
- TV and other media use (frequency and control of use, affinity, interaction)
- Navigation and orientation (indoors / outdoors, time and space)
- Medical context (medication, contact with doctors and other health staff)

In this study, we have also interviewed two professional carers about their views of the people they care for, about organisational issues in the daily procedures as well as about problems of communication with other instances such as family members, doctors and health insurances. They were further encouraged to talk about how they think specific problems could possibly be overcome.

However, people at more advanced stages of dementia and / or requiring more intense care have not always been able to answer all questions, or did not finish the entire interview. We further had some difficulties to transcribe what has been said due to incomplete sentences and / or limited intelligibility.
Results and discussion
There is a wealth of insights we gained from our studies, revealing a complex picture of the needs as well as of the social, emotional, technical, and financial issues associated with the members of the concerned ecosystem. Given the scope of this paper, we will focus on the implications on the design of current and future assistive systems for people with dementia. This will later allow us to elaborate on the long-term perspective of an intelligent assistive environment. We will also present important “non-technical” findings, hoping to stimulate some reflexions about today’s practices and opinions.

General implications and recommendations
With an emphasis on those results going beyond the state of the art, we argue that one should …

• ... look at how things are perceived by people with dementia, rather than on how they are in reality. With respect to such basic needs as for independence and self-responsibility, the perception of being able to do something by themselves, of being in control of things, of having the choice should actively be stimulated. This also applies to the perception of the utility and usefulness of a specific device or aid. Our approach to achieving this is what we call “benevolent manipulation” (details see below).

• ... keep people with dementia motivated both to initiate and to pursue ongoing activities. This can be achieved by clearly showing what can be done or should be continued at any specific moment, by adequately segmenting or simplifying complex tasks, and by not exceeding remaining attention spans. Beside tailored multimodal prompts, active engagement, presence / company of relatives or other trusted persons can effectively trigger and maintain motivation.

• ... move from abstract control and modes of operation to more natural ways of interaction. Designing systems and services for intuitive use so as to exploit accessible knowledge is one way to arrive at solutions that may easily be understood by people with dementia. More precisely, we propose to focus on a “graspable” touch-based / tangible interaction with “intelligent” familiar objects and devices, to use speech input (primarily intended to encourage people to tell what they want), to integrate gently insistent ask-and-confirm paradigms at critical decision points, as well as some mechanisms for information repetition.

• ... offer (simple) ways of customisation. The huge variability of sensory and cognitive impairments found in people with dementia, specifically in those hosted in fulltime care facilities, require a high degree of flexibility and adaptability of the assistance being employed (appearance and behaviour of user interfaces, pace of interaction, personal presets). Systems may moreover be shared between users.

• ... integrate diverse means of entertainment and communication. For some it may work out to have single-purpose devices which help direct attention towards a specific task. But others may have problems remembering the diversity of entertainment and communication devices, and how to use each of them. Thus, a smooth integration appears to be a promising opportunity.

• ... consider the preferred and most efficient modalities for system feedback. This includes evoking reminiscence using a variety of stimulating
media (music, photographs, videos), as well as choosing the right multimodal response cues (reminders, prompts, triggers), e.g., for guidance, information, and entertainment.

- **facilitate the introduction of new things (devices, places, people).** Although often a challenge to both parties (i.e., those who offer technological aids and those who are to use them), if new assistive approaches were introduced by someone familiar and trusted, acceptance seems much higher.

- **enable company by real human beings.** The actual level of required presence of that human companion is still a matter of research. However, focussing solely on devices and technology will most likely make us fail in our endeavour to offer an effective long-term support.

- **let people with dementia have fun (despite their particular constraints).** This means fostering active engagement, joy of use of interactive technology and contents, and avoiding frustrating and discouraging events whenever possible. This latter point also translates into more general social and emotional dimensions of care and dealing with people with dementia.

We further found that people with mild dementia would still like to go out for shopping or visiting friends, but need help in order to feel comfortable and safe outside. Navigation aids as being developed, for instance, in the CONFIDENCE project [14] would generally be appreciated, but, again, human company is still clearly favoured over technological company.

**“Benevolent manipulation”**

Among the most important findings from both interview studies is the insight into how people with dementia feel about their personal situation, changing abilities, relationships, their freedom to make their own decisions (even regarding suicide), independence, self-responsibility, as well as care and treatment. So, the perception of what is going on with and around them has, as in most human beings, strong effects on their emotional states. Although some of our interviewees retained freedom in particular areas of their everyday life, the majority consciously experiences the constraints imposed by their own limitations, but also by other people and (technical) barriers in their environments.

We propose to address these issues by means of “benevolent manipulation”. One prominent, large-scale example of such a manipulation is De Hogeweyk [15], a village in the Netherlands which has been designed to offer an illusion of independence and self-responsibility to its inhabitants. There, inhabitants are people at different stages of dementia. They live, either alone, in groups and / or supported by caregivers, under similar material conditions as they did before coming to De Hogeweyk. They can go out shopping, to the restaurant and do whatever they desire. They can pay with knobs, leave their flats dressed in pyjamas or bathrobes – nobody would intervene to correct them. Because everything is well observed and controlled behind the scenes. Visitors (mainly scientists, doctors, and family members) report that the people there seem very calm and balanced, although they live in an illusion of normality. This fact is equally motivating recognition and debate. But what does really matter in the end?

We believe that, despite ongoing ethical discussions, the most important point is to meet people’s needs. And if one way to do this would be to create the effective
impression of being (a little bit more) independent, self-responsible, and in control of things and situations, then this might be the way to go. Simplified and intelligent modes of interaction and operation, which subtly support weak or substitute missing capabilities, is what we focus at here. It may neither be necessary nor optimal to develop and then introduce new devices, itself a challenge to many people suffering from dementia, to those who are no longer able to operate their “old” devices. Making these old and familiar devices more intelligent may be a promising avenue for future developments. For instance, operating a record player requires knowledge about the correct order of actions to perform, as well as a certain minimum quality of visual perception and visuomotor coordination. However, the intentions of listening to some music, controlling volume etc. could also be inferred from the actions performed in a certain context (e.g., using markerless tracking with the MS Kinect), from object relations and configurations (e.g., RFID-driven proximity checks between a record and the player), or from other observable information. Simply put: Let the person take a record and place it somehow onto the player, and then make the music play. If the person is still able to manipulate the pick-up is some way, the system could wait until a certain trigger event has been recognised and then start playing the music. This creates or reinforces the impression of being able to achieve one’s goal (in this example, to operate even more complex parts of the record player), and this is what we consider a “benevolent manipulation”.

Other “non-technical” findings
Some aspects of support that we extracted from the interviews are only loosely related to our view of a long-term assistive environment as detailed in the next sections. The following list provides additional insights that may be of interest to researchers and practitioners across the fields:

- **Assistance by other elderly people.** It has been mentioned more than once that people with dementia would appreciate help and company offered by other elderly people. In a few regions, voluntary initiatives have been founded to overcome at least some of the (organisational / administrative / financial) constraints imposed by overregulated health (insurance) systems – in particular, in Germany.
- **Stronger integration of the health ecosystem.** Professional carers reported a lack of interaction with doctors and other health service providers. They further seem to share some of the low appreciation that people with dementia seem to receive from the concerned ecosystem as well as from the society as a whole.
- **Limited support and poor working conditions.** Carers in Germany bewail a lack of time (average time for direct care is less than ten minutes a day) that is generally caused by poor financial support (“time is money and money is short”), but also by tedious documentation work and reporting requirements that again reduce the available time.
- **Relevance of direct contact.** Professional carers report that direct (physical) contact is very important, but time constraints make it hard to satisfy this need.
- **Future perspectives.** Future generations may adapt assistive technology involving (visible) computers much more readily. In fact, a few cases have already been reported in which this “inherent affinity” has become reality.
Intelligent assistive environment

One of the major challenges for assistive systems made to support people with dementia in natural environments is the degree of uncertainty inherent in both the people and the environment. Suppose we knew what kind of support a person would need in a specific situation. How would a support system determine who that person actually is, what her or his intentions are, whether the task to be performed requires any support at a given moment, and how that support could be given and optimised? How can we afford all this without introducing cumbersome (hardware) constraints on those who should instead feel more independent, self-responsible and self-confident?

To address these questions is the goal of this section. Conceptual work and future developments have been and will continuously be influenced by our interview studies, as well as an agile and participatory design approach [16].

Conceptual considerations

Based on our interview data and extending the work presented in [4], we propose a multimodal information exchange and delivery architecture (see the extended version in Fig. 1). It relies on stepwise transitions between different levels of assistive function and trigger representations within an adaptive “fallback hierarchy”. This hierarchy can be understood as a laddered descriptor of the functionalities and stimuli to offer to a person, dependent on her or his current state and context. The “intelligence” of the system resides in the modules for state and context determination as well as in the assistance effect simulation.

State and context determination in an uncertain environment will be performed using probabilistic methods (Bayesian as well as hidden and partially observable Markov models for categorisation and decision making [10]). Intention detection is part of this process and will rely on both environmental sensors (RFID-based person tracking, Kinect-based motion histories, video-based mood analysis, see also [17]) and temporal action traces. Although results are likely to become more robust, if we captured personal sensor data as depicted in Figure 1, our impression is that, in terms of practical use, we would lose more than we would win by attaching sensors at various spots around a person’s body. So, our motivation is to do without such sensors – at least as long as they cannot be employed without imposing additional constraints on the people with dementia.

The principal objective of the assistance simulation engine is to probe the selected aid (details on the hierarchy of aids are detailed in the section below) – similar to what cognitive tutors have been designed for in the context of learning support and optimisation [18]. To achieve this, the system will run dedicated cognitive models specified in ACT-R [19] which reflect well-understood deficits found in people with dementia [20]. For instance, parameters at the subsymbolic level of operation permit to address individual differences in information retrieval and processing. Whenever the simulation yields limited effectiveness of one particular means of support, the system will fall back to the next lower level of assistance and run the simulation again. If no appropriate reaction can be generated to respond to the given needs of a particular person, an agreed carer will be called up. Conservative effectiveness thresholds (during
selection probing) minimise the risk of confusion and other immediate mental and emotional side effects.

**Aid hierarchy and selection**

The assistance the system provides has to be flexible in order to ensure optimal support – at virtually any stage of dementia (i.e., before even minimal perceptual, cognitive and motor capacity losses occur). With respect to [4], the main interaction levels are:

1. Operational skills acquired before disease onset or before reaching stages of severe impairment [5]; can typically be maintained for a long time, if actively used, and can be improved up to subconscious behaviour by intensive training.
2. Image schemata (common action patterns reflecting lifelong experience [21]).
3. Basic perception-action responses (possibly unreflected, intuitive reactions to specific multisensory stimuli [22, 23]), up to “hardwired” reactive behaviour.

As an example, if the system had to guide a person to a secure place, it will select its aids from a variety of multimodal instructional, directional information, or lower-level multisensory stimuli based on what is most appropriate to this particular person at a given moment. This requires a model of the patient to be known to the system. Such a model can be determined by both medical experts, and, on runtime, a collection of tracking and sensor devices. We will further use a network of multimodal, mobile, and tailorable input and output components to be deployed in an intelligent environment.

Aid selection always begins at a point within the hierarchy which proved most successful in supporting the person in the same or a similar context.

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**Figure 1:** Overall closed-loop (observation-response) system architecture. Details are provided in the text.
Conclusions and future work

Dementia is an important field of study in Human-Computer Interaction and (Inclusive) Design. Our interview studies showed that technological solutions alone would not be successful, if they did not take individual and social contexts into account. A number of recommendations were developed.

One of the main conclusions is that we should focus more on the world as it is perceived by people with dementia instead of how it really is. Inspired by the De Hogeweyk village [15], which creates a powerful illusion of independence and self-responsibility, and as a key consequence of our analyses, the concept of “benevolent manipulation” has been proposed. Although assistive, it helps to subtly remove at least some of the felt limitations.

We further found that the principal aim should be to develop assistive technology that can be adapted / tailored, intuitively used, does not feel intrusive, and at best disappears as any device, tool or aid that need to be operated or learned (in the spirit of ubiquitous computing [24]). To ensure consistent functioning across all supportive entities and to guarantee optimal support, we argue that we need a larger framing in the sense of an intelligent assistive environment for long-term support [4].

Future work will include continue elaborating our view of the concerned ecosystem in all its facets. We moreover will design and test concrete solutions to the problems that matter most, and transfer all these developments to our larger architectural framing.

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