Diplomarbeit / Diploma thesis

Philipp Jordan

Analyse, Design und Evaluation eines interaktiven Systems zur Unterstützung von Menschen mit Demenz im Frühstadium und Ihrer Angehörigen

Analysis, design and evaluation of an interactive system to support early stage dementia patients and their families
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cand. mach. Philipp Jordan
Matrikelnummer 216 83 64

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Analysis, design and evaluation of an interactive system to support early stage dementia patients and their families

Diese Diplomarbeit ist im engen Kontakt mit dem Institut auszuarbeiten und bleibt dessen Eigentum. This diploma thesis has been conducted in close contact to the Institute of Design Engineering and is property of the same.

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Hauptfachprofessor / Supervising professor: Prof. Dr.-Ing. T. Maier

Hauptfachprofessor / Supervising professor: Prof. Dr.-Ing. D. Elias

Betreuer / Supervisor: Dr. Paula Alexandra Silva

Bearbeiter / Student: Philipp Jordan
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Work plan description:

World population is aging and forecasts predict that in 2050 older adults will correspond to a third of the population. This will require technology-related products to be designed with this specific type of user in mind while respecting their physical and cognitive limitations. A great percentage of these users suffers from some form of dementia. Therefore this should be a privileged audience to research on.

The aim of this project is to explore potential uses of a mobile device as a companion for the older adult, for instance as a virtual nurse, birthday calendar or shopping list.

Besides the exploration of different contexts of use, this project should also study ways of integrating the mobile device with other technologies, such as the TV in the house of the older adult or a public display situated in the health center.

A limited number - at least one - of the scenarios selected by the student and the supervisor should be fully prototyped and tested under Human-Computer Interaction design methodologies.

Work plan overview

1. Study of Human-Computer Interaction (HCI) fundamentals: methods and tools
2. Analysis of the elderly user characteristics
3. Develop an understanding of mobile devices characteristics and context
4. Design and evaluation of the work in the scope of the project
5. Definition of a user interface model and guidelines for the developed application
6. Thesis writing
Abstract

In 2025 every fourth European will be older than 60 years. This number is immense and will continuously grow in size in the upcoming years. Nowadays, senescence poses a threat to the already limited capacities of medical health care systems and economically exhausted governments. Especially age-related, long-term chronic conditions are both psychologically burdening and financially challenging for the patient and the caregivers. Since the number of cases are expected to double every 20 years, dementia, one of the most common chronic conditions, is going to play a significant role in the caregiving management of the 21st century worldwide.

Innovative technology may have the potential to mind the gap between exploding costs of long-term caregiving and assisted living at home of a dementia patient. While following a user-centered design methodology, this paper presents the development of an interactive system to support early stage dementia patients and their families. Each of the phases – analysis, design and evaluation – are described individually while keeping the central theme.

The project starts with a thorough literature study considering the fields of older adults affected with dementia, their technology affinity, their skills and a benchmark of available technical solutions and research projects around the scope. Exploratory interviews with 9 informal and 2 professional caregivers, respectively totalling 213 and 80 minutes of audio record, enhance and complement the theoretical research and outline a broad bandwidth of problems of dementia patients and their caregivers while living together and dealing with the disease.

The user research revealed that dementia patients are most of the time older adults with a late dementia diagnosis and multiple other age-related diseases. Furthermore, concealment of the disease due to the cognitive decline causes a loss of hobbies and social withdrawal. Technologically-wise, the television (TV) is the only device which is known and accepted in the dementia patients’ environment while the ability to use a phone - if existent - gets lost early.

Regarding the caregivers, the user research outlines major life changes when a dementia case appears. Struggling psychologically- and socially-wise in between their own responsibilities in life e.g., school, job, hobbies and friends challenge. Therefore, continuous stress and emotional difficulties in dealing with the new situation are observed. The fear of leaving the patient temporarily alone is one of the main causes of distress. Additionally in home caring environments, the research indicates that informal caregivers already organize their life around the patient by using classic tools such as phones, paper calendars and notes and rarely forget disease-related tasks or appointments.
The outcomes of the theoretical and qualitative user research shaped the design alternatives which concluded in an interactive system for caregivers and relatives:

Since the current generation of older adults has practically no experience with IT technology, the nearly impossible task to introduce an “alien” artefact to a dementia patient - e.g. a smart-phone – is circumvented by using the TV as a display. The TV offers limited, but unexploited possibilities as a passive interface for supporting a dementia patient in cases of temporary lonesomeness. In broad, the general idea of the solution designed consists of the usage of the TV to display dynamic, customized and illustrated information in the house of the dementia patient in situations of temporary lonesomeness.

The information displayed on the TV is defined by the caregivers in “mobileWAY” (mobile-where-are-you), a platform-independent application that enables caregivers to display easy and very simple information about:

- who they are (provided by her name and portrait)
- their whereabouts (illustrated by a picture of the place or activity they are occupied with)
- and the time remaining until the caregiver is back in the house of the patient (represented with a dynamic time metaphor)

Organizational helps, even if secondary, are considered by offering multi-caretaker accessible calendars, to-do lists and a forum for exchanging information among themselves.

Follow-up usability tests with two dementia patients and four of their caregivers indicate patient-side-wise partial to full comprehensibility of the information displayed on the TV. Stimulation and memory support due to association and usage of real images of locations and persons of their individual environment is also observed. Caregiver-side-wise, usability tests revealed high effectiveness and efficiency in using mobileWAY controllable from a mobile device, e.g. a tablet or a smartphone. Caregivers also reported that the solution would likely improve their life as well as the life of their dementia affected person.

Avoidance of introducing new hardware in the dementia patient’s home, little to nonexistent acquisition costs of additional infrastructure and no training or other prerequisites of patients and caregivers are positive characteristics of the designed and tested solution. Moreover, the involvement of caregivers in the patient tests has been as a valuable addition for the conduction of usability tests with dementia affected persons and is a side result of this work. By way of illustration, a high-fidelity (Hi-Fi) tablet interface set of mobileWAY has been created. A demonstrator video visualizing the possibilities of the system in a typical use case perfects this project.
Acknowledgments

Initially, I would like to thank Prof. Dr.-Ing. Thomas Maier, Prof. Dr. Dirk Elias and Dr. Paula Alexandra Silva who made this thesis possible in first place. Additionally, I am heartily thankful to my supervisor, Dr. Paula Alexandra Silva, whose encouragement, guidance and support from the initial to the final level enabled me to successfully conclude this research project.

Moreover, many thanks go to,

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Finally, I want express my thanks to Fraunhofer Portugal and all employees as a whole for integrating me here.

It is indeed a superb working place in terms of people, working atmosphere and "off work" activities.

Sincerely,
Philipp Jordan
Preface

"Every 7 seconds a new dementia patient worldwide." /1/

A healthy person can use the following analogy - similar to a nightmare - to superficially understand the agonies of a dementia affected person:

Imagine yourself abandoned all alone inside a Chinese town. You neither speak the language and nor are able to read anything. Everywhere you are confronted with strange conventions, e.g. eating food with chopsticks. And on top of that all the time you meet persons who continuously persuade you on something. Simultaneously, they act in a way knowing you for a long time and furthermore assume you know and understand all the things they talk about. The same as this example, the real dementia affected persons often feel about what they are supposed to be able to do and understand. As they don’t succeed in fulfilling these expectations, fear and anger is created - about themselves and about the too demanding fellow human beings. /2/

Everybody is familiar with the term dementia, has heard of it or even may know somebody in the closer kinship who is affected by this indeed tragic disease: Characterized by an irreversible cognitive decline over years, sometimes over decades causing a person - typically old-aged - to loose slowly all abilities a grown-up adult inherits:

- short- and long-term memory
- fine- and gross motor skills
- use of language and sensation of hunger, and
- ability to walk, to swallow and to control bowel and bladder functions

Dementia and dementia-caregiving represents a long-term, cost-intensive and extreme burdening situation for the affected individual and the social environment surrounding them. Besides of this huge individual impact on the psychological and social situation of the patient and the people around - which are most of the times the close family – dementia-caregiving is going to be one of the most important challenges for the already financially and structurally overwhelmed health care systems and society within most developed and industrialized countries.

Being diagnosed with dementia means objectively a long-term, sometimes even for decades lasting caregiving situation evolving at a certain point into a round-the-clock support. Besides of the financial aspect, not every patient wants to move into a caregiving facility out of their well-known environment at home. In terms of an intergenerational contract also families or friends prefer to take care of their dementia affected loved ones and deny the usage of caregiving facilities. Somebody bear in mind the context, that usually the children and grandchildren of dementia affected persons already have a lot of responsibilities within their own lives: occupation with school or work and their own
social life while arranging with the caring of a dementia affected person naturally causes a high psychological strain and stress for caregivers.

This work is dedicated to those and settled in such a context: The early and middle dementia patient living most of the times independently at his home with or without his family.

At the end, I want to recite the initial quote from this preface: Every 7 seconds a new dementia patient. Considering you - sincerely reader - took 2 minutes reading this test, keep in mind there are about 17 newly diagnosed dementia patients worldwide.
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1 Introduction

This chapter introduces the scope and research questions investigated and underlying this project. The thesis outline, main objective and formalities concerning the structure of the work are also presented.

1.1 Problem introduction

Chronic conditions - the health challenge of the 21st century:

The World Health Organization (WHO) /3/ stated in 2002 that: “Chronic conditions will not go away; they are the health care challenge of this century.” As chronic conditions (CC) are an age-related incidence and every fourth European in 2025 will be older than 60 years (60+), this target audience is immense and will only grow in size in the upcoming years. /4/

In Germany - an exemplary industrialized and well developed country - a total rise of the population of older adults (65+) from 16.9 million in 2009 to 23.5 million in 2040 is prospected. /5/ But overaging and senescence is found across all continents as well in the whole world. In 2010, more than 700 million individuals (or about 10% of the total population) already have reached the age of 60 years and more. /6/

These persons are naturally exposed to CC and physical impairments. One of the most severe CC in this context is dementia, a syndrome of various diseases connected with a long-term cognitive decline of the brain. In consequence, dementia has been identified as a major cause of caregiving. /7/ Logically, rising numbers of older adults are likely to result in increasing numbers of dementia cases. Finally, the clinical course of dementia treatment is equivalent to years – sometimes even decades – of caregiving. Therefore society needs solutions on any level for facing that challenge.

Fossilized, cost-expensive and overburdened healthcare systems:

Besides of this huge and massive amount of affected and prospected vulnerable individuals, health care systems (HCS) are nowadays financially expensive, in general overallocated and fossilized. The problem of the rapid and extreme demographical change will cause even higher costs in the upcoming years. Furthermore, HCS already cope with cost restrictions on one side while barely maintaining their minimum service quality on the other. /8/ There is even a probability of collapse due to overburden. Unfortunately, high qualitative and affordable health management and emergency medical services (EMS) are essential for the life of elderly people.

For example the fact, that “44 % of emergency medical services system resources are dedicated to patients over 70 years” /8/ emphasizes the current situation and is alarming for the upcoming century in the context of overaging.
1.2 Possible solutions

Information technology for older adults:

Technology offers chances for improving the situation of elderly people in general. A BITKOM /9/ study of 2010 concerning older adults and information technology (IT) identified the following advantages and trends:

- increase of contact with the family and friends by email and phone
- preservation of relationships and hobbies in communities and forums
- prevention of exhausting shopping tours and waiting queues with online-shopping and citizen services
- improvement of experience exchange with doctors and hospital by individualized health information
- in general, improved access to specially designed, high usability devices, such as e-readers and tablet’s with a high contrast, a light-weight design and variable font size

Also the ENABLE project (see chapter 4.4.8), a 3 year running European research project states towards dementia and the potential of IT that:

“People with dementia have traditionally not been considered as potential users of new technological products, except for products to ensure safety […] but products can in fact be designed and adapted to benefit this rapidly growing user group […]” /10/

Furthermore, the integration of specially adapted and designed products is clearly outlined as “[…] there may be a large market for such products.” /10/

For example, the market of mobile healthcare is a rapidly growing area: In 2015, 500 million people are prospected to use some kind of mobile health application worldwide. /11/

Individualized information and support systems:

The WHO identifies the challenges and opportunities of new HCS in terms of support through information and surveillance: “Primary health care must be reinforced to better prevent and manage chronic conditions. […] Health care that provides appropriate information, support, and on-going surveillance can improve adherence, which will in turn reduce the burden of chronic conditions and enhance patients’ quality of life.” /12/

The WHO states furthermore, that integrated and individualized systems and services are necessary for a successful and efficient care of CC: “That means, modern health care needs to pay more attention to individual patient behaviours and health care worker communications which are crucial factors for a successful care of CC.” /13/
Focus on home caring situations:

Research is already developing assistive technology (AT) for independent living as home caring will play a significant role in the future: "Due to the growth of the elder population in the western world, there has been an increased focus on developing technology for assisted living. Research and technology development within the field of computer-human interaction explores how elderly citizens can be assisted in the hope that this will help them to stay longer and care better for themselves in their homes." /14/

In harmony with Doherty et al., “systems can also aim to provide clients with increased support in their own homes or using mobile devices, thereby providing clients with greater flexibility in the delivery of services and again offering service providers with an opportunity to save on costs and therapists time.” /15/

1.3 Research argument

The research argument for this thesis is established by the problem presented in section 1.1 and the possible solutions in section 1.2 which build the framework of the following research. Figure 1.1 outlines the investigated areas of this project.

![Figure 1.1: Investigated areas of research](image-url)
1.4 Scope and objective

**Scope:**

The scope of this work focuses the support of early stage Alzheimer’s disease (AD) patients - the most common form of dementia worldwide - and their caregivers.

**Main objective:**

To support the everyday life of both – the patients and informal caregivers - the main objective is the creation of two representable graphical user interfaces (GUI) for

i) elderly people with early stage AD dementia at home

ii) as well as a complementing interface for their caregivers.

**Research questions:**

To solve the main objective, the following research questions are leading the way to the goal.

RQ1: What are the general physical, psychological and social prerequisites of an older adult?

Objective: Identification and analysis of the physical, psychological and social prerequisites of older adults.

Answer: Addressed in chapter 3.

RQ2: What would define a state of dementia?

Objective: In-depth investigation on dementia in terms of cause, occurrence, distribution, variations and symptoms.

Answer: Addressed in chapters 5 and 6.

RQ3: How to improve the life of the dementia patient and the caregivers around?

Objective: Analysis and consolidation of RQ1 and RQ2.

Answer: Addressed in chapter 7.

RQ4: Is the designed concept working and satisfying for both - the dementia patients and their caregivers?

Objective: Assessment of qualitative and quantitative data with prototypes.

Answer: Addressed in chapter 8.
1.5 Thesis outline

This thesis can be chapter-wise outlined in the following paragraphs:

Chapter 2 presents the research methodology and systematic approach being followed. Rapidly, the for this work most important terms and tools of Human-Computer Interaction (HCI) are introduced.

Chapter 3 introduces the target audience of this work, the older adult. By analysing differences and changes a 60 to 65+ year old individual experiences, an initial starting point for the user research is set and further enlarged in the following chapters 4, 5 and 6.

Chapter 4 connects the older adult with technology and exposes the state-of-the-art in the fields of information- and assistive technology. Furthermore, an investigation of actual research projects and a benchmark of consumer products for older adults with CC complement this chapter.

Chapter 5 discusses dementia, an umbrella term covering many variations of an - at the moment - incurable, slowly progressing disease causing a physical and cognitive decline of the affected individuals over years.

Chapter 6 presents the first piece of qualitative research of this work: It describes separately the prerequisites, analysis and interpretation of 9 exploratory interviews with informal caregivers of dementia affected persons.

Chapter 7 uses the findings of chapters 3 to 6 for a user-centered low-fidelity (Lo-fi) design process of a tablet interface for the caregivers and a television (TV) interface for the dementia patients.

Chapter 8 represents the second qualitative and quantitative assessment of data. A row of comprehensibility and usability tests with two dementia patients and four caregivers is conducted and documented. Similarly as in chapter 7, the results and interpretation of those is being treated separately.

Chapter 9 discusses the results of the previous research while chapter 10 includes conclusions, improvement recommendations and possible future work.

To maintain the central theme and also enable the reader to separately review the content, in the following a short introduction as well as a summary will accompany every main chapter.
2 Research methodology

2.1 Introduction

This chapter introduces the most important HCI tools and techniques used in this research for the novice reader. Not at all, it claims to introduce HCI and related disciplines as a whole from a holistic point of view. Moreover it will directly address and explain what tools have been used and which techniques have been selected for reaching the main objective and are the scientific fundament of the research. At the end of this chapter, the reader should be aware of the methods used for the user research, the design process and the evaluation of the user interfaces developed. A row of standard state-of-the-art HCI references are closing this chapter for further information.

The Association for Computing Machinery (ACM) defines HCI as a “discipline concerned with the design, evaluation and implementation of interactive computing systems for human use and with the study of major phenomena surrounding them.” /16/ A fundamental part of HCI is user-centered-design (UCD) and usability engineering (UE). A default user-centered-design process (UCDP) - as analysed in previous work /17/ - is found in the standards, e.g. in DIN EN 9241-210, while well-known usability-measurements are specified in DIN EN 9241-110. These fundamental tools and basic methods are applied in this work.

Therefore, the main steps of the research methodology can be mapped to the four steps of the human-centered design for interactive systems methodology /18/:

**Understand and specify the context of use**

By reviewing the literature and conducting qualitative interviews with subjects from the context of work - in particular caregivers and relatives from dementia affected persons and healthcare professionals – knowledge is acquainted.(chapter 2.2).

**Specify the user and organizational requirements**

By crossing the context of use with economical, realizable and technology-wise available solutions, the organizational requirements are defined (chapter 2.3).

**Produce design solutions**

Lo-Fi prototyping and expert revisions of functionalities supposed to address problems and issues of the user research led to interface solutions for the selected technology (chapter 2.4).
Evaluate designs against requirements

By bilateral comprehensibility- and usability tests for the dementia patient (TV interface) and usability tests for the caregivers (tablet interface), the concept is evaluated (chapter 2.5).

2.2 Understand and specify the context of use

The theoretical and qualitative study of the user group and target audience - the older adult with dementia - will set the scene and define the requirements for the complex UCD approach this thesis addresses. In harmony with the scope of the work and to complement the theoretical user research found in chapters 3 to 5, semi-structured, recorded interviewing is the method of choice for identifying qualitative user requirements.

2.2.1 Qualitative interviews and verbatim transcriptions

Exploratory interviews are the method of choice because they initially "help build an understanding of the needs, practices, concerns, preferences and attitudes of the people who might interact with a current of future computer system." /19/

In this context, the conducted interviews can be sorted into the "initial exploration" category. /19/ By asking the caretakers and patients what kind of problems occur and which technology is in use, the primary goal is to reveal user needs and problems which then allow the definition of requirements for a following design. Out of the available interview techniques

- structured interviews
- semi-structured interviews
- unstructured interviews

semi-structured interviews are selected. Semi-structured interviews offer various advantages and challenges when compared the other types available. /20/

Advantages of semi-structured interviews:

- can be open-ended, exploratory and extremely flexible
- can be re-ordered or adapted “on-the-fly”
- allow limitless subject responses and the possibility to dive “in-deep” in certain moments
- may encourage reflection and consideration on questions, generation of ideas and insights that would have been lost to in a survey, for example
Challenges of semi-structured interviews:

- challenge of managing potentially unbounded discussions
- interviewing is a skill and interviewers need experience in terms of pondering which questions to pursue more, paying attention to non-verbal reactions while simultaneously listen to the subject and taking notes etc.
- usually administered to a small numbers of participants
- much more difficult to conduct than surveys

For the recording of the content, different techniques are available, e.g. paper protocols or audio and video recording. Audio recordings of interviews offer a number of advantages and disadvantages: First of all, verbatim transcriptions of audio recordings allow a detailed examination of the content. On one side audio recordings allow complete and unfiltered access to the complete data set while on the other side the time exposure is remarkable high. Nevertheless, the detailed reconstruction of details - also for further research - and the possibility of time independent analysis of the data justified the usage of verbatim transcriptions of the audio records for the analysis (see appendix 12.1.2). Furthermore, analysis of qualitative data is a highly subjective task and depends on the interviewer’s skills and experience. As semi-structured interviews allow flexible adaption to the individual subject by asking additional questions or digging into a specific topic, a consequent coding and categorizing of the content is necessary for the identification of the common themes and the most important ideas. /168/

2.3 Specify the user and organisational requirements

As this work focuses on older adults affected by dementia, the author combined the results of the theoretical (chapter 3-5) and qualitative user research (chapter 6) for the followed iterative UCDP (chapter 7-8).

Organizational and environmental requirements are considered and explained simultaneously throughout the complete user research, e.g.:

- feasibility: technological limitations of the available hardware (chapter 5)
- resources: financial limitations of the target audience
- knowledge: usage of the well-known TV for the patients (chapter 7)
- context: social and structural environment of the target audience (Figure 2.1)

The ambitioned user research and context of the work lead concluded in using the TV display in the dementia patient’s house to provide non-intrusive information in situations of lonesomeness. For displaying content on the TV and providing tools for organizing themselves, caregiver-sidewise, a mobile tablet application was designed.
2.4 Produce design solutions

One of the many definitions of design is that “design is a practical and creative activity, the ultimate intent of which is to develop a product that helps its users achieve their goals” /21/ while “user-centred system design is a process focusing on usability throughout the entire development process and further throughout the system life cycle.” /24/

This work will design a double-sided application using well-known standard tools running on a TV and a mobile device. After the user research, the goal was to support the dementia patient with information in his home. The immense learning difficulties of the target audience are the main argument using the passive TV interface to provide information. /22/

The complementary tablet interface will tribute considers the caregiver(s) of this particular dementia patient and allows them to manipulate the displayed content dynamically.
2.4.1 Low-Fidelity prototyping and internal expert revisions

For conceptualizing and iterating the concept, Lo-Fi prototyping - a widely known HCI design tool - is applied in this research.  

Lo-Fi prototyping enables a cheap, fast and accessible interface design from scratch while successfully maintaining the balancing act of maximum feedback at minimal costs. Furthermore, Lo-Fi prototyping allows relative easy, dynamic design changes and iterations while designing the solutions.

Additionally, working in an interdisciplinary team inside a collaborative environment, naturally designs are reviewed and iterated before challenging the prospected target audience with the interface. Internal reviews, test evaluations and preliminary implementations of the designs and workflows initially conceptualized are carried out to eliminate fundamental mistakes and to avoid demanding subjects too much in terms tests numbers and time expenditure.

2.5 Evaluate designs against requirements

From the quiver of available usability evaluation methods e.g. /25/; /26/ Lo-Fi usability testing with end users using the Wizard-of-Oz methodology and after-questionnaire evaluations are conducted and will be outlined in the following:

The usability tests are conducted in the scope of Nielsen’s definition of usability /27/. In order to measure efficiency, users’ success rates and number of clicks needed for task accomplishment are collected. Therefore, the error rate is defined as the difference of steps needed to solve a task and the minimum steps needed:

$$\text{Error rate} = \text{Steps needed} - \text{Steps minimum necessary}$$

In summary, two types of data are collected.

Direct or objective measures:

- task success
- steps needed to solve the task
- error rate

Indirect or subjective measures:

- experimenter notes of the subjects behavior and comments while performing the tasks

The notes derived from the users' behaviour and thoughts while performing the tasks as well as the answer towards the evaluator questions while the users where performing tasks are indirect or subjective measures.
To assess subjective satisfaction, a questionnaire was given to the subjects after the tasks. In consequence, learnability is underlying the execution of the requested tasks while memorability is not measured since this criterion requires the user to return to the interface after a certain period of time which was not possible due to time constraints.

### 2.5.1 Wizard-of-Oz and think-aloud protocols

To simulate the system responses within the usability tests, the Wizard-of-Oz\(^1\) method is the preferred tool. It is “essentially a simulation of functionality that doesn’t exist yet in an interface application. The user perceives that they are interacting with the actual interface and system. In reality, the user is interacting with another human being that is providing the responses to the user. […] Wizard-of-Oz can be used “when the functionality has not been built due to cost concerns and when the technology doesn’t exist, to test potential future interfaces.” /28/

The obvious advantage of the Wizard-of-Oz\(^1\) method is the possibility of testing without a fully implemented system. Of course, disadvantages are also existent: Lack of reality caused to delays in system responses due to the human-controlled system feedback as well as limited simulation possibilities in terms of animations, transitions and fluid interaction are disadvantages.

Also subjects were encouraged to think aloud while performing the task to capture their thoughts or problems while performing the tasks. Thinking-aloud is a method for “capturing conscious, action-related cognitions and emotions” /29/ and originates from psychological science.

Nielsen /30/ explains the additional value of the think-aloud technique in terms of improved understanding and feedback: “By verbalizing their thoughts, the test users enable us to understand how they view the computer system, and this again makes it easy to identify the users’ major misconceptions. One gets a very direct understanding of what parts of the dialogue cause the most problems, because the thinking-aloud method shows how user interpret each individual interface item.”

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\(^1\) The name comes from the man behind the curtain in the movie “The Wizard of Oz.” /27/
2.6 Further references on HCI and usability engineering

Further information about usability evaluation methods can be found in /17/, /30/, /31/.

An in-depth discussion and review of the state-of-the-art concerning the topics of HCI and design can be found in /32/ while a complete and updated overview of actual quantitative and qualitative methods of HCI is found on Matthias Rauterberg’s homepage /33/ or in /28/.

2.7 Summary

This chapter introduced the research methodology. The goal was to present an overview of the methods applied in this worked as framed in a UCDP. A literature study and qualitative interviews represent the initial part of the user research. The economical, technological and social background of the user and environment is acknowledged as well. Design solutions are created by iterative Lo-Fi prototyping. Follow-up comprehensibility- and usability-tests and questionnaires are used to evaluate the designs in the field, in fact in the homes of dementia patients together with their families and caregivers. Objective usability measurements like success and error rates are measured as well as subjective measurements such as satisfaction and usefulness, which are collected with questionnaire evaluation.
3 The older adult

3.1 Introduction

Chapter 3 is dedicated to the physical and psychosocial prerequisites and changes of the older adult and his social environment. Furthermore, this chapter represents the first step of the user research:

Initially, the older adult, geriatrics and gerontology will be clarified by definition. The changes and impairments an individual at the age of 60 years and more will be investigated afterwards. Finally, the overaging of society will be outlined by recent statistics.

3.1.1 What is an older adult?

Before describing the overaging problem, the term older adult needs to be clarified. One definition of the WHO /34/ defines “elderly or older persons as individuals at the chronological age of 65 or more.” The United Nations (UN) state in this context that "at the moment, there is no United Nations standard numerical criterion, but the UN agreed cut-off is 60+ years to refer to the older population." /34/

The American College of Sports Medicine (ACSM) differentiated older adults in terms of chronic conditions with a: “separate recommendation for older adults as men and women age ≥ 65 years and adult’s age 50 to 64 years with clinically significant chronic conditions and/or functional limitations.” /35/

Furthermore, it is important to mention that there is a difference in terms of “being old” regarding the geographical area and development stage of a nation as it is: “also subject to the constructions by which each society makes sense of old age. In the developed world, chronological time plays a paramount role. The age of 60 or 65, roughly equivalent to retirement ages in most developed countries is said to be the beginning of old age.” /34/

Finally, terms like “young” and “old” elders, considering differences in e.g. interest in computers are identified in the literature as well. /36/

Overall, this vagueness in terms of definition is salient but not severe for the following research: For this work, the older adult is viewed as a person of a minimum age of 60 years. If necessary – and to maintain clarity – the older adult is in specific statistics and references defined by adding a parenthesis indicating the minimum age in the individual case, e.g. (60+) refers to a minimum age of 60 years.
3.1.2 Statistics around the elderly

To understand the huge impact of overaging an overview, this section outlines recent statistics and estimations of various.

Europe:

The German federal bureau of statistics prospects a rise of older adults (65+) from 16.9 million in 2009 to 23.5 million in 2040. /37/

According to Eurostat in 2008, about 13 million older adults (3 million older than 80 years) live in Germany, 1.2 million (0.3 million older than 80 years) in Austria and 1 million (0.3 million older than 80 years) in Switzerland. /38/

Within the 25 member states of the European Union, the relative percentile of the group of (65+) will increase from 9.2% in 1950 to 30.3% in 2050 compared to the total population (15.7% in 2000). /39/

The ENABLE Project (detailed chapter 4.4.2) – a recent EU research project on older adults with CC - confirmed in 2007: “that by 2025, 25% of the European population will be over 60 years” and furthermore that “this target audience is immense and while only grow in size in the years to come.” /4/

Worldwide:

According to the UN /40/, the top three countries with a ratio of population aged 65+ over to the total population in 2008 were Japan (19.7%), Italy (19.7%) and Germany (18.8%)

The situation in 2008 did not change that much: The Organisation for Economic Co-operation and Development (OECD) /41/ confirmed these numbers (Japan 22%; Italy 20.2%; Germany 20%) and the dramatic increase of the older population in these countries.

From a continental point of view, more than 700 million older adults with (60+) are currently living on the globe while the total population in 2010 has been estimated around 6.93 billion. /6/

This immense overaging problem and process becomes salient when comparing the relative increase of older adults (65+) from 5.16% in 1950 to prospected 6.46% in 2050. /42/
3.1.3 Impact of overaging on society

On top of these numbers, CC and dementia mainly affect older adults and therefore the medical healthcare systems and caregiving facilities: Every 2\textsuperscript{nd} person above 85 years needs some kind of assistance in everyday activities. /43/

For example, the value of caregiving needs in a representative, industrialized country as Germany are prospected to increase from 2.2 million care-dependent cases in 2007 to 3.3 million cases in 2030. /44/

When asking the younger generation, the overaging problem is acknowledged and identified as well: A 2009 study from TNS Infratest /45/ in Germany asked people between 12 to 25 years about the problem of the overaging of society: 70\% of the younger generation assessed the overaging problem as a problem for society (severe problem 44\%; very severe problem 26\%).
3.2 Age-related changes of an older adult

3.2.1 Aging, gerontology and geriatrics

Aging can be defined as a “progressive functional decline, or a gradual deterioration of physiological function with age, including a decrease in fecundity, or the intrinsic, inevitable, and irreversible age-related process of loss of viability and increase in vulnerability.” /46/

Becoming old generally means an exponential increase in mortality, physiological changes that typically lead to a functional decline and an increased susceptibility to certain diseases and CC. As aging and mortality are clearly related, it can also be defined “as the collection of changes that render human beings progressively more likely to die.” /46/

In simple words: The aging process causes our senses to degrade in general. Nevertheless, there may be individual differences on the impact of the degradation of unique functions still, deteriorations are without a doubt existent. /48/

Human aging goes along with a wide range of physiological changes e.g.: /46/

- changes in appearance
- decline in audition, olfaction and vision
- decline in certain memory functions and sexual activity
- decline in exercise performance and multiple endocrine changes
- decline in kidney, pulmonary and immune functions
- gradual reduction in height and weight
- longer reaction times
- loss of muscle and bone mass
- lower metabolic rate
- menopause (women)

The two professional disciplines studying the problems and changes of aging are gerontology and geriatrics. In this context, gerontology is defined as the: “scientific study of the aging process and old age” /46/ and “tries to find the reason we age and the details of aging such as biological problems of senescence.” /48/

Geriatrics on the other side is a “related science that is concerned with the disease characteristics of aging and the medical care associated with this process.” /47/
3.2.2 Physical changes

The physical changes of the human body due to the process of aging like greying of hair, a stooping stature and wrinkles are well-known visible sign of “becoming old”.

Additional general physical changes are moreover e.g.: /49/:

- balance problems / insecure walk
- constipation
- decrease of the tactile sense
- decreased circulation of blood and therefore a higher risk of strokes
- frailty due to elasticity loss of the ligaments
- medication dependence
- loss of finger dexterity and fine motor skills decrease
- strength loss
- slowdown of movements and motor reactions
- trembling

3.2.3 Physiological changes

Vision:

Visual perception is the sense which allows a human being to process the most amount of information. Older adults usually have to cope with significant changes in vision, such as: /47/; /49/:

- accommodation problems and visual acuity decline
- cataracts, glaucoma and blindness
- clouding of the lens;
- decrease of reading speed
- decreased color and contrast perception
- degeneration of eye muscles;
- delayed bright-dark adaption
- higher glare sensitivity and necessity for more brightness
- hyperopia
- impaired proprioception
- peripheral vision loss;
- presbyopia and farsightedness

For example, the absolute near point wanders from a distance of 8cm (16 years) to a distance of 100cm (60 years) over time. That, in consequence, is a big problem when older adults try to read newspapers or any other text in a small size /47/.
Audition:

According to Smith /49/, 30% of older adults (60+) years have a hearing impairment. Furthermore, 33% of those in the age range of 75 to 84 years and 50% in the age range of 85+ years have a complete hearing loss.

Another source /43/ reports that 48% of men (75+) and 37% of woman 75+ experience hearing difficulties.

Summarized, common audition problems are e.g.:

- decreasing hearing threshold (HTL)
- impairment of voice perception
- localization problems of auditory sources
- open Eustachian tubes
- presbycusis

The same as the acoustic perception changes with age, also the vocal mechanism is affected by e.g.: /47/ /50/

- alterations in vocal pitch
- hoarseness
- reduced intensity
- trembling
- weakness

These changes may cause the need to repeat conversations. Furthermore, embarrassment, misunderstandings and frustrations can occur and ultimately result in a withdrawal from friends, family and outside activities.

Gustation:

Compared to the other senses, gustation and olfaction are the least affected abilities of an older adult. For example, a minor loss of tongue sensitivity and smell can be a side effect of aging while the gustation system itself is more sensitive towards emotions. Moreover, depressions, worries and anger can result in stomach problems or appetite loss. /47/

Tactition:

In general, vascular diseases cause up to 25% of the older adults loss of tactile functions. /47/

Discriminating the texture, shape, temperature of a surface are examples of tactile sensitivity. Regarding these functions, age-related changes can result in a decline of the
manual dexterity and sensory capability of the human hand, which in consequence, is a vital input method for today’s IT devices and touch-driven devices. /170/

**Cognition:**

Mental changes, cognitive impairments and memory problems are well-known changes an older adult experiences and may include: /51/

- decrease of information absorbing and processing speed
- decrease of total amount of simultaneous information processing capacity
- dropping reaction rate
- higher disturbance sensitivity in cases of sensory overload, distractions and irritations
- longer learning durations
- massive detriments in short-term memory
- problems in learning new concepts and schemes
- problems in selecting relevant from irrelevant material
- slower perception speed and inefficient decision processes

Zajicek /52/ summarizes that “they also found difficulties in remembering sequences of actions that they had performed previously. Impaired memory seriously interfered with exploratory activity that involves remembering many combinations of actions and outcomes.”

**Psycho-social changes:**

Psycho-social changes are most of the times born out of a physiological change and then affect the social behavior of the older adult. For example, changes in vision may cause individual’s to give up driving at night which then affects their mobility /49/. More psychosocial changes are e.g.: /53/

- depression caused by isolation and loneliness
- fears, recent bereavement, retirement
- health problems, wrong medications
- intellectual skills, which affects the absorption of new information
- reduced sense of purpose

**3.2.4 Dynamic changes**

A big problem about the changes of the older adults is their dynamic character. Older adults do not inherit a static set of user requirements. Moreover, age-related disabilities occur with different rates for each individual. Compared to younger people, it is wrong to assume homogeneity and static prerequisites of the group of older adults:
“The older user group does not have a static set of user requirements. Requirements differ between individuals at any one time. Requirements also vary for a particular individual from time to time due to tiredness, or over use of one of the senses e.g. eye-strain, and as we know when people age their abilities tend to decrease over time. We see that for older adults we have requirements changing between users, and over time.” /54/

The most obvious dynamic change is the deteriorating visual acuity and the memory impairment. The consequence of seeing problems can go along with problems in developing conceptual models for a successful interface manipulation. /52/

Also older people have varying conditions over the day: "As people age they are more prone to variability in their level of impairment through the day, and over longer time periods when experiencing degenerative illness. Changes might depend on drug regimens they are following, levels of tiredness throughout the day, and in the longer-term, life situations such as previous illness or bereavement.” /53/

This is very important for the interface design of hard- and software for older adults:

“Continual use of one form of input device or output mode can also lead to tiredness and can be helped by switching to another mode or alternating between two. Similarly eye-strain can affect levels of visual impairment where older adults may be able to read text at the beginning of the session, but start later on to rely on voice output as it becomes less clear. The level of impairment or tiredness, as it changes, changes the interface requirements of the system, and this must be reflected in the design methods used.” /53/

3.3 Summary

Chapter 3 described the group of older adults in terms of definition, changes and global impact. Various statistics and forecasts indicate a massive growth of the elderly population in the upcoming years and decades. Besides of providing evidence for this development, this chapter also called attention to the different meanings and definitions of an older adult and presented common changes of aging.
4 Information and assistive technology

4.1 Introduction

This chapter develops an understanding of information and assistive technology, available products for older adults as well as research projects around the scope of this research. Also, the chapter is supplemented with recent statistics and predictions concerning older adults and IT.

4.2 Information Technology and the elderly

New technologies are able to attract and support the elderly theoretically and practically:

Makedon /55/ states towards the integration of older adults in technology and the digital divide: “As the world’s population ages at an unprecedented rate, societies find themselves in a predicament where the communicative power of technology strides ahead, leaving behind an underserved population segment that stands to gain immeasurably from its full and proper adoption. The term “digital divide” refers to that gap between those people with effective access to digital and information technology and those without access, and reveals just how critical it is to include a growing elderly population in every technological advance made.” /58/

In this context, Samsung /56/ e.g., recently promoted a touch-driven smartphone especially for older adults on the World media Congress in April, 2011:

Amy, a stereotype of a healthy and active senior aged woman which uses social applications and video phoning is the exemplary user in the marketing campaign. But even Amy, as a proficient old-aged woman acknowledges at the end of the advert: “Don’t contain yourself... it’s never too late.” /57/

This commercial line is indeed remarkable. IT progresses at such an incredible pace that older adults are still left behind most of the times. Reasons for this digital divide or gap can be e.g.: /59/

- Many older adults have less computer and mobile device experience than young adults, decreasing opportunities for positive transfer. They also generally have more difficulty than young adults in acquiring new computer skills.
- Their ability to learn is hindered by natural declines in processing speed, and in verbal and visual spatial working memory.
- Interacting with mobile device interfaces may be more difficult for older adults as they place demands on the user’s working memory;
Proposed advantages of IT for the elderly:

Possible advantages and opportunities for the successful integration of IT and communication in the life of a senior can improve his social situation, e.g. /60/

- Affection: By feeling accepted and esteemed.
- Emotion: Through support and feelings of security.
- Information: Due to acquisition of information and advice.
- Perception: By receiving feedback.
- Social support: Provision of goods and services.
- Social environment: Due to relieve of tension, decrease of isolation and in social participation.

Nevertheless, as mobile devices have the “potential to support many older adults (age of 65+ years) in their daily lives, especially to compensate for natural declines in cognitive, sensory, and physical abilities still many older adults find it difficult to learn to use existing mobile device applications and their user interfaces.” /59/

Accessibility of mobile devices:

Important key points for the accessibility and usability of mobile devices for older adults are according to Hubert /61/:

- lighter weight of the devices
- smaller screens (smaller buttons, readability)
- smaller size of the mobile devices
- various input methods (touch screens; voice input, gesture recognition)

4.2.1 Statistics around information technology and the elderly

World population is aging. Especially the OECD countries are facing a major demographic change. This subchapter starts with a recent survey of the German federal office of statistics from November 2010 scoping out the usage of IT technologies of the older adults in Germany. As one of the most developed countries according to the Human Development Index, (HDI), /62/ the reality is assessed. By analysing the actual distribution and usage of IT technology within the group of the elderly a snapshot of the reality nowadays is possible.

TV:

According to a recent statistical survey /63/, the infiltration of the TV in Germany is thorough: 98% of senior (65+) households own a TV. For the very popular and more and more affordable widescreen-TV’s (LCD, LED, Plasma technologies), 23% of all German households are already equipped with such devices. Therefore, the TV is a well-known and wide-distributed IT technology in almost every household, regardless of age.
Supplementing the technological advances and connectivity of devices, Goldmedia /64/ prospects a huge increase of internet-capable TV’s in Germany from 2.5 million households in 2010 up to 23 million in 2015. Out of these 23 million internet-capable TV sets, 13.4 million are prospected to be used on a regular basis.

**Mobile phone / smart phone:**

61% of the German older adults (65+) use a mobile phone, while out of these 61% only 6% use a smartphone. That means in relative numbers, 3.66% of all older adults (65+) in Germany use a smartphone – or in a more illustrative value every 27th senior. /63/

After acknowledging a decent distribution of mobile phones within senior citizens in Germany, investigating their usage patterns reveals that 70% use the mobile phone for calling only while 25% uses exclusively besides calling the SMS functionality. In this context the reference identifies a so-called “one-dimensional mobile phone usage.” /63/

At the moment, seniors mainly use their mobile phones to make and receive calls.

Also, the European Interactive Advertising Association (EIAA) conducted a survey with 12500 persons across Europe in 2010 wherein only 5% of the older adults (55+) accessed the internet outside of their house by a mobile phone or a tablet, for example. /65/

**Personal Computer / Notebook / Tablet:**

54% of the senior households in Germany (65+) have access to a computer at home while mobile computers like notebooks and tablets are rarely found in the senior population. /63/ Furthermore, the general usage of computers is extremely rare: In 2011, only every 3rd older adult in Germany is using the PC occasionally. /63/

As tablets represent a very recent trend in consumer products and are successfully invading markets of any age, the worldwide sales of tablet-computers from the 2nd quarter in 2010 (3.3 million units) to the 4th quarter in 2010 (10.1 million units) nearly tripled according to the International Data Corporation (IDC) /66/. Gartner’s estimation of the worldwide sales of „media-tablets” from 20 million in 2010 up to 150 million in 2013 emphasizes this growth. /67/

**Internet:**

As the mobile internet usage has been already scoped out in the mobile phones / smartphone paragraph /65/, a more in-deep investigation of the actual usage of internet in the senior population is opened:

The share of seniors in 2008 using the internet occasionally in selected European countries wobbled around 33%. The top three countries in Europe in this statistic are repre-
sented by Sweden (69%), the Netherlands (68%) and Denmark (62%). Germany is ranked on the 5th place with 45% of older adults using the internet occasionally. /68/

eMarketer’s 2010 survey and prognosis of the internet users in the USA from 2008 to 2014 is in harmony with the numbers found in Germany: In 2012, 50% of senior citizens (65+) will use the internet in the USA. /69/

4.2.2 Résumé of the statistics

The infiltration and usage of IT within the elderly in developed countries was investigated by looking into recent statistics and surveys. When comparing the results of the distribution and the actual usage of television, mobile phone and internet of German older adults (65+) - as a snapshot of the situation today and not as a trend - obviously (Figure 4.1) the TV is adopted by nearly every older adult while smartphones e.g., are very rarely in use.

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Figure 4.1: The older adult and IT distribution in Germany in 2011 /63/ /65/ /68/

Figure 4.1 represents the summary based on the previously presented statistics and surveys in one single diagram for the older adult in Germany:

The percentiles for the TV (98%), mobile phone (61%), PC (54%), flat screen TV (23%) and smart phone usage are identified in the 2011 Silver Surfer BITKOM /63/ study. The internet usage (45%) was evaluated from Eurostat /68/ in 2008, while the mobile internet usage was assessed throughout complete Europe (and not exclusively Germany) by the European Interactive Advertising Association /65/ in 2010 and moreover considered adults at the age of 55 years or more.
4.3 Assistive technology and the elderly

"Assistive technology" (AT) is a broad term used to describe all assistive, adaptive and rehabilitative devices for older people and for those people with disabilities." /58/

This broad definition includes either low-tech (e.g. hearing aids or canes) and high-tech devices (e.g. speech-recognition systems or advanced communication devices). They are especially designed for a certain purpose and aim to “improve a person’s ability to live and function independently." /70/

Bookman et al. /71/ describes AT as: “products, devices or equipment used by individuals with disabilities to maintain, increase or improve their functional capabilities. Assistive technology can include mobility devices such as walkers and wheelchairs, as well as hardware, software, and peripherals that assist people with disabilities in accessing computers or other information technologies."

A final, holistic definition is found in Bullinger’s /72/ Technology Guide:

“All devices, systems or technology-based services that aim at increasing, maintaining or improving the functional capabilities of people with disabilities, or at reducing activity limitations, are referred to as "assistive technology" (AT). AT products are usually specially designed or modified for this purpose, and often specialised to suit a specific application disability. It is essential that AT products be adapted to the special needs of individual users, especially when it comes to the human-machine interface. It is also important to avoid a stigmatising design so that the products are more readily accepted by the users.

AT are pushing into the lives of elderly as “emerging technologies are extending the ability of elders to live independently for longer periods of time, reducing the need to live in assisted living facilities or care homes, and reducing reliance upon family or paid caregivers to provide support. Technologies for the home range from those that aid in activities of daily living, that monitor and generate alerts based upon usual (and unusual) behavioural patterns, that improve physical safety, to those that bring essential health care services directly into the home." /73/

AT have the potential to allow elderly people in participating into specific social settings or communities as well: "The physiological and psychological changes caused by ageing often prevent seniors from participating in the community to the extent they may wish. Visual and hearing impairment and decreased mobility are common among senior citizens, and have the tendency to affect seniors’ socialisation. Assistive communication technologies have the potential to allow senior citizens to continue their engagement in specific social settings or communities by providing necessary support and assistance. At the same time, these technologies may create access to new communities, thus ei-
“ther changing or increasing the individual’s social network and possibilities of engaging actively in social relations.”

Available technologies and products on the market for seniors are commonly found in the fields of:

- personal emergency response system, e.g. emergency medical alert systems
- integrated solutions, e.g. staff alerting and alarming
- GPS wander management and fall/elopement prevention, e.g. networked cameras and wireless network infrastructure
- portable speech system and communication accessories
- digital memory products, e.g. card games, brain teasers
- advanced and adapted communication devices, e.g. elderly-friendly phones

Figure 4.2 shows a row of available consumer products specially designed for meeting the elder’s needs: A medication carousel, a specially adapted landline phone, a colour coded keyboard and a digital memory.

Figure 4.2: Four examples of assistive technology

Besides of adapted products, a major focus of science lies on the development and adaptation of communication devices for older adults to overcome the digital divide. Common design characteristics found in these produces are large physical dimensions and display sizes, high contrasts, big buttons, easy-to-grip surfaces and included emergency systems.
Figure 4.3 shows an end-consumer mobile phone for older adults while two more examples of available communication devices for older adults are illustrated in Figure 4.4. Common design characteristics found in these devices are few keys in a typical bigger design, high contrasts due to colour coding and simple shape and surface design. An emergency button is very common too (e.g., red circle in Figure 4.4).

**Figure 4.3:** Exemplary adapted mobile phone /81/

**Figure 4.4:** Examples of elder friendly phones /82/ /83/
A non-available solution is the smart companion (Figure 4.5), an internal Fraunhofer Portugal research project /101/. It develops a customized, android-driven smartphone interface designed to meet older adults needs while encouraging them to adopt touch driven devices without stigmatization. A direct emergency call feature, medication reminders and a simple, but effective voice control are some of the extended functionalities of the system. Design-wise, a high contrast, minimalistic layout and well-sized buttons characterize the interface.

![Smart Companion android interface](image)

**Figure 4.5:** Smart Companion android interface /102/

The general diversity and obvious fragmentation of the market is caused by a low awareness, a confusing array of options and high acquisition costs consumer-sidewise as well as the obstacle in reaching economies of scale developer-sidewise. /84/
4.4 Research projects concerning older adults

In the last decade, various research projects in the healthcare and IT domain addressed diverse areas of older adults with CC. A common characteristic of all research projects is a focus on ease of use, learnability and memorization as crucial aspects for a successful adoption. /61/

4.4.1 ENABLE (2001 – 2004)

The ENABLE /93/ project investigated products for people with dementia (e.g. AD). The landline phone and a locator device in Figure 4.6 are two examples of the tested products of ENABLE.

![Figure 4.6: Landline phone and locator device /94/ /95/](image)

4.4.2 LOCOMOTION (2002 - 2004)

An EU project from 2002, LOCOMOTION /86/ investigated, developed and tested a location service for elderly and disabled citizens. A side goal was to include the patients and their caregivers into a remote location based service. It was specially aiming at the telecare of people with dementia while considering their learning difficulties. The promotion of independent living and avoidance of social exclusion were also considered in LOCOMOTION.

4.4.3 COGKNOW (2006 – 2009)

COGKNOW Limited /97/ is a commercial successor of the EU COGKNOW /98/ research project and developed a complete assistive system – the so-called “DayNavigator” for persons with mild dementia. The system uses a mobile device if people are outside of their house and a stationary, touch-driven interface they are home.
Personalized functions and customized interfaces are considered in the solution, e.g. usage of real photos and pictures from the environment of the individual patient. The system focuses on memory support, social contacts, daily activities and safety. Proposed benefits are independence and quality of life for the patients and less caregiver burden for the families.

Figure 4.7 shows the stationary and mobile interface solutions of COGKNOW.

![Figure 4.7: COGKNOW Day Navigator system](image)

4.4.4 CAALYX (2007 – 2008)

The EU funded CAALYX /89/ project developed an extensible health monitoring platform – a so called wearable light device - that uses GPS to support health monitoring and emergency handling. Data collection at the home of the elderly, a high degree of personalization and an individual health agenda are some of the characteristics of CAALYX.
4.4.5 EMERGE (2007 – 2010)

EMERGE /87/, another EU project aimed to develop recurring models of elderly people for detecting deviations from their typical behaviour. For maintaining user acceptance, the usage of ambient, unobtrusive and non-invasive sensors in the home of the elderly was an important sub goal. /88/

The integrated emergency systems and social and structural environment of the project is illustrated in Figure 4.8.

![EMERGE integrated emergency system](image)

Figure 4.8: EMERGE integrated emergency system /87/

4.4.6 Netcarity (2007 – 2011)

Recently finished in February 2011, the Netcarity /92/ project developed a networked, multi-sensor system for the home of elderly people with the aim to turn them into supportive environments. Besides of postponing or avoiding the move into a care home, wellbeing, safety, independence and health at home are major key points of Netcarity.
4.4.7 ENABLE (2007 - 2010)

With the similar title ENABLE (see chapter 4.4.1) but a different scope, this EU project /96/ developed a wearable device for older adults in form of a watch (Figure 4.9). It claims to innovatively address integrated social and healthcare applications, combined fall prevention / detection and embedded language-independent control in a single, wrist worn device.

![ENABLE prototype](enable_prototype.jpg)

**Figure 4.9:** ENABLE prototype /96/

4.4.8 SENIOR (2008 - 2009)

The EU funded SENIOR /85/ project focused on a policy and technological roadmap for older adults and considered technology, ethics and socio-anthropological work in information and communication technologies. The main goal of the project is inclusion; dialogue with older adults is the measuring instrument for getting feedback while an appropriate technology design represents the target.

The main outcome of this project is that older adults prefer to live as long as possible in their own homes. Even beyond that, a willingness to consider significant changes in their environment was observed.
4.4.9 eCAALYX (2009 – 2012)

eCAALYX /90/, the successor project of CAALYX expanded the target audience to older people with comorbidity and multiple CC. Besides of maintaining safety and confidence of the elderly, deterioration prevention, health education at home and also the commercial viability of the project for a real-word deployment is considered. Figure 4.10 illustrates the integrated eCAALYX system.

Figure 4.10: eCAALYX healthcare system /91/
4.4.10 Résumé of the research projects

When summarized, it is possible to detect of trend to customized solutions for supporting elderly in- and outside of their homes is detected. Most of the projects use new or adapted devices, either a stationary, touch-driven display or a mobile phone; sometimes even both. Also, complete integrated assisted living environments prefer to use unobtrusive and non-invasive sensors technology to promote independent living and to avoid deprivation.

Sadly, as current technologies are incapable of satisfying the needs of elderly people with CC, most of the times new hardware needs to be acquainted. This means, another new learning effort for the user first place, a significant financial investment in sensor and display technology and occasionally stigmatization.

4.5 Summary

Chapter 4 investigated the distribution of IT and AT in the context of older adults with CC. The situation nowadays was outlined by recent statistics. Also available and upcoming solutions were outlined by benchmarking the market and peeking into research projects around the scope.

It can be stated that nowadays, the TV is the only IT which is widely adopted by the older adults besides of the classic landline phone. This might change in the future; nevertheless, the digital gap has been confirmed in general. Even though, the trend for individualized, custom products and easy-to-use solutions is salient a broad adoption of smartphones or integration of internet and the older adults is still in the very early stages of development.
5  Dementia

5.1  Introduction

This chapter approaches dementia as a syndrome from a general point of view:

Initially, the most important definitions around the scope and a couple of types of this disease are introduced. Next, the economic impact on society in terms of psychological, social and economic burden is outlined. Recent statistics about dementia supplement the information and outline the scale of the investigated field.

Chronic conditions:

In general, CCs are associated with all health problems which require continuous health management across a long period of time, e.g. over years or even decades. Examples are long-term mental disorders and physical impairments. The serious danger CC propose to humanity is the punctual concentration of different facts resulting in a massive, multi-dimensional problem: /104/

- CC increase worldwide in every country, regardless of region, nation or continent
- unprepared health care systems in terms of effectiveness, efficiency and immediate response
- in consequence, serious economic and social impact as well as a future threat to all health care resources worldwide
- lack of awareness of society and governments in general

Diabetes, arthritis, heart diseases, AIDS, cancer and also dementia are only some examples of popular and widely-known CCs throughout the world. According to the Fritz Beske Institut für Gesundheits-System-Forschung Kiel (IGSF) /105/, CCs are projected to rise dramatically the upcoming decades in Germany. /105/ Furthermore, they are the leading cause of disability worldwide. /106/ From an economical point of view, the caregiving and treatment of CC will become by the year 2020 – if not successfully managed – the most expensive problem of health care systems. /107/

5.2  Dementia in a nutshell

Dementia originates from Latin and can be translated as “irrationality” or “senselessness” and describes the sneaky loss of cognitive abilities and capacities. The only risk factor for dementia susceptibility clearly identified nowadays is age. In consequence, "dementia is one of the major causes of disability in later life." /103/

5.2.1  Impact of dementia on society

A look at the facts and statistics (see chapter 5.2.2) surrounding dementia clearly indicate that there is a massive issue, maybe even a possible medical catastrophe in the
making. /108/ Civilizations diseases are expected to rise until 2050: Compared to 2007, dementia will increase by 113%. /109/

As dementia is the leading cause of the institutionalization of older adults is, Alzheimer’s Disease International (ADI) stresses the urge to develop new solutions and products to improve the life of dementia patients and their caregivers, e.g.:

- cost-effective packages of medical and social care
- consideration of the needs of people with dementia and their caregivers across the course of the illness
- evidence-based prevention strategies

This urge is emphasized when considering the yawning gap in-between rising numbers of care-dependent persons one side and dropping potential and capacities for informal caregiving one the other side.

### 5.2.2 Statistics around dementia

Similarly to chapter 3.1.2 and chapter 4.1.2, statistics and projections are enlisted in this section to underline the global problem and impact of health care systems and society caused by dementia.

**Germany:**

In 2010, about 1.2 million (or 1.5% of the total population) in Germany have some form of dementia. 66% of those 1.2 million are affected by Alzheimer’s dementia (AD). /7/ /110/ /111/ Considering only the 60+ population, 5.2% are having some form of dementia. /113/

This number is projected to increase /112/ over 1.8 million in 2030 (or to 2.3 million of the total population) to 2.5 million (or 3.8 million) in 2060 (Figure 5.1) which means that in 2060, 2.5 to 2.6 million of Germans are prospected to have some form of dementia. /7/ /110/ The age-dementia dependency is illustrated in Figure 5.2 presenting the prevalence rates in Germany.

**Portugal:**

According to the recent proposed Portuguese national strategy of Alzheimer Portugal /114/, 153,000 people are currently affected by dementia in Portugal. Out of these, 90,000 are AD cases corresponding to 1% of the total population.
Figure 5.1 illustrates the projection of dementia cases in Germany from 2010 to 2050 while Figure 5.2 introduces the gender-wise dementia prevalence rate in specific age groups.

**Figure 5.1:** Projected dementia cases in Germany until 2050 /112/

**Figure 5.2:** Age-related dementia prevalence in Germany genderweise /110/
Europe:

Compared to Germany’s neighbourhood countries, e.g. Switzerland and Austria, less dementia cases are observed: For 2010 e.g., 1500 dementia cases per 100,000 inhabitants are found in Switzerland and Austria while Germany has 1,600 dementia cases per 100,000 inhabitants. But the projection shows an increase in all of the three countries. In 2050 e.g., Germany will have 3,500 dementia cases per 100,000 inhabitants, while in Switzerland and Austria the estimation is around 3,000 cases per 100,000 inhabitants. This difference is negligible. /110/

Moreover, ADI’s /115/ projection for the development of dementia cases in Europe and other continents up to 2050 is shown in Figure 5.3 and indicates a doubling of cases in Europe from 9 million in 2010 to 18 million in 2050.

Figure 5.3: Projection of the development of dementia cases worldwide

Worldwide:

Globally, ADI’s 2009 prognosis estimated that in 2010, 35.6 million of people have some form of dementia worldwide. As the number nearly doubles every 20 years in 2030, 65.7 million and in 2050, 115.4 million cases are prospected (Figure 5.4). /116/

In the recent report form 2010 /117/ these numbers were confirmed and it was added that “nearly two-third of these 35.6 million dementia affected persons live in and middle income countries where the sharpest increases in numbers are set to occur.” /117/
According to the Alzheimer’s association /118/, the number of AD patients in the USA has been doubled since 1980: In 2004, 4.5 million Americans were estimated affected by AD.

Finally - and in comparison to the complete and total population of the globe - 0.5% i.e. 35 million individuals are living with dementia nowadays (Figure 5.4).

**Figure 5.4:** Estimations of dementia cases worldwide from 2010 to 2050 /119/

### Economical costs of dementia for society

“The societal cost of dementia is already enormous. Dementia is already significantly affecting every health and social care system in the world. The economic impact on families is insufficiently appreciated.” /117/

Dementia, and in particular dementia care, causes substantial costs for informal caregivers and families as well as for the medical health care (MHC) systems and caregiving facilities as a whole. /128/

For example, in the USA, the average lifetime care costs for an AD patient in 2004 have been estimated around 170.000 dollar while the national direct and indirect costs are estimated around 100 billion dollar. /118/

In 2005, the Karolinska Institute estimated the worldwide social costs of dementia around 330 billion dollar. /130/
Moreover in 2009, ADI /129/ estimated the worldwide annual economic costs of dementia around 315 billion dollar. In 2010, this number doubled 604 billion dollar wherein 70% of the costs occur in Western Europe and North America. /117/

To illustrate this theoretical value, ADI /117/ further assumes dementia care would be a country and states that “it would be the world’s 18th largest economy, ranking between Turkey and Indonesia. If it were a company, it would be the world’s largest by annual revenue exceeding Wal-Mart (US$414 billion) and Exxon Mobil (US$311 billion). /117/

In harmony with the overaging factum outlined in chapter 3, the projected increase of dementia in the year 2030 and 2050 compared to the year 2007 is alarming (Figure 5.5).

![Diseases of civilization: Projection for 2030 and 2050](image)

**Figure 5.5:** Diseases of civilization: Projection until 2030 and 2050 /109/
5.2.3 Definition

Dementia is not a specific disease; moreover it is a syndrome or a group of symptoms caused by a number of progressive illnesses that affect memory, thinking, behaviour and the ability to perform everyday activities. Nearly all forms of dementia are currently not curable and lethal which, in consequence, results in long-term treatment and caregiving scenarios. /120/ /121/

Rebenitsch et al. /122/ defines dementia as a “long-term chronic decline of cognitive function due to disease or damage to the brain.”

A more detailed term is found in ADI’s /123/ definition:

"Dementia is a syndrome due to disease of the brain, usually chronic, characterised by a progressive, global deterioration in intellect including memory, learning, orientation, language, comprehension and judgement."

5.2.4 Occurrence

Dementia mainly affects older people, although there is a growing awareness of cases that start before the age of 65. After the age of 65, the likelihood of developing dementia roughly doubles every five years. /124/

When comparing a 30-59 year old woman with a 85-89 year old woman, the risk of dementia affection increases dramatically from 0.09% to 22.76%. Above 95 years - regardless of gender - every 3rd individual is exposed to some sort of dementia. /110/

Rothgang et al. /7/ calculates that every 3rd man and every 2nd of woman are becoming dement at a certain point in their lives.

5.2.5 Cause

A general and well-documented cause of most forms of dementia is advanced age. ADI e.g., estimates that the “prevalence roughly doubling every five years over the age of 65. Onset before this age is relatively uncommon and, in the case of Alzheimer’s disease, often suggests a genetic cause." /123/

More advanced causes are e.g.: /124/

- certain types of hydrocephalus, an accumulation of fluid in the brain that can result from developmental abnormalities, infections, injury, or brain tumors
- diseases that affect blood vessels, such as stroke, which can cause a disorder known as multi-infarct dementia
- diseases that cause degeneration or loss of nerve cells in the brain such as Alzheimer's, Parkinson's and Huntington's disease
- head injuries, either a single severe head injury or longer term smaller injuries,
• illnesses other than in the brain, such as kidney, liver, and lung diseases, can all lead to dementia
• infections that affect the brain and spinal cord, such as AIDS dementia complex and Creutzfeldt-Jakob disease
• nutritional deficiencies, like vitamin B12 and folate deficiency
• toxic reactions, like excessive alcohol or drug use

5.2.6 Diagnosis and treatment

The mini-mental state examination (MMSE) or Folstein test is a 30-point questionnaire used by doctors for dementia screening. As the test can be repeated during the course of the disease, it can also be used for tracking the history and the degradation or improvement of the individual patient.

As today no cure for dementia is available, symptoms can only be decreased in dimensions of exposition time and severity.

Besides of medication with anti-dementives, anti-depressants and neuroleptics, physical activity and cognitive stimuli like individual and well-levelled memory games or exposition to familiar music can slow down the progress of the cognitive decline. There are also indications of positive reactions e.g., when dementia patients are in contact with to the smell of coffee or popular perfumes which stimulate emotional reactions and memory. /125/
5.2.7 Duration

A big problem of dementia is its duration. Figure 5.5 shows an exemplary AD course over time. According to experts, duration lasts roughly from 5 to 10 years. As the diagnosis is often later determined than the actual onset, exact numbers are hard to assess. /127/

![Alzheimer's disease: clinical course](image)

**Figure 5.6:** Exemplary Alzheimer’s disease clinical course /126/

Without surprise, the WHO /131/ ranked dementia worldwide on the 2nd place (7.4 years average lifetime) of affected years living with a CC after blindness (13.3 years) and before deafness (6.5 years).
5.2.8 Common variations of dementia

“Dementia can be caused by nearly forty different diseases and conditions, ranging from dietary deficiencies and metabolic disorders to head injuries and inherited diseases.” /132/

With a ratio of almost two-thirds of all types, AD represents the most common form of dementia worldwide (Figure 5.7). The next section swiftly introduces the most common forms of dementia while outlining their differences and unique characteristics.

![Worldwide shares of dementia types](image)

**Figure 5.7:** Worldwide shares of dementia types /133/

**Alzheimer’s disease (AD)**

In 1901, the German psychiatrist and neuro-pathologist Alois Alzheimer published the first-ever case of “presenile dementia” diagnosed in a 50 year old woman. /134/

Later his name was used for describing Alzheimer’s disease, a “progressive, irreversible disorder that attacks the brain and results in memory loss, confusion, impaired judgment and personality changes.” /135/

Makedon /55/ explains AD as “a neurological affliction that impacts primarily the aged and brain tissue deterioration.” In the beginning, common symptoms are confusion, short-term memory loss and deterioration of language skills. As the disease progresses, the patients are unable to think for themselves and require later on round the clock supervision. As with many other forms of dementia, AD is often diagnosed after the onset of the first symptoms. Also, the duration of the disease ranges from 8 to 10 years while
the average survival time is around 8 years, respectively 4 to 6 years after the diagnosis. /136/

**Vascular dementia (VD) / Multi-infarct dementia (MID)**

After AD, the 2nd most common form of dementia /138/ (33% of all cases) is vascular dementia (VD) or multi-infarct dementia (MID) depending on the cause of the disease. For example, a subtype of VD isBinswanger´s disease, caused by “high blood pressure, thickening of the arteries and inadequate blood flow." /137/

Alzheimer Australia /137/ describes VD as a “broad term for dementia associated with problems of circulation of blood to the brain.”

Usually, a series of strokes deprive the oxygen support of the brain causing a decline of mental abilities. Symptoms, such as confusion, disorientation and emotional changes are common. The duration and average survival time is around 8 years and therefore quite similar to AD. More parallel features of AD and VD result in difficulties to distinguish between both diseases. Besides of the problem of a clear diagnosis, mixed forms of both types can occur. /138/

The stepwise progress of MID along with rapid changes is one unique characteristic compared to AD. Also the fact that some abilities may be unaffected while others decrease rapidly (patchy quality of the disease) is different compared to the more general and steady decline found in AD.

**Dementia with lewy bodies (DLB) / Parkinson’s disease (PD)**

In the early 1900s, while researching Parkinson’s disease, the German-American neuro-psychiatrist Friederich H. Lewy discovered “abnormal protein deposits that disrupt the brain’s normal functioning.” /139/

More terms for dementia with lewy bodies (DLB) are Lewy body disease (LBD), diffuse lewy body disease (DLBD), cortical lewy body disease (CLBD), Parkinson´s disease with dementia (PDD) and the lewy-body variant of Alzheimer´s (LBV; LBVA). Differentiating all these terms is difficult and can be confusing. Conventionally, regarding PD and DLB e.g., the primary occurrence of motor symptoms before dementia symptoms is defined as PDD while the development of motor symptoms after the cognitive decline is defined as DLB. /140/

Moreover, DLB is associated with similar behaviour and memory symptoms of AD and overlaps with many different forms of dementia. Hallucinations, as a unique characteristic, are usually reported while in general symptoms can widely fluctuate during a day resulting in symptom-free days. Caused by a degeneration of nerve cells in the brain, the average survival time after onset is 5 to 7 years. /71/
PD, or the co-occurrence of dementia, PDD, is besides of the initial occurrence of motor symptoms like tremor, stiffness in the extremities, muscle rigidity and difficulties in initiating physical movements similar to DLB.

**Frontotemporal dementia (FTD)**

Frontotemporal dementia (FTD) is a name “given to a group of dementias that involve degeneration in one or both of the frontal or temporal lobes of the brain. It includes frontotemporal dementia, progressive non-fluent aphasia, semantic dementia and Pick's disease.” /141/

Besides of language and speech symptoms, personality changes like euphoria, aggressiveness or apathy are characteristic for this type of dementia. Noticeable are indications for family inheritance of the disease while the cause is often a mutation in the genome causing an abnormal production of a certain protein. /137/

**Creutzfeldt–Jakob disease (CJD)**

"Creutzfeldt-Jakob disease (CJD) is a form of brain damage that leads to a rapid decrease of mental function and movement." /142/

CJD is an extremely rare disorder, occurring in about 1 out of 1 million persons. A protein folding abnormality from a so-called prion causes surrounding proteins to behave in harmony and therefore affect the function of the remaining ones. As the symptoms of CJD progress very fast considering the time from onset until death, it is well distinguishable from the other forms of dementia. /142/

Early symptoms are failing memory, behaviour changes and coordination problems. In later stages, the mental deterioration becomes worse as blindness and weakness, speech impairment, muscle stiffness and eventual coma can appear. /137/; /142/

**AIDS dementia complex (ADC)**

The AIDS related dementia, or AIDS dementia complex (ADC), is a complication that affects some people with human immunodeficiency virus (HIV) and acquired immune deficiency syndrome (AIDS). As ADC often affects younger people, special problems regarding employment, identify and sexuality are side-effects along with this rare disease /137/

**Huntington’s disease (HD)**

The American physician George Huntington wrote 1872 about an illness that he called "an heirloom from generations' away back in the dim past." /143/ One of its earliest names was chorea, referring to choreography which can be associated to the Greek word for dance. /144/
Huntington’s disease (HD) is a genetically inherited disease due to a programmed degeneration (autosomal dominant disorder) of a specific neuron. The peak of onset lies between the ages of 30 to 50 years and distinguishes HD from the other forms of dementia while an onset after 55 is rare. /143/ /145/ Dementia occurs in the majority of Huntington’s cases and is coming along with symptoms e.g., normal, rapid and jerky movements of all extremities and an intellectual decline are usual symptoms. /137/ /144/

If symptoms occur very early, the term juvenile or early onset HD is common. Besides of memory disturbance and slurred speech, also personality changes such as mood swings, apathy and depression are typically found. HD occurs very rarely worldwide. The prevalence is 5 to 10 cases per 100,000 individuals. The common duration of the course lasts from 15 to 20 years while juvenile HD has significant shorter duration from 8 to 10 years. /143/ /145/ /146/

**Wernicke-Korsakow syndrome (WKS)**

In the 19th century, Carl Wernicke, a German neurologist and psychiatrist and Sergei Sergejewitsch Korsakow, a Russian neurologist, described two different disease patterns caused by the same pathogenesis: The Wernicke-Korsakoff syndrome (WKS), also known as alcohol dementia, is a neurological disorder caused by excessive alcoholism and nutritional deficiencies. Important to mention is that this type of dementia is completely preventable due to denial of alcohol consume or a proper diet. Symptoms like mental confusion, short-term memory loss and amnesia are typical. Also, WKS patients are observed to confabulate information to compensate the memory impairments and to maintain confidence. Physical impairments, like ataxia, tremors and fine motor impairments go along with WKS. /147/

After pointing out 8 variants of dementia, chapter 5.3 outlines now a more general scheme of dementia, common symptoms and stages. Besides of the previously introduced individual characteristics, the following symptoms apply roughly to all types of dementia and therefore count globally.
5.3 Changes of an older adult with dementia

5.3.1 Symptoms and stages

Generally, dementia can be categorized into three stages:

The early stage refers to the 1st or 2nd year, the middle stage usually goes from the 2nd to 4th or 5th year and the late stage is usually the 5th year and after. /148/

ADI /149/ introduces a more specific mapping by categorizing dementia into 7 individual stages and is enlisted below:

Stage 1 - No cognitive impairment:

Unimpaired individuals experience no memory problems and none are evident to a health care professional during a medical interview.

Stage 2 - Very mild decline:

Individuals at this stage feel as if they have memory lapses, forgetting familiar words or names or the location of keys, eyeglasses or other everyday objects. But these problems are not evident during a medical examination or apparent to friends, family or co-workers.

Stage 3 - Mild cognitive decline:

Early-stage Alzheimer’s can be diagnosed in some, but not all, individuals with these symptoms. Friends, family or co-workers begin to notice deficiencies. Problems with memory or concentration may be measurable in clinical testing or discernible during a detailed medical interview.

Stage 4 - Moderate cognitive decline:

At this stage, a careful medical interview detects clear-cut deficiencies.

Stage 5 - Moderately severe cognitive decline:

Major gaps in memory and deficits in cognitive function emerge. Some assistance with day-to-day activities becomes essential.

Stage 6 - Severe cognitive decline:

Memory difficulties continue to worsen, significant personality changes may emerge, and affected individuals need extensive help with daily activities.
Stage 7 - Very severe cognitive decline:

This is the final stage of the disease when individuals lose the ability to respond to their environment, the ability to speak, and, ultimately, the ability to control movement.

5.3.2 Cognitive and psycho-social changes

Cognitive-wise, a decline or even a loss of memory and the ability to think rational is common. Furthermore, changes in emotional reactions and social skills are typical./117/ /137/

Usual psycho-social changes are enlisted below and consist e.g. of: /123/

- aggression
- agitation
- anxiety
- calling out
- delusions hallucinations
- depression
- personality, mood and behaviour changes
- sleep disturbance
- wandering and apathy
5.4 Dementia care

5.4.1 Caregiving and caregivers

"Caregiving is the act of providing unpaid assistance and support to family members or acquaintances who have physical, psychological, or developmental needs." /154/

Caregiving can be categorized into formal care and informal care. /150/

Formal care is usually a paid health service which can take place in a social or community center as well as in a long-term residential or nursing homes. Informal care therefore refers to unpaid care provided by family members, friends or other individuals to an extent, that they lost the opportunity to earn income. Important to mention is that more than 7 out of 10 people affected by AD live at home, wherein 75% of their family and friends provide the major part of care. /118/

Organizational-wise, caregiving can also be mapped to instrumental, emotional, and informational caring: /154/

Instrumental caregiving includes activities, such as shopping, taking care of appointments and the patient’s hygiene. Emotional caregiving usually refers to psychological support like counselling, advising or listing to a patient while informational caregiving concerns future perspectives such as learning how to alter the living environment of someone in the first stages of dementia for example.

Having defined caregiving, this section focuses on the caregiver, which is defined as a "person, either paid or voluntary, who helps an older person with the activities of daily living, health care, financial matters, guidance, companionship and social interaction. [...] Most often the term refers to a family member or friend who aids the older person.” /151/

Stebbins /151/ defines caregivers as “informal, unpaid assistance for the physical and emotional needs of another person. Family members or friends frequently provide this type of care.”

Commonly, the person most responsible for a patient is defined as a primary caregiver. This term is often used in family caregiving environments, wherein the tasks are divided within the family. /152/

One side of dementia-care represents the patient and his problems while the other is the impact on the social environment, families, caregivers and the society in general. Sooner or later the patients need care. In consequence, this research focuses on the patients and informal caregivers considering both sides within an integrated approach.
5.4.2 Responsibilities and challenges of caregivers

Usually caregiver responsibilities vary within a wide range of tasks that may include tracking of medication regimes, taking care of financials and administrative work, providing walking support and aiding in the food preparation.

The most relevant problems of informal caregivers are the behavioural and psychological symptoms of the patients (chapters 5.2.9 to 5.3.2). Another big problem with informal caregiving of dementia patients is the caregiver’s strain and depression. Anger, frustration or loneliness is found due to the overtaking of the caregiving task, neglect of the own life and psychological burden with the new situation. /124/

The world Alzheimer report of 2010 /117/ states towards this issue, e.g.:

"People with dementia, their families and friends are affected on personal, emotional, financial and social levels. Lack of awareness is a global problem. A proper understanding of the societal costs of dementia, and how these impact upon families, health and social care services and governments may help to address this problem. Besides of the economic burden the families of dementia patients have to cope, the emotional and psychological exposure they have to carry should be considered especially in the context of designing an interface for supporting these people." /117/

Factors found to be associated with carer strain according to ADI /70/ /156/ are behavioural and psychological symptoms wherein 40-75% of caregivers have a significant psychological illness and 15-32% a clinically diagnosable major depression. Higher mortality rates are also mentioned. Concrete examples for caregiver problems are exhaustion and strain, insomnia, depression and social isolation. Also financial concerns and social isolation can occur. Caregiving often comes along with ending the regular full-time employment of the caregiver. /159/

Also mentionable is the so-called zarit-burden interview for measuring the caregiver stress. This interview asks caregivers 22 questions in five categories to assess their physical, psychological and social burden. In 2000, a shorter 12-item questionnaire was proposed. /157/ /158/ /160/
5.4.3 External caregiving facilities

Care facilities are expensive and often used when the family of the dementia affected person is unable to handle the disease themselves. Common care facilities are e.g., respite care, adult day care, residential care and – in very late stages - hospice care. These types of care facilities are swiftly presented in the following.

**Respite Care:**

Respite care is a temporary or periodic care service provided by an external party for people with disabilities and CC such as dementia. Examples are community organizations or residential facilities. Respite care can release pressure of the usual caregivers in exceptional situations and disengage them from their responsibilities for a certain time.

**Adult day care:**

Adult day care centers are regular sites which offer programs for functionally and / or cognitively impaired older adults. The promotion of well-being and in a protected environment is the main focus. Popular examples of adult day care are senior or community centers which offer diverse services like social games and recreational activities (speech and music therapies) for dementia patients. Commonly, geriatric specialties and trained nurses are supervising the older adults in these settings. /71/

**Residential Care:**

Residential care is a permanent living environment in a specialized apartment complex or institution that proves full-time caring services for older adults with specific disabilities. Residential care is widely used for assisted living facilities, care or nursing homes.

Typically found underneath the residential care umbrella are: /124/
- retirement housing
- basic assisted living
- nursing homes
- continuum care retirement communities;

**Hospice care:**

A hospice is a: "public or private organization that provides pain relief, symptom management, and supportive services to terminally ill people and their families in the home or in a separate hospice facility." /71/

Typically, a terminally-ill person at the final stages of life is the target audience of hospice care which can also be applied at home or in facilities similar to the ones found in
residential care. In this context, “terminally-ill” refers to a life expectancy of six months or less. /161/

There are more terms like board and care home, custodial care, assisted living (AL) and assisted living facilities (ALF) which can be categorized into one of the four previous mentioned care facilities. The author states - again - a lack of clarity in terms at this point of research.

5.5 Summary

Dementia is a complex syndrome involving a whole group of diseases. So this chapter provided an overview on dementia as a whole, from an economical to a global perspective. The focus was to present a snapshot of the situation today and the prospected development in the 21st century.

AD was clearly identified as the dementia disease occurring the most of times. Dementia, as a long-term disease, also progresses through different stages. Late stage dementia often means that patients are physically completely bedridden, have lost control over almost all the body functions and are as well in the end stage of the cognitive decline.

The caregiving situation was also outlined. As this work addresses the problems of the dementia patient and his caregiver(s), their problems and responsibilities were introduced with special focus on caregiver burden.

In consequence this project will focus early stage AD patients and his informal caretaker in a home-caring environment.

As shown, the progress and symptoms of are mostly comparable to VD and DLB (representing together 99% of all forms of dementia), hence the results of this research are likely to be valid for the other two variants as well.
6  Qualitative user research

6.1  Introduction

In this chapter the consequent user research is followed by conducting semi-structured interviews with 9 informal caregivers. This research’s focus is on the early stage dementia patient and the corresponding caregivers which are - most of the times - close related persons within the family in a home caring environment. As detailed in this chapter, these informal caregivers are facing common problems and disadvantages e.g., psychological problems, and neglect of hobbies, friends and daily life.

6.2  Semi-structured interviews

For enriching the results of the theoretical user research, qualitative interviews with informal caregivers of dementia patients were conducted. Additionally, two healthcare professional from an adult day care center were interviewed. The interview guideline used assessed information about the patients and caregivers, changes and problems as well as technology usage of both groups within the context of home-caring. The data confirmed and enriched most of the theoretical user research as presented in chapters 3 to 6.

This approach is in harmony with Lazar’s recommendation of drawing interviewees from all categories of stakeholders. In this context a stakeholder is “is anyone who is affected by the use of a system.” /162/

In consequence, the study tried to assess mainly the necessary requirements by interviewing relatives and informal caretakers of dementia patients as well as professional caregivers and nurses. The nature of the disease explains the avoidance of stepping directly towards dementia affected patients. Therefore the relatives, informal and formal caregivers have been selected as interviewees.

With reference to /163/ as well as previous experiences of the author with empirical data assessment /17/ /164/, the subjects have been introduced to the scope and nature of the study, the alternative to exclude and skip certain questions as well as interrupt or cancel the study any time at free will.

An obligatory privacy statement regarding the confidentiality of the assessed data as well as the anonymity of the names of subjects, patients and relatives was followed by the introduction. Readers can review the complete interview guideline in appendix 12.1.1.
6.2.1 Subject data and sample size

First of all, it is important to understand that out of the 9 subjects interviewed, subject 4 to 7 (marked in a light blue frame in table 6.1) were referring to the same dementia patient as well as subjects 8 and 9 (marked in a dark-blue frame in Table 6.1) refer to another patient. Therefore in total, a total of 9 subjects interviewed refer to 5 individual dementia patients.

Also this study had limited resources regarding time and human resources available: While the number of interviews was relatively low at first glance, the main goal of the user research was qualitative input for the design. As the aim was no assessment of statistical data, the number of eleven subjects has been found to be sufficient enough for this purpose.

As two subjects (S10, S11) came from a significant different background (professional caregivers of a local adult day care center) and were moreover not directly related to an individual dementia patient, these two interviews nor formally coded and neither officially included in this thesis. Nevertheless, they contribute to the work by knowledge enhancement of the author in the context of topic.

Referring to Table 6.1., the total time of audio records is 213 minutes and the median age of all 9 subjects representing the informal caregivers is 55 years. The median age of the 5 dementia affected patients is 77.4 years. While the median age of the dementia onset according to the informal caregivers is 72.2 years, the median age of the confirmed diagnosis from a medical doctor is found to be later, at 74 years (arithmetic means). More details of the interviewed subjects can be found in tables 6.1, 6.2 and 6.3.
<table>
<thead>
<tr>
<th></th>
<th>S1</th>
<th>S2</th>
<th>S3</th>
<th>S4</th>
<th>S5</th>
<th>S6</th>
<th>S7</th>
<th>S8</th>
<th>S9</th>
</tr>
</thead>
<tbody>
<tr>
<td>Interview conducted by Author or a third party [A / TP]</td>
<td>A</td>
<td>A</td>
<td>A</td>
<td>TP</td>
<td>TP</td>
<td>TP</td>
<td>TP</td>
<td>A</td>
<td>A</td>
</tr>
<tr>
<td>Date of interview [MM/DD/YY]</td>
<td>10/12/10</td>
<td>12/12/10</td>
<td>28/12/10</td>
<td>25/12/10</td>
<td>25/12/10</td>
<td>25/12/10</td>
<td>15/01/11</td>
<td>22/01/11</td>
<td></td>
</tr>
<tr>
<td>Type of interview [Phone / Personal]</td>
<td>PHO</td>
<td>PER</td>
<td>PER</td>
<td>PER</td>
<td>PER</td>
<td>PER</td>
<td>PHO</td>
<td>PHO</td>
<td></td>
</tr>
<tr>
<td>Length of interview [min]</td>
<td>8</td>
<td>24</td>
<td>44</td>
<td>22</td>
<td>15</td>
<td>19</td>
<td>16</td>
<td>45</td>
<td>20</td>
</tr>
<tr>
<td>Number of questions asked</td>
<td>13</td>
<td>13</td>
<td>13</td>
<td>14</td>
<td>14</td>
<td>14</td>
<td>14</td>
<td>13</td>
<td>13</td>
</tr>
<tr>
<td>Additional questions asked</td>
<td>5</td>
<td>18</td>
<td>29</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>12</td>
<td>6</td>
</tr>
<tr>
<td>Interview completed</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Video / audio record [VR / AR]</td>
<td>AR</td>
<td>AR</td>
<td>AR</td>
<td>VR</td>
<td>VR</td>
<td>VR</td>
<td>VR</td>
<td>AR</td>
<td>AR</td>
</tr>
<tr>
<td>Interview guideline used [x.x]</td>
<td>1.0</td>
<td>1.0</td>
<td>1.0</td>
<td>1.1</td>
<td>1.1</td>
<td>1.1</td>
<td>1.1</td>
<td>1.2</td>
<td>1.2</td>
</tr>
</tbody>
</table>

**Table 6.1:** Interview-related information
<table>
<thead>
<tr>
<th>S1</th>
<th>S2</th>
<th>S3</th>
<th>S4</th>
<th>S5</th>
<th>S6</th>
<th>S7</th>
<th>S8</th>
<th>S9</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender of dementia affected person</td>
<td>Female</td>
<td>Female</td>
<td>Female</td>
<td>Female</td>
<td>Female</td>
<td>Female</td>
<td>Female</td>
<td>Female</td>
</tr>
<tr>
<td>Age of dementia affected person</td>
<td>78 (died)</td>
<td>87</td>
<td>59</td>
<td>82</td>
<td>82</td>
<td>82</td>
<td>82</td>
<td>81</td>
</tr>
<tr>
<td>Relationship of dementia affected person to subject</td>
<td>Mother</td>
<td>Grandmother</td>
<td>Friend</td>
<td>Mother</td>
<td>Mother</td>
<td>Patient</td>
<td>Wife</td>
<td>Mother-in-law</td>
</tr>
<tr>
<td>Type of dementia of the affected person</td>
<td>AD</td>
<td>AD</td>
<td>AD</td>
<td>AD</td>
<td>AD</td>
<td>AD</td>
<td>AD</td>
<td>AD</td>
</tr>
<tr>
<td>Dementia affected person is</td>
<td>Deceased</td>
<td>Alive</td>
<td>Alive</td>
<td>Alive</td>
<td>Alive</td>
<td>Alive</td>
<td>Alive</td>
<td>Alive</td>
</tr>
<tr>
<td>Age of being diagnosed with dementia</td>
<td>73</td>
<td>80</td>
<td>58</td>
<td>82</td>
<td>82</td>
<td>82</td>
<td>82</td>
<td>77</td>
</tr>
<tr>
<td>Age of onset [years]</td>
<td>68</td>
<td>80</td>
<td>58</td>
<td>82</td>
<td>82</td>
<td>82</td>
<td>82</td>
<td>73</td>
</tr>
<tr>
<td>Living alone</td>
<td>N/A</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>If not living alone, living with</td>
<td>N/A</td>
<td>Husband until he died</td>
<td>Living alone, divorced</td>
<td>Husband</td>
<td>Husband</td>
<td>Husband</td>
<td>Husband</td>
<td>Family, mobile nurse</td>
</tr>
</tbody>
</table>

**Table 6.2: Patient-related information**

<table>
<thead>
<tr>
<th>S1</th>
<th>S2</th>
<th>S3</th>
<th>S4</th>
<th>S5</th>
<th>S6</th>
<th>S7</th>
<th>S8</th>
<th>S9</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender of subject</td>
<td>Male</td>
<td>Female</td>
<td>Female</td>
<td>Female</td>
<td>Female</td>
<td>Male</td>
<td>Female</td>
<td>Male</td>
</tr>
<tr>
<td>Age of subject [years]</td>
<td>51</td>
<td>29</td>
<td>60</td>
<td>57</td>
<td>42</td>
<td>64</td>
<td>87</td>
<td>52</td>
</tr>
<tr>
<td>Nationality of subject</td>
<td>English</td>
<td>Portuguese</td>
<td>German</td>
<td>Brazilian</td>
<td>Brazilian</td>
<td>Brazilian</td>
<td>Brazilian</td>
<td>German</td>
</tr>
<tr>
<td>Relationship of the subject to dementia affected person</td>
<td>Son</td>
<td>Granddaughter</td>
<td>Informal caregiver</td>
<td>Daughter_1</td>
<td>Daughter_2</td>
<td>Informal caregiver</td>
<td>Husband</td>
<td>Daughter-in-law</td>
</tr>
<tr>
<td>Primary caregiver</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
</tr>
</tbody>
</table>

**Table 6.3: Caregiver-related information**
6.3 Interview analysis

The interview analysis consists of four steps. /165/ /166/

6.3.1 Transcription

The audio records are transcribed word-by-word or verbatim into text. The complete and coded transcription can be found in appendix 12.1.2.

6.3.2 Coding

After the transcription, the text is coded into individual fragments (chapter 2.2.) of content and information. The coded fragments can be reviewed in appendix 12.1.3.

6.3.3 Categorization

This study introduced qualitative coding categories for analysing the data. The fragments themselves are ordered into a coding framework and built categories of information of specific topics e.g., the category of early stages symptoms [ESS] of the patient or the category of caregiver changes in life [CH].

<table>
<thead>
<tr>
<th>Category</th>
<th>Category Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>[ESS]</td>
<td>Early stage symptoms are characterized due to changes in behaviour, aggressiveness, memory problems and changes in daily routines.</td>
</tr>
<tr>
<td>[MSS]</td>
<td>Middle stage symptoms are characterized by motor malfunctions as well as progressed cognitive decline; Patients need definitely support.</td>
</tr>
<tr>
<td>[LSS]</td>
<td>Late stage symptoms are characterized to the loss of basic physical abilities like walking, speaking, usually bedridden and not capable of doing anything.</td>
</tr>
<tr>
<td>[LD]</td>
<td>Late diagnoses after ESS symptoms already were observed.</td>
</tr>
<tr>
<td>[COA]</td>
<td>Coincidence of an accident and / or psych. Problems along with dementia.</td>
</tr>
<tr>
<td>[EMO]</td>
<td>Emotional problems family / informal caregivers.</td>
</tr>
<tr>
<td>[CH]</td>
<td>Changes in the everyday life of the family / informal caregiver.</td>
</tr>
<tr>
<td>[FOR]</td>
<td>Forgetting appointments and tasks related to the dementia patient.</td>
</tr>
<tr>
<td>[Oth]</td>
<td>Other content, not applicable to any of the previous categories.</td>
</tr>
</tbody>
</table>

Table 6.4: Interview coding categories
6.4 Interview results

The coded and categorized fragments are then interpreted. The analysis focused on the early [ESS] and middle [MSS] stage symptoms and IT as well as AT usage [ATP] of the dementia patient. Besides of that, it addressed the emotional problems of the caregivers [EMO], the changes in life [CH], the forgetting of certain tasks around the dementia patient [FOR] and the AT and IT usage [ATC].

As subjects were partially referring to the similar dementia patient, quantitative measures besides of demographics are not considered in the analysis. As expected, the personal interviews took in general longer than the phone interviews. Also the fact that a third party was interviewing some subjects concluded in the decision for a pure, qualitative analysis of the information for supplementing the user research.

Regarding the caregivers, this research observed the changes in their life, e.g. the compatibility of the family and career or the social situation and [CH] when the first symptoms occurred.

The actual use of IT and AT was also analysed in the [ATC] and [ATP] categories. Herein the statistics (chapter 4.2.1) have confirmed the little to non-existent infiltration of IT and AT in a dementia patient’s environment.

In the following only some major qualitative findings are presented due to the huge amount of data which extends the space of this research.

6.4.1 Patient-side results

In summary, the general cognitive decline and symptoms presented in chapter 5.3 are widely confirmed. In early phases the patients started to forget or confuse people’s names, birthdates or made up stories fragments illustrating this are: [S1_2]; [S1_3]; [S1_8]; [S2_11]; [S2_12]; [S3_9]; [S5_2]; [S9_1] and more.

Character and behaviour changes like sagging interest in reading newspapers, watching TV as well as shame, retreat, restlessness, anxiety and social isolation are also confirmed; fragments illustrating this are: [S2_35]; [S2_47]; [S3_14]; [S3_16]; [S3_64]; [S5_6]; [S8_3] and more.

Physical problems and coincidences of an accident [COA] are the case e.g., fragments [S5_4]; [S8_3]; [S9_10]; [S7_11].

The IT and AT in use of the patients while in the early stage of the disease unveils that the TV is often used for entertainment purposes; fragments illustrating this are [S2_48]; [S3_60]; [S8_34]. The abilities to actually switch channels on TV or use the telephone independently and reasonable were existent, but got lost early; fragments illustrating this are: [S2_49]; [S3_37]; [S3_38]; [S8_32]; [S9_2].
6.4.2 Caregiver-side results

In summary, the caregiver analysis revealed life changes after the dementia diagnosis of their relative: Regular visits, legal guardianship and organisational tasks like, scheduling of medical appointments, tracking of the condition of the persons and also demand for professional help are observed; see fragments: [S1_6]; [S2_20 – S2_25]; [S2_56]; [S3_45]; [S3_74]; [S3_79]; [S4_8]; [S6_5]; [S7_14]; [S8_13]; [S8_17]; [S9_12]; [S9_13]

Emotional problems are documented as well, e.g., caregiver burden, defamiliarization, control addiction, worries and fear on one side; fragments referring to that are: [S1_6]; [S1_7]; [S2_25]; [S3_48]; [S3_76]; [S4_7]; [S7_8] [S8_26]; [S8_28].

Sometimes closer and more balanced caregiver-patient relationships with higher attention and acceptance of the disease is reviewable in fragments: [S2_29]; [S4_5]; [S4_9]; [S7_8].

Furthermore, informal caregivers rarely forget important tasks concerning the dementia patient; exemplary fragments in this category are: [S1_13]; [S2_55]; [S8_42] [S9_34 - S9_36].

The infiltration and usage of IT and AT caregiver sidewise is narrowed to available and well-known products e.g. medicine boxes, notebook diaries, calendar’s and Post it’s. For communication in between caregivers in multi-caregiver-environments (MCE), oral agreements and the phone is in use; fragments illustrating this are: [S2_52]; [S2_53]; [S3_71]; [S3_65]; [S5_11]; [S6_9]; [S7_10]; [S8_42]; [S9_32].
6.5 Interview interpretation

Briefly the key points of the following interpretation of the previously presented analysis are outlined. As interpretation of qualitative data is a highly subjective case, the analysis and interpretation of the data is presented separately from the analysis in chapter 6.3.4.

6.5.1 Patient-side interpretation

After evaluating the qualitative data, the following conclusions for the patients are made:

- AD dementia patients are most of the time older adults [60+]
- long time interval between symptoms occurrence and official diagnosis
- coexistence of other diseases and age-related impairments are the case
- concealment of the disease and symptoms
- loss of interest in personal and social activities due to the cognitive decline
- the TV is the only IT technology which is widely known and accepted in their environment,
- the ability to use a phone if existent gets lost early

6.5.2 Caregiver-side interpretation

After evaluating the qualitative data, the following conclusions for the caregivers are made:

- there are huge changes in a caregiver’s life when a dementia cases appears
- stress and emotional problems regarding the patient’s well-being and their own psychological health are the main problem
- leaving the patient temporary alone is also a big problem
- the family is organizing it’s life around the patient and rarely forgets tasks or appointments
- classic tools like calendars, phones and notes are used for matters of organization
6.6 Summary

By interviewing 9 subjects (caregivers, relatives) of 5 individual dementia cases, the complete user research is finished.

The qualitative user research confirmed most of the results from chapters 4 and 5. The case of the often too late diagnosis was confirmed as well as the problem of the parallel occurrence of other age-related diseases and accidents (comorbidity). Moreover, the user research indicates theoretical and qualitative little to no IT experience or capacities of older adults with dementia. On the other side, informal caregivers and relatives use basic technology and common aids for memorizing and organizing themselves, which is quite successful due to the integration of the caregiver in the everyday life of the patient as well as the rare and trivial occurrences of forgetting certain tasks.

6.6.1 Conclusions

Multi-caregiver environments are the regular case. Families, friends and informal caretakers, if possible try and want to take care of their dementia affected relative in a home environment. They struggle psychologically- and socially-wise in between keeping track of their own responsibilities in life e.g., school, job, hobbies and friends on one side and taking care of their family member or close friend on the other side.

As the current generation of older adults with dementia has practically no experience with IT technology, it is a nearly impossible task to introduce an alien artefact to a dementia patient - e.g. a smart-phone. Besides of the television and sometimes, regular landline phones the, TV offers limited but unexploited possibilities as a passive interface for supporting a dementia patient in cases of temporary lonesomeness. The concept of using the TV in the house as an individual and informative display for the support of a dementia patient builds the general idea of the solution to be designed.

Around this interactive, informative display for a patient in situations of lonesomeness an application is designed allowing the caregivers to display easily and very simple information about their whereabouts, their activity and the time until they are back at the house. Organizational helps, even if secondary, are considered by offering multi-caregiver accessible calendars, to-do lists and a forum for exchanging information among themselves.
6.7 Intermediate résumé

The previous chapters represent the knowledge acquisition of the author and gave an overview of a multi-dimensional problem. After investigation of the three areas of research, namely the older adult, dementia and IT/AT in the scope of the first two, the complete user research is finished.

As this project cannot match itself with long-term running research projects (chapter 4.4), the implementation of a hypothetical infrastructure and sophisticated sensor and actuator system is not pursued. Moreover, the enormous limitations of the user and financial limitations direct the search for a solution in the setting of the already available technology, in fact the TV.

By introducing an information system which makes use of available hardware in a more intelligent way, the environment of the dementia patient stays untouched, the financial investment is reasonably small and the solution is simple, but still effective. From a humane point of view, a complete monitored and continuous surveilled environment is also questionable. These advantages have of course trade-offs: No interaction effort from the patient, little control if the system is actually used as well as limited functionalities have to be acknowledged.

Still, the usage of the TV as a voluntary, passive, informative display for a dementia patient in his or her house is totally underestimated: The TV is the only IT which is widely known and accepted in nearly every setting observed. In matters of customization by individual information, integration to the cloud by wireless internet and cellular networks, enormous potential lies fallow and will be utilized.

Furthermore, the main objective is not to challenge the cognitive decline of the individual patient or to introduce an already existing solution. Instead, the goal is to provide and easy and simple, but yet effective solution using available knowledge and hardware to support dementia patients and their caregivers. Support means not control, nor surveillance. It means offering a help for both sides they can voluntary use and also adapt to their own preferences.

These considerations and results build the foundation of mobileWAY, an application to display dynamic information directly in the house of the dementia patient from a mobile device. The design process and usability tests of mobileWAY are outlined in the following chapters.
7 Design process of mobileWAY

7.1 Introduction

The complete user research generates a bilateral design approach for the dementia patient living at home in temporarily independent situations and the individual caregiver(s), usually represented by a relative, friend or a nurse.

This double-sided design also causes on one side a quite standardized target audience with relatively similar age and physic-social prerequisites (early stage dementia patients) and on the other side a significant younger but more diverse target audience (caregivers).

A logical frame for applying the design process after the user research can be found in various references. Exemplary, the 4 steps of the BlackBerry /177/ design process are mapped to the design process and the following sections:

- understand the product requirements and user goals (see chapter 8.1)
- develop the concepts and build the workflow (see chapter 8.2)
- organize the content on the screen (see chapter 8.3)
- incorporate the visual design (see chapter 8.4)

Finally, this chapter presents simultaneously the evolvement of two interfaces, in particular:

- a stationary, TV interface for the dementia patient
- a mobile, tablet interface for the caregiver

7.2 Understand the product requirements and user goals

Chapters 3 - 6 are reviewed and built the conclusion of using the passive TV interface for the dementia patient and the interactive, mobile device for the caregiver. In the following, the design process is outlined.

7.2.1 Possible scenarios

Derived out of the user research three exemplary scenarios for mobileWAY are generated and considered in the user goals, a short-term scenario, a long-term scenario and a reoccurring scenario.

Short-term scenarios:

The caregiver realizes a shortage of groceries and goes for a short shopping run. Therefore, the patient is left alone for a short period of time, approximately one hour.
Long-term scenarios:

The caregiver finishes the work at the patient’s house sets his status and leaves. The patient is alone and independent in his home until the next morning.

Reoccurring scenarios:

Every morning the husband of a dementia affected woman takes the dog for a walk around the neighbourhood for approximately 30 minutes.

These examples are only a glimpse of the tremendous quiver of possible scenarios. Nevertheless, most of possible situations can be mapped into one of these three scenario categories.
7.3 Develop the concepts and build the workflow

7.3.1 Initial concepts and prototypes

In this section, the initial interface concepts of mobileWAY are introduced.

Figure 7.1 on page 79 shows four early stage user interface concepts of the tablet and TV interface. As a general idea, the TV provides information about the whereabouts of the next person coming back to the house of the patient.

The tablet interface initially has two main areas: The upper part always shows what is displayed on the TV, while the lower part represents the area to select and manipulate the content shown. Furthermore, the concept of text display, e.g. “Ana is shopping and comes back in 30 minutes” is supplemented by big pictures of the caregiver, the place of activity, and a clock icon for indicating the time.

Also on Figure 7.1, an early concept of a TV interface is seen which introduces a two-sided TV interface area for the patient: While the upper area (red rectangle) displays the caregiver activity, the lower area (blue rectangle) is giving the patient individual recommendations for activity. In the example, Peter is shopping and the patient is encouraged to get dressed because they are going out for an ice-cream. While this concept is interesting and can be used for dynamic content, e.g. individual TV series or picture slideshows, it couldn’t be pursued due to limited timeframe and resources.

Moreover, the early design decisions regarding the semantics “until 4 o’clock” and “comes back in 30 minutes” are opened. The time icon “clock” is later on evaluated against an alternative “hourglass” icon (chapter 8).

On the following page 80, Figure 7.2 presents more developed Lo-Fi tablet interfaces: The tablet has three major areas: The TV preview in the upper part (green), the interaction area in the middle (blue rectangle) and a static lower bar providing integrated and global features all the time (red rectangle). The context dialogue is also defined by offering three choices and fading out the background which will be explained later on.

Finally, the application is designed to run without the need to scroll, therefore showing all information on one, single screen if possible. Only in cases of more than 6 activities, which can easily occur after a while of using the application, arrows indicate that a “swipe” is possible to the right or left in the blue area.
Figure 7.1: Early low-fidelity prototypes (TV and tablet)
Figure 7.2: Low-fidelity interfaces (tablet)
7.3.2 Workflow of mobileWAY

Simultaneously to the design process, the workflow of mobileWAY evolved and is presented in Figure 7.3 on page 82. It presents the 1st level of mobileWAY, in particular the main menu, and all designed 2nd level menus which are described clock-wise from the top:

- the zoom functionality (blue rectangle)
- change caregiver (pink rectangle)
- change activity (pink rectangle)
- change time (pink rectangle)
- add message (pink rectangle)
- settings (blue rectangle)
- exit (blue rectangle)

The zoom functionality magnifies the upper area of the tablet representing the broadcast on the TV of the dementia patient and is a feature primarily designed for smaller screen sizes and smartphones.

All four “core” functionalities inherit the same design pattern. Selecting or changing a caregiver or an activity is similar to changing the time or a message. For example, adding an activity follows exactly the same process as adding a new time. Moreover, editing the picture of an activity follows the same process as editing the picture of a caregiver and so on and forth. Moreover, as Figure 7.3 illustrates, no message is displayed, therefore the main menu instantly directs the user to the add message screen.

The settings screen and the exit (1st level) or orange back (2nd level) buttons are located in the lower message bar. The settings consist of a number of options allowing the caregiver to customize mobileWAY due to the patient’s as well as his own preferences. Patient-side, the customization options include the selection of a preferred time icon (hourglass or clock icon) and the visibility of the message bar on the TV. The caregivers themselves can, for instance, choose to share calendars and to-do lists with others or push notifications and reminders on their device.

Due to space restrictions and to maintain clarity, not all lower levels of the application are shown in Figure 7.5.2. Besides of the to-do list, calendar and forum functionalities – which are regularly found on any common device and can be easily integrated - all screens of mobileWAY are completely defined and designed.

Finally, examples of more screens can be found in chapter 7.5.2.
Figure 7.3: Workflow of mobileWAY
7.4 Organize the content on the screen

7.4.1 Advanced design of mobileWAY

The initial concept was outlined in the previous section, the following examples show how the design evolved as a result of the cooperation of the author with internal experts (e.g. the supervisor and the designers). Lo-Fi implementations of the design in simple HTML enabled a better understanding and visualization of the workflow for the scenarios later tested (chapter 8).

Also, a fourth functionality is added to the interface: The “message bar” allows displaying a simple text message in the center position of the lower message bar. Moreover, the TV is now also able to display the actual date and time in the lower area (yellow rectangle).

Figure 7.4 represents a complete and final Lo-Fi TV interface setup. Characteristics are:

- 120pt size font the complete, written message (green rectangle)
- three pictures of the caregiver, activity and ending time of the same (blue rectangles)
- 80pt font size the message bar showing the date and time (red rectangles);
- message bar with date, time and an optional message, in this example a telephone number (yellow rectangle).

Figure 7.4: Complete setup of a low-fidelity interface (TV)
Figure 7.5 compares the initial Lo-Fi paper prototype with a real IPad: The main menu with the 4 core functionalities can be seen as well as the change caregiver menu. Furthermore, the context menu is viewable which presents the user three choices; the “edit” or “delete” button (green rectangle), “cancel” button (blue rectangle) and the OK button (red rectangle) after selecting or highlighting an item.

Figure 7.5: Low-fidelity paper prototype versus real IPad
Figure 7.6 on page 86 is a portfolio of different submenus. The “delete dialogue” as well as the “camera application” are prototyped. Also the zoom functionality (green rectangle) is visible. Main idea is here, that the upper area of the tablet is magnified and the display turns into landscape mode. This functionality is considered as a vital feature for a possible smartphone implementation due to significant smaller display size found in these devices.

Moreover, the similar layout of dialogues and buttons is applied throughout the whole application. In the two top level menus the preview of the TV screen is always visible. The middle part is the dynamic manipulating area for choosing caregivers, activities and different times. The lower part consists of the menu bar, which looks always the same (besides of one small exception) and is always visible. In certain situation, pop-up dialogues are used to confirm changes, e.g. when exiting the application or deleting a caregiver. Also, it is important to mention that the application does not allow to save a caregiver or activity without a corresponding picture. This enforcement of users to add a name and photo is born out of the nature of the system which relies on text and visual output.

Regarding the multi-caregiver functionalities in the menu bar (to-do list, calendar and forum), only the concept can be outlined as no prototypes could be designed for these screens. The to-do list is self-explaining, it should allow the user to add an item on the to-do list using the touch input of the individual device. The calendar is – similar as the to-do list – found in nearly every device. It should enable the caregiver to mark appointments, like medical examinations of the patient or other dementia-related tasks. Finally, the forum functionality is a feature which is supposed to connect all caregivers using the system for exchange of knowledge and experiences. A possible educational benefit as well as creative input for appropriate pictures of certain activities is expected.

As the user research revealed that usually more than one person (primary caregiver) is involved in the caring of one patient, the multicaregiver-settings are supposed to connect the to-do list and calendar in between caregivers. For example, caregiver A adds a task (buy milk) to the to-do list for patient B and goes out of the house. Later on, caregiver C is supposed to come by. Besides of displaying this information in the house of the patient, caregiver C also can access the to-do list and therefore view the tasks and appointments caregiver added to the application and finally buy the milk before arriving at the patients house. If he takes care of the task, it gets crossed by caregiver C which means in consequence, that all caregivers are now seeing a crossed task on the to-do list.

At this point of design, the layout and functionalities were frozen and it was also clear that the first usability tests were ready to run.
Figure 7.6: Advanced low-fidelity design interfaces (tablet)
Figure 7.7 shows a Lo-Fi TV mock-up with real pictures of the informal caregivers and places of their environment. In the case illustrated, Vera (an informal caregiver of a dementia patient) is in the town hall for 2 hours. Also the date and time is displayed in the message bar.

Figure 7.7: Low-fidelity TV interface for the usability tests (PT)
Figure 7.8 shows the paper wireframe of the tablet. The three scenarios visible were later used for the tests. For the case, the subjects didn’t follow the intended path, alternative dialogues were also built. As tests were conducted with Portuguese narrative speakers, all interfaces were translated, but also are available in English language.

Figure 7.8: Low-fidelity tablet interface for the usability tests (PT).
7.5 Incorporate the visual design

7.5.1 Final layout of mobileWAY

The final layout of the tablet and TV interface is illustrated in Figure 7.9 and Figure 7.10.

The complete preview of the TV interface inside the tablet interface is the key feature of the system.

After the Lo-Fi design revealed more space in the middle area of the tablet (blue squares), it was decided to show 8 tiles simultaneously in order to reduce the scrolling amount.

In the following pages, high-fidelity (Hi-Fi) designs are presented and explained.

Figure 7.9: Final tablet layout

Figure 7.10: Final TV layout
7.5.2 Hi-Fi tablet design

The initial start-up of the application (Figure 7.11) is characterized by showing blank tiles and “add” instead of “change” labels for the four main areas as well as an “exit” instead of a “back” button in the menu bar. The grey button in the add caregiver screen (Figure 7.12) is becoming accessible after entering a name and adding a picture.

![Figure 7.11: High-fidelity tablet (1)](image1)

![Figure 7.12: High-fidelity tablet (2)](image2)
The camera application is shown in Figure 7.13, while Figure 7.14 illustrates the dialog box in the case of selecting a caregiver and in the case of editing an activity. Also the orange emphasized “back” button in the menu bar is now visible as well as the design of the context menus.

Figure 7.13: High-fidelity tablet (3)

Figure 7.14: High-fidelity tablet (4)
In the case of more than 8 tiles, an arrow is indicating to “swipe” to the right (Figure 7.15) while the user may simply press the arrow to transition to the remaining tiles. Figure 7.16 presents the time selection screen and the change time functionality.

Figure 7.15: High-fidelity tablet (5)

Figure 7.16. High-fidelity tablet (6)
7.5.3 Hi-Fi TV design

Figure 7.17 presents an exemplary Hi-Fi interface setup on a widescreen TV and Figure 7.18 the corresponding tablet interface of mobileWAY:

**Figure 7.17:** High-fidelity TV mock-up

**Figure 7.18:** High-fidelity tablet mock-up
8 Qualitative and quantitative usability tests

8.1 Introduction

The bilateral evaluation of a stationary TV interface for the dementia patient at home and a mobile tablet interface for the caregiver is the scope of this chapter. Section 8.2 presents 12 comprehensibility tests with two dementia patients, while section 8.3 presents 12 usability tests with four caregivers of the tablet interface.

Table 8.1 presents the scenarios overview for all usability tests included in this chapter. The 6 patient scenarios are coded with an “A” or “B”, referring to patient A or B, while the 12 caregiver scenarios are coded with and “C1”, “C2”, “C3”, “C4” referring to caregiver 1, 2, 3 and 4.

<table>
<thead>
<tr>
<th>Scenario</th>
<th>Short description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scenario 1A</td>
<td>Clock icons</td>
</tr>
<tr>
<td>Scenario 2A</td>
<td>Hourglass icons</td>
</tr>
<tr>
<td>Scenario 3A</td>
<td>Choice of hourglass or clock icon</td>
</tr>
<tr>
<td>Scenario 4A</td>
<td>Wife, pharmacy, 60 minutes (hourglass)</td>
</tr>
<tr>
<td>Scenario 5A</td>
<td>Daughter, supermarket, 30 minutes (hourglass)</td>
</tr>
<tr>
<td>Scenario 6A</td>
<td>Wife – bank – 45 minutes (hourglass; date and time)</td>
</tr>
<tr>
<td>Scenario 1B</td>
<td>Clock icons</td>
</tr>
<tr>
<td>Scenario 2B</td>
<td>Hourglass icons</td>
</tr>
<tr>
<td>Scenario 3B</td>
<td>Choice of hourglass or clock icon</td>
</tr>
<tr>
<td>Scenario 4B</td>
<td>1st granddaughter, school – 30 minutes (hourglass)</td>
</tr>
<tr>
<td>Scenario 5B</td>
<td>Daughter - church- 60 minutes (clock)</td>
</tr>
<tr>
<td>Scenario 6B</td>
<td>2nd granddaughter, town hall, 30 minutes (hourglass; date and time)</td>
</tr>
<tr>
<td>Scenario 7C1</td>
<td>Add yourself as a caregiver to the application</td>
</tr>
<tr>
<td>Scenario 8C1</td>
<td>Edit the picture of the working activity</td>
</tr>
<tr>
<td>Scenario 9C1</td>
<td>You are out for work for the next 2 hours. Set it up</td>
</tr>
<tr>
<td>Scenario 7C2</td>
<td>Add yourself as a caregiver to the application</td>
</tr>
<tr>
<td>Scenario 8C2</td>
<td>Edit the picture of the working activity</td>
</tr>
<tr>
<td>Scenario 9C2</td>
<td>You are out for work for the next 2 hours. Set it up</td>
</tr>
<tr>
<td>Scenario 7C3</td>
<td>Add yourself as a caregiver to the application</td>
</tr>
<tr>
<td>Scenario 8C3</td>
<td>Edit the picture of the working activity</td>
</tr>
<tr>
<td>Scenario 9C4</td>
<td>You are out for work for the next 2 hours. Set it up</td>
</tr>
<tr>
<td>Scenario 7C4</td>
<td>Add yourself as a caregiver to the application</td>
</tr>
<tr>
<td>Scenario 8C4</td>
<td>Edit the picture of the working activity</td>
</tr>
<tr>
<td>Scenario 9C4</td>
<td>You are out for work for the next 2 hours. Set it up</td>
</tr>
</tbody>
</table>

Table 8.1: Complete usability tests overview
8.2 Patient-side comprehensibility tests

It is difficult to conduct an evaluation, while following a standardized UCDP (chapter 2) with an 80+ year old, dementia affected person in terms of paperwork, test purpose, standardization and bond of trust. Therefore, the tests took place in a natural and simple environment and involving the caregivers as well, being them at times the ones informally asking the questions to assess the comprehensibility of the shown scenarios, e.g.:

- can you read the message displayed?
- what do you see on the TV?
- do you know the person who is away?
- when does he / she come back?
- if the patient performed well, the understanding of date and time was asked as well

Since the available methodology is rudimentary, a skilled experimenter with profound knowledge of the user interface is necessary to evaluate the dementia patient’s reactions and answers. For the qualitative data assessment in the patient tests, simple written protocols were used for registering the answers.

8.2.1 Subject data

The details of the two tested dementia patients are enlisted in Table 8.1. It is important to mention that patient B was in a more progressed state of AD and needed continuous support and supervision.

<table>
<thead>
<tr>
<th></th>
<th>Patient A</th>
<th>Patient B</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>79</td>
<td>87</td>
</tr>
<tr>
<td>Gender</td>
<td>Male</td>
<td>Female</td>
</tr>
<tr>
<td>Age of onset</td>
<td>72</td>
<td>80</td>
</tr>
<tr>
<td>Age of diagnosis</td>
<td>72</td>
<td>80</td>
</tr>
<tr>
<td>Living with</td>
<td>Wife, son</td>
<td>Daughters, Nurse</td>
</tr>
<tr>
<td>Type of dementia</td>
<td>AD</td>
<td>AD</td>
</tr>
<tr>
<td>Stage of the disease</td>
<td>Early stage</td>
<td>Middle</td>
</tr>
</tbody>
</table>

Table 8.2: Subject data patient-wise
8.2.2 Scenarios

Table 8.3 presents the complete scenarios tested with the two dementia patients while Figure 8.4 on page 98 illustrates the real on-site test of scenario 5A at the home of patient A.

<table>
<thead>
<tr>
<th>Scenario</th>
<th>Short description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scenario 1A</td>
<td>Clock icons</td>
</tr>
<tr>
<td>Scenario 2A</td>
<td>Hourglass icons</td>
</tr>
<tr>
<td>Scenario 3A</td>
<td>Choice of hourglass or clock icon</td>
</tr>
<tr>
<td>Scenario 4A</td>
<td>Wife, pharmacy, 60 minutes (hourglass)</td>
</tr>
<tr>
<td>Scenario 5A</td>
<td>Daughter, supermarket, 30 minutes (hourglass)</td>
</tr>
<tr>
<td>Scenario 6A</td>
<td>Wife – bank – 45 minutes (hourglass; date and time)</td>
</tr>
<tr>
<td>Scenario 1B</td>
<td>Clock icons</td>
</tr>
<tr>
<td>Scenario 2B</td>
<td>Hourglass icons</td>
</tr>
<tr>
<td>Scenario 3B</td>
<td>Choice of hourglass or clock icon</td>
</tr>
<tr>
<td>Scenario 4B</td>
<td>1st granddaughter, school – 30 minutes (hourglass)</td>
</tr>
<tr>
<td>Scenario 5B</td>
<td>Daughter - church- 60 minutes (clock)</td>
</tr>
<tr>
<td>Scenario 6B</td>
<td>2nd granddaughter, town hall, 30 minutes (hourglass; date and time)</td>
</tr>
</tbody>
</table>

Table 8.3: Patient-side scenario overview

In the following, two dementia patients were testing separately 6 individual scenarios. To maintain clarity, the individual scenario is referenced by a number and the patient by a following character, e.g. scenario 4B refers to the 4th scenario of patient B. Scenarios 1A (1B), 2A (2B) were measuring the comprehensibility of the dynamic time icon (clock / hourglass). Afterwards, scenario 3A (3B) assessed a preference of the patients by simply asking which metaphor is preferred. The goal was to decide a preferred time icon for the later scenarios.

Scenario 1A (1B):

The patient is presented with a row of 5 tiles of a growing clock icon labelled with 60 minutes, 45 minutes, 30 minutes, 15 minutes and 0 minutes and is asked about his / her association of the pictures and illustrated concept (Figure 8.1).
Scenario 2A (2B):

The patient is presented with a row of 5 tiles of a decreasing hourglass icon labelled with 60 minutes, 45 minutes, 30 minutes, 15 minutes and 0 minutes and is asked about his / her association of the pictures and illustrated concept (Figure 8.2).

![Figure 8.2: Comprehensibility test for the hourglass icon (PT)](image)

Scenario 3A (3B):

Based on the results of scenario 1A (1B) and scenario 1A (1B), the patient was asked for his personal preference regarding the time icon. If a preference was stated, the individual icon was used in scenarios 4 to 6 (Figure 8.3).

![Figure 8.3: Preference of the time icon](image)

Scenarios 4 to 6 consisted of individual, custom Lo-Fi TV setups displaying the patient specific information about the whereabouts of his / her informal caregivers. The goal was to assess the patient’s ability to understand the information displayed on the TV.

Scenario 4A (4B):

Scenario 4A displayed the wife (by her name and a high quality photo), the local pharmacy (by name and a high quality photo) and the “empty” hourglass icon (60 minutes). The patient was asked about his understanding of the information displayed.

Scenario 4B displayed the 1st granddaughter (by her name and a high quality photo), the school her granddaughter goes to (by name a high quality photo of her real school)
and the half-full hourglass icon (30 minutes). The patient was asked about his understanding of the information displayed.

**Scenario 5A (5B)**

Scenario 5A (Figure 8.4) displayed the daughter (by her name and a high quality photo), the local supermarket (by name and a high quality photo) and the “half-full” hourglass icon (30 minutes). The patient was asked about his understanding of the information displayed.

Scenario 5B displayed the daughter (by her name and a high quality photo), the local church (by name a high quality photo of the church) and the full clock icon (60 minutes.) The patient was asked about his understanding of the information displayed.

**Scenario 6A (6B):**

Scenario 6A displayed the wife (by her name and a high quality photo), the bank she works (by name and a high quality photo) and the “quarter-full” hourglass icon (45 minutes). Also the date and time was displayed in the message bar. The patient was asked about his understanding of the information displayed.

Scenario 6B displayed the 2nd granddaughter (by her name and a high quality photo), the town hall of Porto (by name a high quality photo of the town hall) and the “half-full” hourglass icon (30 minutes.) Also the date and time was displayed in the message bar. The patient was asked about his understanding of the information displayed.

![Figure 8.4: Usability test in the home of a dementia patient A (Scenario 5A)](image-url)
8.2.3 Results

This section encloses the original records of the comprehensibility tests with patient A and B are enclosed. For the following Table 8.4 on page 100, the following abbreviations are introduced:

- [S] is a genuine subject’s statement within the specific scenario
- [EC] is an experimenter comment, a verbal statement within the individual scenario
- [EN] is an experimenter note within the individual scenario
- [Name] is a genuine statement from an informal caregiver within the scenario, who were included in the comprehensibly tests
<table>
<thead>
<tr>
<th>Scenario</th>
<th>Notes</th>
</tr>
</thead>
</table>
| 1A       | [S]: "Traffic sign."  
[EN]: With simultaneously showing the minutes and some hints he said maybe it is a clock.  
[EN]: Yes, but only after the hint with the minutes. |
| 2A       | [S]: "It is an object that tells us the time. It is an hourglass. The liquid increases on the bottom side."  
[EN]: Yes, understood it completely. |
| 3A       | [EN]: He chooses the clock. The hourglass was more direct; the clock not so much, so we chose the hourglass for the remaining scenarios. |
| 4A       | [EC]: OK (How long is she away?) OK (Where is she? OK, etc.) |
| 5A       | [EC]: OK (How long is she away?) OK, Where is she? OK, etc.) |
| 6A       | [EC]: OK (How long is she away?) OK (Where is she?) OK (What date is today?) |
| 1B       | [Granddaughter]: “She doesn’t understand the concept.”  
[EN]: Understood the concept not. |
| 2B       | [Granddaughter]: “She didn’t recognize the clock, because there was no clock face.”  
[EN]: Understood the concept not. |
| 3B       | [EN]: Subject didn’t make a choice. She didn’t know what to choose. |
| 4B       | [EN]: Association between the image of the caregiver and name of the caregiver works; Subject can read the complete sentence.  
OK (Where did the caregiver go?)  
Not understood (When is she coming back?)  
Didn’t recognize the person on the photo regarding the kinship. It was a general person for her and not her granddaughter. |
| 5B       | [EN]: Was able to tell who went to the church. The relationship of caregiver to activity was also understood.  
[S]: “60 minutes... I don’t know how many hours this is. I also don’t know how much time she will need to come back.”  
[EN]: Didn’t recognize the person on the photo regarding the kinship. It was a general person. |
| 6B       | [EN]: OK (Who went to city Hall?)  
[EN]: Same as 4B and 5B: Subject associates the town hall as the town hall of Porto herself but don’t understands the whole concept and furthermore doesn’t recognize her children (neither in the photos nor in the reality). Subject repeats about 4 times:  
[S]: “I remember when the city hall was being built. I remember when the pope came here. I remember going there. It was a touching moment.” |

Table 8.4: Comprehensibility test results of patient A and B
8.2.4 Interpretation

Patient A, a male, 79 year old, early stage AD patient, mastered the comprehensibility tests very well. Besides of the clock icon (scenario 2A), which he associated more likely to a traffic sign, he understood the hourglass icon as well as every single TV scenario entirely and without any problems. He could read all the text from approximately 3 meters distance, answered every question correctly and, furthermore understood the additional time and date information shown in scenario 6A.

Patient B, a female, 87 year old, middle stage AD patient with a distinct cognitive decline, did not perform that well at first glance. She simply did not understand the time indicators in both cases (scenario 1B and 2B) and therefore was not able to choose a specific icon (scenario 3B). Regarding the TV scenarios (scenarios 4B, 5B and 6B), she continued to have problems and did not understand the message as a whole in every scenario. To understand the actual stage of her disease it is important to mention, that she could not address her own granddaughter sitting next to her as well.

But partial success can also be reported. Besides of forgetting the sense of the message, she had no problems in reading the text which indicates again an appropriate font size. Moreover, she was able to associate the caregiver to the activity (scenario 4B). Finally, the most satisfying results were observed in scenarios 5B and 6B wherein patient B neither had an idea about the complete message, nor about the own daughter displayed on the TV, but was able to associate the church located close to her house. This usage of common locations and the remaining memory of the patient paid off in scenario 6B as well. Patient B was able to associate the town hall locally-wise (by saying herself that it is the specific town hall of Porto) and reminisced memories of her past associated to that place by telling a story about the time the town hall has been constructed as well as the pope coming for a visit.
8.3 Caregiver-side usability tests

The usability tests with four caregivers comprised essentially three stages:

- introduction and explanation of the system
- execution of the three scenarios
- completion of the questionnaire

During the introduction of the system, the experimenter explains the two parts of the system to the subject: the TV interface and the tablet interface along with the four core functionalities consisting of:

- select a caregiver
- select an activity
- select the expected ending time
- and display a static message

Obligatory privacy statements, assumed handling time and information about data recording are also part of the introduction. The complete script can be reviewed in appendix 12.2.1.

8.3.1 Subject data

The details of the four informal caregivers are enlisted in Table 8.6. The relationship to the individual dementia patient is herein also visible, e.g. S1 and S2 belong to patient A while S3 and S4 belong to patient B.

<table>
<thead>
<tr>
<th></th>
<th>S1</th>
<th>S2</th>
<th>S3</th>
<th>S4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>28</td>
<td>63</td>
<td>30</td>
<td>58</td>
</tr>
<tr>
<td>Gender</td>
<td>Male</td>
<td>Female</td>
<td>Female</td>
<td>Female</td>
</tr>
<tr>
<td>Relationship to the dementia affected person</td>
<td>Son</td>
<td>Wife</td>
<td>Grand-daughter</td>
<td>Daughter</td>
</tr>
<tr>
<td>Referring to patient</td>
<td>Patient A</td>
<td>Patient A</td>
<td>Patient B</td>
<td>Patient B</td>
</tr>
</tbody>
</table>

**Table 8.5:** Subject data caregiver-wise
8.3.2 Scenarios

As situations of lonesomeness in an assisted living environment are focus of the mobileWAY, use cases are easily derived from the responsibilities of the caregivers identified in the qualitative user research in chapter 6. For example, short-term shopping scenarios, long-term overnight scenarios or regular social activities represent typical use cases of part-time caregivers of early-stage dementia patients.

The four caregivers were confronted with three scenarios to solve (Table 8.7). Moreover, the same references as in chapter 8.2.1 are applied here. For example, scenario 8C1 refers to the 8th scenario of caregiver 1. The task instructions can be reviewed in appendix 12.2.2.

<table>
<thead>
<tr>
<th>Scenario</th>
<th>Short description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scenario 7</td>
<td>Add yourself as a caregiver to the application</td>
</tr>
<tr>
<td>Scenario 8</td>
<td>Edit the picture of the working activity</td>
</tr>
<tr>
<td>Scenario 9</td>
<td>You are out for work for the next 2 hours. Set it up.</td>
</tr>
</tbody>
</table>

Table 8.6: Caregiver-side scenario overview.

8.3.3 After questionnaire

After performing the three scenarios, a short questionnaire was handed out to the subjects. This questionnaire covered basic participant data such as age, gender and relationship to the dementia affected person. Moreover, the subject’s agreement to 11 predetermined statements was assessed in four dimensional multiple-choice answers (Always, Most of the times, Sometimes, Never). Finally, the questionnaire included three questions to assess the most liked and disliked features of the application as well as the improvement potential. These three questions allowed an open answer format in a bullet point list. The after questionnaire can be reviewed in appendix 12.2.4.

8.3.4 Results

Every subject completed all 12 scenarios successfully. Besides of S4, who needed some help in scenario 9, all subjects solved the scenarios independently.

Figure 8.5 represents the detailed results of the three scenarios from the four caregivers showing the steps needed to solve each individual scenario. Also the broken line represents the minimum amount of steps needed to solve the individual scenario. The detailed task results are available in appendix 12.2.3
**Figure 8.5:** Usability test results

**Figure 8.6:** After questionnaire results
8.3.5 Interpretation

First of all, all four subjects succeeded in all scenarios without any, or very little help. Although in one case, a hint was given to a subject (scenario 9C4), the interface was generally understood and the tasks were solved without problems. Furthermore S1, a 28 year old male and S3, a 30 year old female solved all tasks without errors and did not visit any additional screens. S2, a 63 year old female made minor errors (4 additional screens visited in total) while S4, a 58 year old female needed a hint in scenario 3 and in total 9 additional steps to solve all three scenarios (Figure 8.5).

The questionnaire analysis (Figure 8.6) indicates across all caregivers high ratings for general usability (questions 1, 2, 3) and subjective satisfaction (questions 4, 5). When asking the informal caregivers in questions 6, 7 and 8 about the benefits of the system for their dementia affected relatives (improved quality of life, increased calmness and feeling of security), respectively subject 1 starts dropping out of the general very well evaluated satisfaction of the other subjects. As mobileWAY also aims to help the informal caregivers by providing tools for organization and adjustment in multi-caregiver-environments, questions 9, 10 and 11 were also mostly positive rated. Besides of subject 1, which assessed question 11 with the most negative category possible throughout all questions and caregivers, mobileWAY was positively assessed in terms of decreased patient-concern and increased caregiver-support.

In general, the interface and application was received well from the patients and caregivers. The usage of real pictures of their families and environment in the Lo-fi prototypes created an initial positive feedback. While the sample size for both groups (patients and informal caregivers) is somehow limited, the following qualitative interpretation applies to the observed results and is not representative for a greater population.
8.4 Summary

This chapter presented the 2nd row of qualitative data assessment with four informal caregivers and two dementia patients. Usability-tests with Lo-Fi prototypes on tablet- and TV mock-ups were planned, conducted, analysed and interpreted. In general, caregivers had little problems in solving the tasks on the tablet indicating minor problems in specific situations while the two tested dementia patients indicate a partial understanding of the TV interface. Furthermore, mobileWAY was assessed very beneficial in terms of usability and increased quality of life for both, the dementia patients and the caregivers in the after questionnaire.

Regarding the sample size, only a limited number of dementia patients could be tested (2 subjects) due to access problems and limited human resources. Doherty et al. /22/ confirms this issue: "Mental health care (MHC) settings place a number of constraints and limitations on the designer, particularly with regard to access to end-users and to evaluations involving users with mental health difficulties."
9 Discussion

This work applied a user-centred design process to create a technological solution for supporting an early stage dementia patient in his or her own home and the caregivers around. The temporary or permanent attendance of the primary caregiver is a prerequisite of the context of use as mobileWAY is neither replacing human caregiving, nor a complete round-the-clock surveillance system. Moreover, it is a non-invasive, unobtrusive system which can run on any connectable TV or display situated in the more and more “alienating” home of a dementia patient.

The design decision for a passive, stationary TV interface for the patients and an interactive, mobile interface arises from the theoretical and qualitative user research. As the idea of displaying content remotely on a TV screen may appear simple and obvious at first glance, the author recalls the user research and emphasizes the extreme cognitive decline an older adult (60+) with early stage dementia symptoms has to deal with. The balancing act between available technological possibilities, the acquaintance costs of additional hardware and the user research outcomes concluded in an easy-to-use application which informs a dementia patient about the whereabouts and time remaining of the next person coming back to his or her house. Multi-caretaker environments – which represent the reality – are respected by specific functionalities such as shared calendars, to-do lists and the possibility to push notifications on any device.

Recent research projects tend to prompt the field with new technologies and hardware. The approach of this work is different. Instead of introducing another new artefact to the dementia patient, it uses the available and well-known technology, the TV, in a highly individualized and illustrative way for transmitting information. The caregivers, which are likely to know the patients for a lifetime, can use this solution with appropriate photos of real places to inform and maybe even stimulate the memory of their affected relative. And this is the big advantage of this system; it’s level of customization. It is noteworthy that the usage of individual visual memories of a patient seems to improve comprehensibility and stimulate memory, as indicated in the results of patient B.

It is hard to predict if the dementia patient is actually paying attention to the TV while a specific scenario is displayed. This may be interpreted as an issue that can be i) easily solved by adding a permanent display in the house of the patient while leaving the regular TV on or, ii) justified with the non-obligatory character of the system. In general, the human factors in this extreme difficult area of research - user interface evaluation for people with dementia – are difficult predict and still need to be modelled. Nevertheless, the usability- and comprehensibility tests indicate sufficient comprehensibility of the patients and high usability and perceived improvement of life for both user groups (caregivers and patients).
Also, the TV offers limited interaction possibilities for the patient while leaving the control and responsibility totally on the shoulders of the caregivers. This limited patient interface on the other side results in a minimal error probability in terms of patient-side interaction while offering a dynamic, customized and integrated display.

Finally, the available methodology for comprehensibility tests with dementia was found to be insufficient. Therefore, a simple, but effective way of assessing the understanding of the TV scenarios caused the i) involvement of the informal caretakers and ii) avoidance of standard formalities such as privacy policies and test explanations towards the subjects. User-centered design methodologies for dementia patients or cognitive impaired user groups are still in the early stages of development and would benefit from e.g., adapted design guidelines and methodologies to maintain a comparable standard and equalize the design methodologies for these target audiences.
10 Conclusions and future work

10.1 Conclusions

Summarized, mobileWAY uses the TV in the house of the dementia patient to display dynamic, customized and illustrated information in situations of temporary lonesomeness. Therefore, it enables caregivers to show very simple information about who they are (provided by name and portrait), their whereabouts (illustrated by a picture of the place or activity they are occupied with) and the time remaining until the caregiver is back in the house of the patient (due to a dynamic time metaphor). Organizational helps are considered as well via multi-caregiver accessible calendars, to-do lists and forum functionalities.

Initially, the conduction of the comprehensibility tests at the home of the dementia patient is a valuable side result of this research. The common environment of the patient as well as the involvement of the caregivers in the tests was very beneficial in terms of patient trust, calmness and participation willingness. It may be already strange enough for an older adult with dementia having “aliens” in his house who ask question; hence a relative which much more experience about the individual circumstances and situation of the patient can help to construct a bond of trust easily involved in the testing. Moreover, the improvement of the low fidelity prototypes with high-detailed, real photos resulted in a better understanding of the system and caused a very positive perception towards the tests of the caregivers.

Additionally, patient B was clearly a middle stage patient with severe cognitive decline needing 24/7 support, the comprehensibility tests still indicate partial to full understanding for the two tested dementia patients and indicate the potential of mobileWAY.

Finally, as the comprehensibility- and usability tests indicate very promising results, it has to be admitted that the total sample size was quite small and tests with more users are desirable to verify the indicated results. Nevertheless, the research unveiled sufficient results to justify the development of a working prototype which than can be used for further evaluations as proposed in chapter 10.2.
10.2 Future work

Individualized information system, if well designed, are able to support patients with a cognitive decline by dynamic and customized information. mobileWAY offers such a system: Designed as a platform-independent application the implementation of a working prototype for a tablet computer is desirable.

Also, the smartphone version of mobileWAY should be designed and implemented based on the results of this research. Herein, a redesign considering the significant smaller display sizes will be necessary to optimize mobileWAY for a smartphone.

The workflow of the application itself can be revised according to the think-aloud notes from the informal caregivers (see appendix 12.2.3). For example, after selecting a caregiver, mobileWAY could redirect the user automatically to the main menu. Also, the informal caregivers mentioned improved labels in terms of more natural semantics, e.g. instead of “change time” a subject proposed using “How long are you out of the house?” which can be iterated as well.

Moreover, an idea in the early stage of the design process of mobileWAY can also be followed to extend the functionalities of the system: The usage of the TV interface to display the caregiver information together with an “enduring” task for the dementia patient seems very interesting. For example, while the caregiver is in the supermarket for a specific amount of time, the patient can empty the dishwasher or rinse the flowers in the garden.

Furthermore, other modalities could be included in the system such as the acoustic modality in terms of an auditory reminder. For example, someone imagine a predetermined, reoccurring, timed voice output of the message displayed on the TV. By adding this feature, a visual and acoustic representation of the information can be easily realized.

Finally, the integration of mobileWAY into the regular TV broadcast, for instance by the introduction of automatic alarms in situations where the patient enjoys a TV broadcast should be investigated.

All these improvement suggestions should be considered in the implementation of a working prototype of mobileWAY for further tests and demonstration purposes.
# 11 References

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<td>&quot;Gavin Doherty, David Coyle, Mark Matthews&quot; 08.05.2010, &quot;GAVIN DOHERTY; DAVID COYLE; MARK MATTHEWS&quot;: Design and evaluation guidelines for mental health technologies, page 2</td>
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<td>23/</td>
<td><a href="http://tinyurl.com/3qdl9br">http://tinyurl.com/3qdl9br</a>, verified on the 16/11/2010</td>
</tr>
</tbody>
</table>
References

0471492787, page 89
/Nielsen_92/ /26/ http://tinyurl.com/6ghnpl2, verified on the 08/11/2010
/Nielsen_30/ /27/ http://tinyurl.com/qie7, verified on the 12/12/2010
/Gediga_02/ /29/ http://tinyurl.com/66ruuxb, verified on the 14/12/2010
/ACSM_07/ /35/ http://tinyurl.com/3ohmm8e, verified on the 22/12/2010
/Ballegrd_06_b/ /36/ Ballegard, Bunde-Pedersen, Bardram 2006 BELLEGARD, Stinne Aaløkke ; BUNDE-PEDERSEN, Jonathan ; BARDRAM, Jakob E.: Where to, Roberta?: Reflecting on the Role of Technology in Assisted Living (2006), page 2
/Eurostat_08_a/ /38/ http://tinyurl.com/3nkheyx, verified on the 12/04/2011
/EU_07/ /39/ http://tinyurl.com/6e6l65q, verified on the 14/12/2010
/UN_05/ /40/ http://tinyurl.com/4ys2jcc, verified on the 14/12/2010
/OECD_08/ /41/ http://tinyurl.com/3d155i2, verified on the 14/12/2010
/OECD_09/ /42/ http://tinyurl.com/6zbdpbk, verified on the 14/12/2010
/Stat_10_b/ /44/ http://tinyurl.com/6dzw7p9, verified on the 17/05/2011
/Shell_10/ /45/ http://tinyurl.com/6j9ahe3, verified on the 10/05/2011
/Smith_05/ /49/ http://tinyurl.com/6d3zrvn, verified on the 20/12/2010
/Bussaco_99/ /50/ Debra Bussaco 1999, DEBRA BUSSACO: Normal Communication Changes in Older Adults. Let’s Talk… for people with special communication needs (1999), Nr. 72, S. 49–50
/Zajicek_01_a/ /51/ Mary Zajicek 2001, MARY ZAJICEK: Interface Design for Older Adults, 2001, page 1
/Zajicek_01_b/ /52/ Mary Zajicek 2001, MARY ZAJICEK: Interface Design for Older Adults, 2001, page 3
/Zajicek_01_d/ /54/ Mary Zajicek 2001, MARY ZAJICEK: Interface Design for Older Adults, 2001, page 5
/Makedon_10/ /55/ Makedon u. a. 2010 MAKEDON, Fillia; ZHANG, Rong; ALEXANDRAKIS, Georgios; OWEN, Charles B.; HUANG, Heng; SAYKIN, Andrew J.: An Interactive User Interface System for Alzheimer’s Intervention. 2010-11-23
/Samsung_11_a/ /56/ http://tinyurl.com/44ud3by, verified on the 20/03/2011
/Samsung_11_b/ /57/ http://tinyurl.com/65jshdm, verified on the 20/03/2011
/Wadhwa_10_a/ /58/ Wadhwa 2010, WADHWA, Kuh: A Survey of Technology for the El-
derly, verified on the 23/11/2011, page 1

/Leung_09/ /59/ Leung 2009, LEUNG, Rock: Improving the Learnability of Mobile Application Interfaces for Older Adults. page 3125


/Scheer_10_b/ /63/ http://tinyurl.com/422q2dt, verified on the 23/11/2010
/Goldmedia_10/ /64/ http://tinyurl.com/69xd3vg, verified on the 15/04/2011
/ElAA_10/ /65/ http://tinyurl.com/3ty4bka , verified on the 17/05/2011
/IDC_11/ /66/ http://tinyurl.com/5v5s5dws , verified on the 17/05/2011
/Gartner_10/ /67/ http://tinyurl.com/3pg2lte , verified on the 17/05/2011
/Eurostat_08_b/ /68/ http://tinyurl.com/6lbda98 , verified on the 20/05/2011
/Emarketer_10/ /69/ http://tinyurl.com/64knvh9 , verified on the 20/05/2011

/Qudah_10/ /76/ Qudah, Leijdekkers, Gay 2010 QUÐAH, Islam; LEIJDEKKERS, Peter; GAY, Valerie: Using Mobile Phones to improve Medication Compliance and Awareness for Cardiac Patients, page 2-3
/Pic_1/ /77/ http://tinyurl.com/62d2xmy, verified on the 03/03/2011
/Pic_2/ /78/ http://tinyurl.com/62y43q4, verified on the 03/03/2011
/Pic_3/ /79/ http://tinyurl.com/5uyw5g, verified on the 03/03/2011
/Pic_4/ /80/ http://tinyurl.com/5uwz3u, verified on the 03/03/2011
/Pic_5/ /81/ http://tinyurl.com/3pe2z3l, verified on the 03/03/2011
/Pic_6/ /82/ http://tinyurl.com/3wtk3z, verified on the 03/03/2011
/Pic_7/ /83/ http://tinyurl.com/3p8uqw2, verified on the 03/03/2011
/SENIOR_08/ /85/ http://tinyurl.com/3zkxt8g, verified on the 13/03/2011
/LOCOMOTION_02/ /86/ http://tinyurl.com/3ssesu9e, verified on the 13/03/2011
/EMERGE_10_a/ /87/ http://tinyurl.com/3cvty5t, verified on the 13/03/2011
/EMERGE_10_b/ /88/ http://tinyurl.com/6nhbufs, verified on the 13/03/2011
/CAALYX_09/ /89/ http://tinyurl.com/3h74c8b, verified on the 14/03/2011
/eCAALYX_11_a/ /90/ http://tinyurl.com/66uwpdz, verified on the 14/03/2011
/eCAALYX_11_b/ /91/ http://tinyurl.com/3tjttd4, verified on the 14/03/2011
/Netcarity_11/ /92/ http://tinyurl.com/64nltwb, verified on the 14/03/2011
/ENABLE_08_a/ /93/ http://tinyurl.com/3m4lntw, verified on the 14/03/2011
/ENABLE_08_b/ /94/ http://tinyurl.com/3qpbh, verified on the 15/03/2011
/ENABLE_08_c/ /95/ http://tinyurl.com/5rhpv7u, verified on the 15/03/2011
/ENABLE_10_a/ /96/ http://tinyurl.com/3fp2u2, verified on the 15/03/2011
/COGKNOW_11_a/ /97/ http://tinyurl.com/6xxg3do, verified on the 15/03/2011
/COGKNOW_11_b/ /98/ http://tinyurl.com/66agqrq, verified on the 15/03/2011
/Pic_10/ /100/ http://tinyurl.com/64agqrq, verified on the 15/03/2011
/Pic_11/ /101/ http://tinyurl.com/3ugyc3t, verified on the 15/03/2011
/Internal source.
11 References


/WHO_02_d/ http://tinyurl.com/64tbf8, verified on the 18/04/2011


/Net_10/ http://tinyurl.com/7krk7v, verified on the 29/11/2010

/IGSF_10/ http://tinyurl.com/3sqxzg3, verified on the 17/05/2011

/Spiegel_11/ http://tinyurl.com/67byyow, verified on the 01/05/2011


/Handelsblatt_09/ http://tinyurl.com/3kejyhk, verified on the 17/05/2011


/Rebenitsch_10/ Rebenitsch u. a. 2010 REBENITSCH, Lisa; OWEN, Charles B.; FERRYDIANSYAH, Reza; BOHIL, Corey; BIOLCA, Frank: An Exploration of Real-Time Environmental Interventions for Care of Dementia Patients in Assisted Living, page 1


/Makedon_10_a/ Makedon u. a. 2010 MAKEDON, Fillia; ZHANG, Rong; ALEXANDRakis, Georgios; OWEN, Charles B.; HUANG, Heng; SAYKIN, Andrew J.: An Interactive User Interface System for Alzheimer’s Intervention.

/Pic_12/ http://tinyurl.com/3kh6slv, verified on the 23/01/2011
11 References


/Karolinska_05/  /130/ http://tinyurl.com/4xvpyp8, verified on the 16/05/2011

/WHO_04/  /131/ http://tinyurl.com/5wnwngr, verified on the 17/05/2011

/Net_13/  /132/ http://tinyurl.com/6344r4y, verified on the 17/05/2011

/Berlin_11/  /133/ http://tinyurl.com/6ggbgwv, verified on the 22/04/2011

/IBRO_11/  /134/ http://tinyurl.com/3p54efs, verified on the 03/03/2011

/USC_11/  /135/ http://tinyurl.com/3msblkl, verified on the 03/03/2011

/AA-07/  /136/ http://tinyurl.com/5sbsvh3, verified on the 12/12/2010

/AA_10/  /137/ Alzheimer Australia Victoria 18.09.2010 Alzheimer Australia Victoria: Dementia - different types - Better Health Channel

/Purandare_05/  /138/ Purandare, Burns 2005 PURANDARE, Nitin; BURNS, Alistair: Vascular dementia - factsheet. http://tinyurl.com/3co94n6, verified on the 23/01/2011

/Net_14/  /139/ http://tinyurl.com/69b8jk6, verified on the 13/01/2011

/Net_15/  /140/ http://tinyurl.com/69h4hnz, verified on the 13/01/2011

/Net_16/  /141/ http://www.lbda.org/node/7, verified on the 13/01/2011

/Hoch_09/  /142/ Daniel B. Hoch 2009 DANIEL B. HOCH, PhD MD Assistant Professor of Neurology Harvard Medical School Department of Neurology Massachusetts General Hospital: Creutzfeldt-Jakob disease - All Information, http://tinyurl.com/63f7qdl, verified on the 22/04/2011


11 References

/Stebbins_01/  

/Net_22/  

/Drentea_07/  

/ADI_10_e/  

/ADI_09_g/  

/Zarit_83/  
http://tinyurl.com/4yxk2y2, verified on the 23/05/2011

/Zarit_83_b/  
http://tinyurl.com/6hmsvnv, verified on the 23/05/2011

/Net_23/  
http://tinyurl.com/3gqg5o4, verified on the 27/02/2011

/Net_24/  
http://tinyurl.com/6zc24wk, verified on the 27/02/2011

/Net_25/  
http://tinyurl.com/3z4dvqv, verified on the 19/03/2011

/Lazar_10_d/  

/Lazar_10_e/  

/Jordan_09/  

/Lazar_f/  

/Greindl_03/  
Hiermansperger, Greindl HIERMANSPERGER, Petra ; GREINDL, Sabine: Durchführung qualitativer Interviews und Auswertung : Am Fallbeispiel: Opportunistisches Verhalten im Ein- und Verkauf von Obst und Gemüse

/Blackberry_10/  

/Lazar_g/  

/Pic_12/  
http://tinyurl.com/63fu68q  
http://tinyurl.com/63ayt67  
http://tinyurl.com/5vtk2fo  
http://tinyurl.com/657yrc4  
http://tinyurl.com/6z4m9r8, all verified on the 22/04/2011

/Murata_10/  
http://tinyurl.com/64i27tp, verified on the 01/03/2011
11.2 List of abbreviations

[ATC] Assistive Technology Caregiver-side
[ATP] Assistive Technology Patient-side
[CH] Changes in the everyday life
[COA] Coincidence of an accident
[EC] Experimenter comment
[EMO] Emotional problems
[EN] Experimenter note
[ESS] Early stage symptoms
[FOR] Forgetting tasks and appointments
[LSS] Late stage symptoms
[MSS] Middle stage symptoms
[OTH] Other
[S] Subject
ACM Association for Computing Machinery
ACSM American College of Sports Medicine
AD Alzheimer's dementia
ADI Alzheimer's Disease International
AIDS Acquired Immune Deficiency Syndrome
ALF Assisted Living Facility
BPSD Behavioural and psychological symptoms of Dementia
CC Chronic condition
CJD Creutzfeldt-Jakob disease
CSCW Computer-supported cooperative work
DLB Dementia with lewy-bodies
EIAA European Interactive Advertising Association
EMS Emergency medical service
FTD Frontotemporal dementia
GPS Global positioning system
GUI Graphical user interface
HCI Human-Computer Interaction
HCS Health care systems
HDI Human development index
HF Human factors
Hi-Fi High-fidelity
HIV Human immunodeficiency virus
HMS Health management systems
HTL Hearing threshold level
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<td>HTML</td>
<td>Hyper Text Mark-up Language</td>
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<td>Hertz</td>
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<tr>
<td>IGSF</td>
<td>Fritz Beske Institut für Gesundheits-System-Forschung Kiel</td>
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<tr>
<td>IT</td>
<td>Information technology</td>
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<td>LCD</td>
<td>Liquid crystal display</td>
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<td>LD</td>
<td>Late diagnosis</td>
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<td>LED</td>
<td>Light-emitting diode</td>
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<td>Lo-Fi</td>
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<td>MCE</td>
<td>Multi-caregiver-environment</td>
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<td>MHC</td>
<td>Mental health care</td>
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<td>MID</td>
<td>Multi-infarct dementia</td>
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<td>MMSE</td>
<td>Mini–mental state examination</td>
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<td>OCED</td>
<td>Organisation for Economic Co-operation and Development</td>
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<td>PC</td>
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12 Appendix

12.1 Qualitative interviews

12.1.1 Interview guideline

Interview Introduction

Hello, my name is Philipp Jordan and I am conducting a research project concerning older adults with dementia. First I would like to thank you for your time and willingness supporting my project! To design a product for elderly adults with dementia as well as their caregivers and relatives, it is very valuable for me to talk with people like you in order to get first-hand information about the problems and challenges a dementia patient and caregiver face every day. So again, I express my gratitude for your time and participation in this short interview. It will take about 20 minutes at most and consists of 14 questions. You can answer the questions freely at your will. Please, don’t be afraid saying anything wrong, if you need time to think – or you want to make a break – just tell me.

Privacy policy

Your personal data and information won’t be delivered to any third party and the results will be treated with confidentiality. To further analyse the information gathered during this interview session I kindly ask you for your permission to record it on digital audio. Of course, if you don’t feel comfortable with that, please feel free to deny on recoding the interview session. Before we start, I finally inform you that you can stop and interrupt the interview anytime, for the case you feel uncomfortable or due to another reason.

I. Basic information:

1. What is / was your relationship with the person you know that has / had dementia? (Parental status? Age? Dead or Alive?)

2. What type of dementia has / had your [...]? (Type of dementia?)

3. When was it diagnosed? (Age of onset? Duration?)

4. Do you know when the patient was diagnosed with dementia?

5.1 What were the first signs that something is / was wrong? (Early Symptoms?)

5.2 How would describe the patient’s general condition when you started taking care of her / him? (Question referring to a professional caregiver)
6. How is the stage of the disease / situation of the patient today? *(Stage today? Duration?)*

II. Trying to figure where to help people:

7. What changed in the life of your [...] after being diagnosed with dementia? *(Changes regarding the patient?)*

8. What changed in your life and daily routine and the people around your [...] after she / he was being diagnosed with dementia? *(Changes in the life of the caregiver regarding the social environment of the patient?)*

9. Can you describe some of the everyday situations and problems you have and had to face while taking care of your [...]? *(Examples of problems and challenges after diagnosis?)*

10. Try to remember delicate situations where things went not the way they should. Maybe you can provide me some examples. What happened exactly in these situations and what could have prevented these? *(Where did stuff go wrong? Functionalities? Potential for AT?)*

III. Specific questions

11. Is / Was the patient autonomously using any Assistive Technology (e.g. Phone, Wheelchair, Medication scheduler, Calendar)? *(Previous user experience of the person with dementia?)*

12. Have you used any kind of Assistive Technology specifically targeted at dementia? *(Previous user experience of the caregivers / caretakers with AT?)*

13. How did you manage all the extra activities (doctors’ appointments, medication schedules, paying the bills, going shopping…) that came along with the disease of your [...]? *(Where is potential to replace traditional tasks with AT?)*

14. Have you ever forgotten appointments and / or tasks related to the dementia patient? *(Where are acute problems?)*
12.1.2 Interview transcription

In the following, the coded interview transcription of the 9 subjects is enclosed.

To differentiate the fragments, the coding is using two alternating colours (green, blue). The reader can use the interview coding in appendix 12.1.3 to review the fragments referenced in the transcription.
What is/was your relationship with the person you know that has/had dementia?
She was my mother in law.
She is still alive?"
No.
What type of dementia did she have?
I think it was Alzheimer’s.
Do you remember when it was diagnosed?
I think officially maybe only four or five years ago. But she had symptoms maybe 10 years ago.
Ok so when it was diagnosed four to five years ago... that means how old was she at that time?
She was in the early 70ts; I think 72, 73 something about;
Yeah. Late 60ties when she had the symptoms.
What were the first signs that something was wrong?
Repeating things that she already said; repeating the same story.
Do you remember more examples?
Getting people’s names wrong. I think.
As she sadly died the next question I have to avoid.
Ok.
So let’s continue during the time the disease was diagnosed.
What changed in the life of your mother-in-law after diagnosed with dementia?
Well I think it was only diagnosed after she had a car accident and she was injured. So then she had to go [20 seconds lag in the record]. So then she had to go back into the care home and I think from there she kind of deteriorated.
I just got some part of the information right now because there was some kind of lag. So she had an accident and then the dementia was diagnosed and then she came to a caretaker’s home?
That’s right.
What changed after the diagnosis and when she was living in the caretaker’s home e.g. in your life and daily routine or the people around during that time?
The people and me they had to kind of visit her on a daily basis and also we were having to cover further for the mistakes she was making and worry about her. Cause she was confined to the nursing home.

Can you give me some examples or describe some of the everyday situations and problems you were facing while visiting her?

Yeah. Well mostly with my wife I think it was just the emotional problem. That she won’t really recognize the person that was visiting her. Or she made up stories about the past what she is trying to remember. So it’s kind of question of seeing the person you knew disappear. So that was the problem I think.

Was your mother-in-law patient autonomously using any Assistive Technology (e.g. Phone, Wheelchair, Medication scheduler, Calendar) especially in the early phase when the symptoms were occurring?

No she didn't really use any of those cell phones or IT. And in the care home no. The only thing they had was the menu schedule for the week for food but nothing about medication schedule.

So I guess the nurses did all the work... taking care of her?

Yeah.

Have you used any kind of Assistive Technology specifically targeted at dementia?

No nothing like that.

How did you manage all the extra activities e.g. like doctors’ appointments, medication schedule, payment of the bills, shopping that came along with the disease?

No I think cause of the circumstances that she was in denial about seeing a doctor until she had the accident and then it was kind of too late. When you have to go to the care home it’s too late for any of those aids. It was much like that.

Have you ever forgotten appointments and/or tasks related to the dementia patient, e.g. visiting her?

No.
What is/was your relationship with the person you know that has/had dementia?
It’s my grandmother.
Is she still alive?
Yes.
She is still alive.
Do you know what type of dementia she has?
Alzheimer.
Do you remember when was it diagnosed?
Yes. When she was 80 years old. It was when we started to notice that there were something that wasn’t right with her. Do you want to know how it started?
Yes. It’s the following questions so just talk freely.
Ok. We started noticing it because she forgot the water on the cooking plates. She left the door open. Acting strangely, saying that everybody left her when we were at home and stuff like that. So we put her to the psychiatrist.
First you thought she had a psychological illness?
Yes, Because of the age; she was 80 old. They told us from some exam that it was AD.
So the psychologist sent her to another doctor?
No, no the psychologist is treating her. And now she sometimes forgets the stuff, sometimes she remembers. But usually she talks from about her 40 years old back. She forgot that she is 87.
I understand that all she remembers is more or less around the time she was 40 or younger. Yes. Usually. And she confuses sometimes that I am her daughter and not her granddaughter. She confuses the names of the people in the house. But she recognizes that she knows the people, but she confuses their names.
How is the stage of the disease today?
In our days, we got some luck – unfortunately - because during these days she broke her hip.
She had an accident, she fell?
Yes. She only walks supported by us. So she can’t walk by herself which is good because she can’t run away from us. So she needs help to dress, to take a bath; sometimes when she is in
the worse stage she needs help to eat. But when she is good she eats (referring to: herself) but not with a fork and a knife, she eats with a spoon because it's the only way she can grab the food. She doesn't have the fine motor skills anymore. It's easier for her to use the spoon.

[aQ6]

I kind of guess she is living with u in the house?

[04:00]

Yes. She stays in her house because when we noticed that when she is in our house, she misses her house. So we pay to a person to stay there (in her own house) by night and my mother and my godmother go to her house during the day and are staying with her when she comes to our house she stays with us.

[Com2]

So there is somebody paid, a caretaker for the night and during the day your mom and your godmother go there for looking after her and on the weekend you just bring her to your home-

Yes.

[05:00]

[Q6]

What changed in the life of you or your mother after the dementia was diagnosed?

In the beginning when the disease appeared we went to their house. My grandfather is still alive so we didn’t were so worried about it because my grandfather could look after her; but we found a woman to clean the house, to cook for them because my grandfather was also 80 years old and he didn’t how to cook.

[06:00]

But my grandfather died so she stayed alone and we needed to go there. So in the beginning the woman stayed during the day with my grandmother and went to sleep at her own place every night because she didn’t wanted to live in the house. And in the weekends we went one weekend (me, my mother and my sister) there, stayed the weekend and the following weekend my mother’s sister and the cousins spent the weekend there. But we realized that our houses became confused because we didn’t stay in our house, our jobs got neglected so we decided to pay someone to stay there by night.

[07:00]

[Com3]

At the beginning you tried to distribute the visits and caring of her within the family but it was just becoming too hard at a certain moment and then you employed a caregiver.

Yes. Too hard. Because she was suffering from a heart operation so she stayed for almost a year in the bed all the time. She didn’t walk, she didn’t get up and she stayed in the bed. So it was a little bit hard for us. Now we have that woman that stays during the night and as my mother and godmother don’t work because they are retired, they stay during the day and in the weekend it’s easier for us because we can take care of our stuff and duties and still take care of her.

[aQ7]

So it was all too time-consuming at the end?

Yes, yes.

[08:00]

[Q7]

What changed around the patient, the dementia person?

Yes, we live in function of my grandmother. She is the centre of our family.

[aQ8]

Can you give me some examples of that?
We handle our Grandmother’s disease not as a tragic thing. Ok, she is sick and we have two choices. Seeing that as a tragic thing and remember and saying oh my god she is sick and stuff like that.

[09:00]
Or enjoying the things and spending the most time with her and sometimes laugh with her even if she is saying stupid things and we are saying stupid things to her, but she is still talking and spending time with us so we decided on the second choice which means living with her and not with her disease. So sometimes she says nonsense, she says things that don’t make any sense and we try to continue a conversation even though it is nonsense at all. Because if we correct her she understands that we are correcting and she doesn’t talk anymore.

[10:00]
she stays quiet so we prefer her to talk. So we don’t correct her at all.

[aQ9]
For what do you have more free time after employing the nurse?

Yes we can take care of our stuff. Our house for example: Tidying up the house, doing the housework. And our housework was being neglected without the nurse. And my job; by that time I bought a laptop because I didn’t had one so I could work in my grandmother’s house by mobile internet.

[11:00]
I and my sister and my cousins adjusted our life to her situation.

[Q8]
Can you describe some of the everyday situations and problems you had to face while being at her place e.g., things were stuff went wrong?

[12:00]
Difficulties with her; We need to dress her. Now she is used too but in the beginning she didn’t wanted to take a bath, she was always complaining – complaining in the good way –

because she didn’t want to give us work. She felt bad, we needed to change her, too dress her.

[aQ10]
So she resisted getting support?

She was feeling ashamed because she lost all her privacy. So it was a little bit hard for her to understand that we need to do that because otherwise she didn’t have any chance doing that stuff. The medication that she needed to take should be controlled by us and the stuff like:

When you need to take a pill you need to drink water. Sometimes she drinks water and then takes a pill and smashes the pill and we have to say: “No! No! You have to drink the water because you can’t smash the pill.”

[13:00]
And when she can’t eat it’s a little bit hard because we need to; it’s like a baby we have in the house. We need to eat our food and give her some food because she sometimes can’t do single stuff like this movement (referring to an imitation band cutting meat with a knife and eating soup with a spoon). Sometimes she confused the napkins; she looks to the napkins but doesn’t recognize them as napkins. She puts them in the mouth and is going to eat them and therefore we have to take them out and say “No, no... this is a napkin.” We are always explaining her what the things are for.

[14:00]
Can you remember any serious situations maybe?

Sometimes we left her in the room. Her house has a garden. And we leave her in the living room and we go to the garden for example. And she for an instance sometimes is lucid and she
got up and – one time went to the bathroom, sat down and then she couldn’t do anything else.

[15:00]

So for us it was a problem, my mother went back to the living room and she wasn’t there. She could fall down in the bathroom. For us that is dangerous. And we are very worried. Or e.g. when she tries to get up due to she doesn’t have any sense of equilibrium. For us that is a big trouble.

[16:00]

Was your grandma autonomously using any Assistive Technology (e.g. Phone, Wheelchair, Medication scheduler, Calendar)?

No, she can’t see the clock now, the hours.

[aQ11]

Because she has vision problems?

No, no because of the disease she doesn’t understand the clock now. The only technology that she uses – if you can call it technology – is the TV. It’s for her a good entertainment. There are some Portuguese programs that she likes to see, but they have to be in Portuguese.

[aQ12]

I guess she always spoke and watched the program in Portuguese?

Yes, but when she didn’t had the disease she read the subtitles and she understood them. But now she doesn’t understand them anymore. She doesn’t read as quickly as in the past. She reads the first part of the subtitle and then the next subtitle already appears.

[17:00]

So she can’t follow the timing of the subtitles anymore. She likes the TV. But sometimes she doesn’t understand the TV as a TV. She is asking me “Oh, why did u allow this stuff happen to him?” and I explain that it is a film, it is fiction it is not real. Sometimes she doesn’t understand the TV as normal thing. She thinks it is real. But still - for her - it’s the best entertainment. Especially if there is Portuguese music; old Portuguese music – from that time she still remembers.

[aQ13]

When she was 40 or younger?

Yes.

[aQ14]

Regarding that point maybe some years ago before it got worse did she then use some kind of technology?

[18:00]

She used a telephone - no mobile – but a telephone, yes. And she understood the telephone. In her house was a very old telephone where you had to dial the numbers on a wheel. But she understood the other ones too, e.g. when she went to pour place. She understood that she had to click the buttons. When we put her on the phone e.g. we have a cousin that is in London. So when he calls, it’s funny because when she is in my aunt’s house and she is looking to my cousin – they speak with him by Skype – she thinks it’s funny because she sees her own face in the computer (the own video) and she doesn’t understand why she sees her face and also how she can see my cousin in the computer.

[19:00]

But she likes it. She thinks it’s funny.

[aQ11]

Have or your family used any kind of Assistive Technology specifically targeted at dementia?
We do it by phone. It’s automatic. We don’t have to write it, to take a note of the days we are going to her place. And if we have to schedule something e.g., in January I think I need to go to a place I just write it in a normal Calendar and check if I am free or not.

[20:00]

[aQ15]

What about the medication e.g., the nurse is taking care of that?

Yes, we made a poster on the wall. No matter who stays with her just looks at the poster and sees what she needs. Because her medication is always the same; always the same amount, type and time, so it’s easy for everybody giving her the medication.

[aQ16]

Did somebody ever forget giving her the medication?

No, never. We forget our medication but not her medication. We never forget my grandmother’s medication; she is the centre of our lives.

[21:00]

(Q12)

How did you manage all the extra activities e.g., the doctors’ appointments, medication schedules, paying the bills, going shopping?

The money that we use to pay the woman that stays with her and the medication is my grandmother’s money. Because my grandfather worked and contributed some money we are using for that. When that money is finished we pay all ourselves.

[22:00]

[aQ17]

For example when the fridge is empty who goes shopping?

It’s the person who stays there.

[Com4]

Somebody is coming, you just look into the fridge, check the medication schedule, ok food is here and medication she has to take in one hour and so on.

Yes, e.g. It’s me who takes care of the bills. Usually it’s my mother that checks if the woman stays in grandmother’s house has some money for food shopping. It’s my aunt that checks if there is some medication is missing. Yes. It’s usually the same person doing the specific “job”, so we don’t mix anything.

[23:00]

[aQ18]

So there are no big organizational problems and everybody knows what to do and you don’t need to talk about?

Yes, yes. Everybody knows what to do; we do not need to have reunions. We just talk when are together and say: “I can do this, you can do that.”

[Q13]

Have you ever forgotten appointments and/or tasks related to the dementia patient?

No. Never ever. Until now.

[Sto]

[24:00]

[Com5]

Subject mentioned herself AFTER the audio recording while saying goodbye that she is often worried and has to “run” when going to shopping while simultaneously being responsible taking care of her grandmother and would like to have support / a solution which offers her the ability for “checking” the location of her grandmother remotely.
Mentioning the fact I am mainly interested in early cases and not late stage AD cases. I was only in the care centre being confronted with late stage cases, where I was working at the “Bethesda” (referring to the name of a deaconry centre) in the “closed” station. Very severe cases were patients who couldn’t make one single step themselves.

Stressing again, that late stage AD care is not the intention of the interview but more the early stages.

It starts sneaky (referring to early stage AD) with forgetting where they keys are, the wallet has been placed. Forgetting which day it is. Or the birthday dates from the children. That’s usually in the beginning; e.g. not remembering if the first (referring to children) has birthday on the first of May or if the second kid has in July.

So I talk about numbers and dates.

What is/was your relationship with the person you know that has/had dementia?

I am doing this (caretaking) on a voluntary base and my relationship to these persons is very close. We are using the informal you for calling our name. It is a very close relationship because I am not doing my work like the welfare centre (referring to the workers there). I am really a reference person for these people. At the welfare centre it always exchanges (the caregivers), so delineating towards this is not that easy because you are putting your back into the thing and you feel too much responsible of the person regarding that everything goes well, that the person is ok, that you don’t make any mistakes, that nothing happens which can harm the person.

If I may ask, are we talking about friends you take care of?

It started with two sons asking me if I would do something like this; taking care of their mother. At that moment I was not completely aware of the fact, how severe Anne (referring to the patient; in the following being referred by Anne) dementia was. That means already in a stage you can also say that this is already “care home ready” stage. But when you actually see the people in the day care centre you say no (referring to the sons), you postpone it a little bit more. Cause it is (referring to the day-care centre) always the same; it’s too consistent, no new impulses from the environment anymore. It is grave. Practically, the dementia is progressing even faster there (day care centre) compared to the individual planning for the single human being within his/her environment.

So they (the sons) came to you asking for taking care of their mother voluntary?

Yes. At the beginning – yes - as they (or it) wasn’t clear what time exposure this is and furthermore;

we thought in the morning half an hour helping her getting dressed, preparing some little lunch on midday; and then in the evening making her (referring to the patient) ready for the night is the job.

But there comes more and more (referring to caretaking exposure) because she just can do less and less.
50 [aQ3]
51 Is she living alone, is she married?
52 She is living alone, she is divorced.
53 [aQ4]
54 How old is she?
55 She is 59 years old. And it started one year ago. With 58 it occurred that she couldn’t work
56 anymore.
57 [Q2]
58 What type of dementia does she have?
59 Alzheimer Dementia.
60 [Q3]
61 [4:00]
62 When it was diagnosed you already mentioned that; it has been diagnosed one year ago, when
63 she was 58?
64 Yes. “Pfalzklinik” (referring to the name of a local psychological clinic); first you go to the neu-
65 rologist where everything regarding the head is being tested if there are any other side-im-
66 pairments. Until you get the final diagnoses it takes a long time. You become a stationary pa-
67 tient and it is a long procedure you have to go through. And in such a stadium wherein it is not
68 clear they often are being stigmatized as simulants. This was actually written inside the medi-
69 cal report: “Misses xxx, being observed everything works better; or the other way, if she is not
70 being observed, everything gets better and when she is being observed the disease pattern
71 gets worse.
72 [Q4]
73 What were the first signs that something was wrong?
74 [05:00]
75 The co-workers! Who constantly took responsibilities in her place, e.g. control of the register
76 money and counting the cash balance. A co-worker of her told me that. They (referring to the
77 ex-co-workers of the patient) absorbed that at the beginning. She was practically incapable –
78 she was working at “Hornbach” at the register (referring to the name of a home depot store) –
79 to count exactly (referring to money). These associations, these are 10’s, these are 20’s and so
80 on; (referring to notes) that didn’t work out. So they (referring to the co-workers) took their
81 responsibilities. Until somebody said: “We can’t do that, that’s not working.” She also had
82 always differences in the balances because with the numbers - it’s really the worst of all with
83 the numbers and number relations. I think she can’t also – I said that to my husband – that
84 watch; that arrow (referring to an analogue watch); that position of the watch hand she can’t
85 classify that correctly. It is now 10 after 2 and so on; if there is a digital watch which shows
86 13:50 or 14:10 that she understands.
87 [06:00]
88 But an analogue watch she doesn’t understand anymore. And the writing; One year ago, or
89 half a year ago she was able to write her name in a nice way and yesterday she needed to sign
90 something and it was only - the type face which is being shaped from a nervous hand - like I
91 am going up; I am going down; there is just no fluent movement anymore.
92 [aQ5]
93 So it started when she was not able to associate numbers at her workplace?
94 Yes, associating numbers.
95 [07:00]
96 [Q5]
97 How was the stage of the disease and situation you faced when you started taking care of her?
I thought first, it’s not that tragic compared to the description of the sons. I can’t image that she has AD. Because she could hide it, e.g. if she couldn’t read something “Ahh.... I can’t find my glasses.” She couldn’t admit it herself. (Referring to her) “I have AD. I can’t do that anymore.” It takes time; it takes minimum a year until she said freely from her side: “I can’t do that anymore.” She hid it very skillfully.

“She felt ashamed?”

Yes. Besides to time that information.

When did you start taking care of her actually?
In January. At this time the diagnosis was just been made; around the 8th of December last year (2010).

So when the diagnosis was been made you started taking care of her?
Yes. But what that means in particular for a person living alone I was aware of. Things you are talking about with her - she appears to be completely normal.

Let’s stay around the time you started taking care of her.
She was more independent, she could do a lot of things. She was able to phone e.g. She could accomplish a phone call, taking her book (referring to an address book with numbers inside of her family and friends) and call. Today she can’t do that anymore.

“So would you say that during these days (referring to the time she started taking care of her) her situation wasn’t that bad at all?”

Yes. She was able to manage her daily routine. She used the microwave; she knew there is something inside the microwave. When I left the microwave open, she realized that there is something inside I can warm myself up.

Ok, then the other way around. What did not work during the time you started taking care of her?
That I talked and confirmed certain things with her and she didn’t remember them. I said I am back in 10 minutes. And when I came back she was in rage saying I didn’t give her any information. You just go and don’t tell me. Or I gave her something to eat and came back one hour and she said “I didn’t eat anything the whole day; you don’t give me anything to eat.”

That constant hunger... She eats just everything because she thinks she didn’t eat for a long time.

To summarize things, at the beginning she was able to manage her daily routine more or less besides of forgetting minor things like you mentioned, e.g. giving notice of departure?
Yes. The short-term memory was affected. Giving notice of departure, saying I’ll be right back, I am going for shopping - she didn’t remember that. Memories from ten years ago they remember. These semiskilled things. But these short-term information she didn’t remember.

With that I had my own problems.
And how is the situation today?

Today, you don't need to say anything because she forgets things mentioned 5 minutes before! The neighbour comes, brings her something to eat and leaves the house. We are meeting her at the front door (referring to her and her daughter arriving at the patient's house). The neighbour (Hannelore) says to us: "I brought Anne something to eat and she immediately started eating."

[11:00]

I enter the house and ask Anne if Hannelore was here. Anne replies: "No, she wasn't here." 5 minutes before! So things which just happened, these time intervals wherein the ability to remember something being experienced right now; they just don't remember them anymore.

[aQ14]

"So you would say it became worse?"

Yes. It became worse. Nothing goes inside the head. No phoning anymore. She doesn't know what green or red is (Referring to the phone). The buttons are too small. I modified the phone putting red dots on it. And I give her rules e.g. red is "dead", red is the end of the call. She doesn't remember it. She presses on red. She takes the phone and presses on red.

[12:00]

She then is saying, the phone rings, I pick up and nobody is on the other side. I ask: "Which button did you press?" She answers: "I don't know." I ask: "Left or right?" Which is actually stupid to ask because she doesn't know right or left. Then I explain what left and right is and she replies "Yes, I know where left and right is!" While always becoming annoyed with little and very simple things you say to her relatively fast, e.g. (20:00) "I am not that stupid! I know where left and right is!" But where on the phone is right then I ask. This should be different regarding the haptic (now referring to the design of the phone of the patient). The buttons should be some kind of different because she is not to differentiate the colour; what is red what is green.

[aQ14]

"Because she forgot what green and red is?"

Because she forgot what green is. What green means. The converting of "what things mean". The meaning of things is not there anymore.

[13:00]

Water: I say" Anne, we don't have any more sparkling water. It's empty." Then she goes e.g. to the water crate and brings two bottles of sparkling water by placing them on her zimmer frame and says:" There is still sparkling water." I answer:" Look at the bottles; how does the bottles feel?" She replies: "Ah yes, there is nothing inside. They are empty."

That relation between things, this is heavy, this is light. She sees a bottle and thinks there is something inside and is finally carrying around the water thinking that there is actually water inside. Or she says:" You have to look inside the freezer. We always have sparkling water inside the freezer." I answer:" In the freezer? What happens in the freezer? It becomes cold and colder." She replies: "Ah yes, there can ice..." and I reply "You can't place sparkling water in the freezer."

[aQ14]

[14:00]

"Did she ever do that?"

Thanks to god, she never ever did it. Moreover she didn't turn on the stove. Because it is into her that the finger stays away from the stove. So far she can handle the stove. She doesn't turn it on. It is a danger.

[aQ15]

That changed compared to one year ago?
One year she [sometimes used it and warmed up a meal for herself]. She also used the coffee machine. One year ago, Today that is not possible anymore. The microwave she can’t turn on.

She says, she turned it on but I check and see that the meal isn’t warm. She then eats it cold.

She takes it outside of the microwave because she thinks it is ready and eats it, nevertheless if warm or cold. She simply doesn’t know if it needs to be warm or cold. A year ago I said: “Turn it on three, that is enough and your meal is nicely warm.” She was able doing that a year ago.

But she can’t do that anymore, she doesn’t know it anymore.

[aQ16]

[15:00]

Would you say that as today she can’t live by herself?

She could – it is always dangerous if you leave a person like her alone for some hours because things like how she uses the toilet. She thinks e.g. there is a trash bin in front of her because if she doesn’t see it, she doesn’t understand you put paper inside. But these days I think I realized that she sometimes tries and uses this paper bin for urinating because she is not able to estimate that this bin is so close to the toilet and therefore she has problems where to actually go to the toilet. It is very dangerous if you change anything in the structure you rattled them completely,

[Com4]

For example, if you change the table from the left to the right.

Yes, that is a total No-Go. You have to leave the things. There is this, here is that. These are common things and movements they know.

[16:00]

Phoning is very severe. She can’t do that. I exercise so often with her. I give her mnemonics:

“You are at the traffic light. You can drive. At which colour?”

She replies: „At green, of course. I know that. I was driving cars.“ And I say: “And that is the same with the phoning. Green means you can make a call. You dial a number, you see the numbers.” But then – when she is alone – doesn’t know if she has to push green or red when picking up a call. You can’t give her any mnemonics like red is referring to “dead” and “green” is speaking. We have to work with symbols, e.g. when she is supposed getting bread: A year ago I could be convinced of the following: “Anne, on midday, when you are going the road straight ahead to the bakery you are arriving at the bakery.” That’s the only you she is able to go, as straight as a die. Even today. But she doesn’t know that she is supposed to get bread.

[17:00]

Practically, I have to present a symbol which shows a slice of bread and a shopping bag next to. I say look at this. This is the shopping bag and that you have to buy. That is old; it is empty [referring to the empty bread]. This is what you have to get. Because she can’t read anymore.

She doesn’t admit it. She is frightened of herself, that she is not able to read the simplest things.

[aQ17]

Probably she directly forgets if she read something?

Yes, she can’t associate the word, why is there written bread?

But when I show a shopping bag and the picture of an empty shopping bag; or I leave the bread cabinet open and she looks inside and says:” Oh, no bread!” And there is next to it the wallet and the shopping bag then she has an association.

[18:00]

You have to be very imaginative to be able to help.

[aQ18]
Trying to maintain at least some independence and autonomy for them by the usage of symbols, games, etc.?

Yes. Phoning is really severe. It was her only social contact. And it rings and she picks it up and basically pushes the red button. Because there is too much red. Maybe I said too often red. And regarding the TV; that switching on of channels;

[19:00]
even if the program is already been chosen she is not able to handle the remote control. They are too complex. They have too many buttons. Wherein she is not able to remember anything.

For AD patients there should be a lot more simplified devices. On and off and symbols;

[20:00]
But for unlocking the door you turn the key basically to the left. She always needs the help from the neighbours. And sometimes she stands 30 minutes or an hour in front of the door and is not able to unlock it.

[AQ19]
A year ago she was able to achieve these things like unlocking the door?

Yes, everything went smooth and without problems. She could undress herself, she knew when you are leaving the house when it is cold you have to wear a jacket, these days she is just going outside in the cold without a jacket.

[21:00]
What changed in the life of her sons after the diagnosis?

They actually over challenged her mother. They (referring to the sons) couldn’t asses her mother correctly and always thought “Mum can handle this. She can handle all that” because they are not in contact with her. They don’t recognize these “trifles” at all. What it means to living together with an AD patient. As I am with her every day, I take everything myself. I am there (at her house) every day. They are (referring to the sons) not living with her, they are visiting her. And the she feigns in a little bit in front of them.

She doesn’t want to be a burden for her sons. We (referring to the interviewee and the patient) are managing this matter somehow. “I have a good caretaker.” she always says

[22:00]
Thank god I have her.

[AQ20]
So do the sons actually know about the situation?

No they certainly don’t. They know mum has AD because it is stated in the medical outcome but what it truly means they don’t know. So far they take everything she says at face value which are things actually don’t happening. Or she is not able to forward information so you actually can’t rely on her statements, but they do that gladly. Whatever is happening with an AD patient, you always have to collect information.

[AQ21]
What do you mean?

She says: “Elisabeth was today not here!” And they take it at face value.

[23:00]
He (referring to a son) calls me at night saying: “Elisabeth, my mother told me today you were not there.” I respond then: “Peter, what has your mother?” (Referring to AD) She doesn’t know what happened ten minutes ago.

[Com5]

And the sons are obviously not sensitized.

They don’t grasp the AD because they are not socializing with her. They don’t have the time to be with her for at least half a day otherwise they would know about how it is. The younger son is in Hong Kong and doesn’t come at all and the older one only comes and brings the money and takes care of the paperwork. He also is the legal guardian and governs the financials.

[aQ21]

[24:00]

So that changed for him, taking care of the bureaucracy and paperwork?

Yes, exactly. He does that well, he wants that his mother is being well, not letting his mother go short but the dealing with the disease.

[Com6]

I understand. You are the main caregiver and they take care about the things around.

Exactly, I also balance out what she can’t do and try to make it in a way, that it (the AD) doesn’t become apparent. It is a little bit of supporting; I am supporting her. Or when she says something false then I say: “Ah, that she yet forgot. It was like this and that…” So that I never accuse her like: “How can you dare saying that! You know exactly that this can’t be true”

[25:00]

Some people say that to her, e.g. the neighbour: “Anne, what ridiculous things you are talking about! You know for sure, that this is not true.” I don’t do that. Because she always assumes that she is right in what she is saying because she is not being aware of it. And I can do that better, I can put myself into her shoes. And I feel sorry that she forgets such important things. Somebody is coming to her place for a visit and she is not able recognizing this person. And that person she always knew.

[aQ22]

“Did she e.g. forget your name?”

Bizarrely not. Because I am there every day. “Elisabeth” she always remembers. It’s an association. This name is settled.

[26:00]

[aQ23]

Do you think it is her wish that her sons don’t know about her real condition?

She doesn’t want to be a burden. I demand to less from them, e.g. saying they should take care of her a whole day and not only giving her a visit at for the Christmas dinner and then running away fast. That’s the way it happened. So I act in her interest and play along with everything. We don’t need the sons and she doesn’t want to be a milestone around their necks and therefore they are not being claimed.

He should buy some sparkling water [referring to one of the sons]. “You should have told me that earlier.” He said on Christmas evening. He comes at 10:30 in the morning and says “We eat in one hour.” Then I replied: „No Peter, we just had breakfast.” You can’t have lunch at 11:30; maybe you can have lunch at 13:30. Simply not taking time; he doesn’t take time for it.

[27:00]

“You could have bought a crate of sparkling water, it is empty” He answered: “No, you should have told me that earlier.” I told him, some days later. I went then off at Christmas evening not telling “Merry Christmas” to him or his girlfriend. They just sit down and think everything is being taken care of. But that is also my fault.

[Q8]
Can you describe some of the everyday situations and problems. You already mentioned a lot, maybe you can remember more?

[28:00]
Yes, I already talked about the most important things. In company of her, e.g. when going out with her, constantly being in danger to expose her. That certain things; we were in the living room and she goes to the bathroom and – she is able doing that more or less – I said: “Anne, there is the toilet.” That she doesn’t have any orientation and doesn’t know in which direction she has to go. That you have to constantly – also in her environment – when she exits her bathroom she walks through her sleeping room and then I say: “We go now into the kitchen.” And then she cardinally walks in the false direction and goes in her living room because she doesn’t inherit these orientation skills anymore. Left is the kitchen and right is the living room so I said: „Anne, the kitchen is to the left.“

[29:00]
And that is sometimes hard for me when other people listen to that and think: „What care-taker is that? She is even telling her go into the kitchen which is left.” For others, strangers it is always very crass. She must know that, she knows her kitchen.” That you have prescribing her the direction.

[Q9]
Did you ever face or experience delicate situations where things went not the way they should.
Maybe you can provide me some examples?

Yes. A lot of people already told me that she basically walks in the middle of the roadway.

[aQ24]
“When she is walking within the village?”

Yes. Basically in the middle and I correct her;

[30:00]
go outside with her and say: „You always go as straight as a die crossing the street the way you tell a kid. And then you go along the roadside” - the pavement is often not useable because it is either being full of parked cars or there are rubbish bins or something else. Or she gets stuck in the roadside ditch. Then she can walk along the pavement on the far right side. Then she walks some meters on the right side in a proper way, then I see while being almost out of hearing and then I shout after her: „Anne right!” She turns around saying: „But I am walking on the right.” She thinks she is on the right. And I was watching her walking in the total middle of the roadway at the bakery and telling her she was in extreme danger because she was walking in the middle of the road. And when she walking along the “Borngasse” (referring to a street in the town she lives in) and somebody in a car comes round the corner, there something can happen really fast.

[31:00]
But then even the people dare telling me, leave that woman alone. She is being seen, she has never been driven over. That the understanding is not there! But when something happens to her and I am in the proximity of her Peter will tell me:“ Why did you leave her walking alone?” And she always comes to me telling me:“ I am not a child anymore. I know how to walk.” That she doesn’t really accept is not aware that she has doesn’t have the orientation anymore. Do I go to the right or the left now?

[aQ25]
Do you remember more examples of dangerous situations?

Until now I didn’t had any dangerous situations. She also didn’t do anything where I thought - oh my god - that could have gone wrong. She is actually very careful. She also doesn’t take anything out of the fridge.
because she is not anymore aware of that it is her fridge. At the beginning, last year it was still like that, she plundered it. I place the food outside – what she likes to eat – an orange, an apple, she noshes them in sequence. Ten minutes later, she finished eating. Because she is not aware of or eventually because her life is boring – it is actually boring – so eating is a variety.

What else she is able to do well. **TV – movies and such things, she can follow well, she adores television crime thrillers a lot.**

[Q10]

Is patient autonomously using any Assistive Technology (e.g. Phone, Wheelchair, Medication scheduler, Calendar?)

“Yes and that would be the next question. TV she can use, what else can she sue? Telephone doesn’t work anymore you mentioned, too”

**The TV she can’t turn on herself. Therefore I often had to come due to her calls.**

[33:00]

– in the time she was still able to make a call – “come over, I shifted everything.” Because she was pushing every button on the remote control. But even if I give her only one remote and say:” Look there is only one big button. And only this one big button you push. Which is in the middle the “OK” button. Then you can already select a few things with that button.” She can’t do that. She can’t imperative the easiest things. She doesn’t remember it. Five minutes later, she doesn’t remember what Elisabeth (referring to her) just said. A green button labelled with an “OK” she doesn’t remember. If she could remember that, she would know how to use it. I set the channels for her; zap through the broadcasted programs and ask her what she would like to see? She likes to watch crime thrillers, so we look out where the best crime thrillers are being broadcasted and is happy when something nice is on-screen.

[34:00]

Turning off (referring to the TV) she is still able to do. That is remarkable. That is being recognized. I don’t have a time switch which will come sometime; when I am going in the evening, setting her a defined time, around 22:00 to 22:30, the TV turns off.

[35:00]

**Because some day she won’t be able doing it herself.**

[Com7]

You also said that she is not able to understand an analogical watch but she can read the digital watch.

Yes. She can read it. 14:11. But I don’t know if she understands if it is referring to noon time. Maybe I should test that. Because with the other watch I tested her and said:” Anne, I can’t read the watch. I forgot my glasses today. Can you read it for me? This analogue watch?” She couldn’t say me what time it is. The same regarding reading; she doesn’t read anything at all.

The neighbour always brings the newspaper and it is just lying there in the same way the neighbour placed it. No interest; probably because she can’t read at all.

[36:00]

[Q11]

Have you used any kind of Assistive Technology e.g. calendar?

**You need to be organized in your schedule as well as recording a lot of things.**

[37:00]

[aQ26]

Did you acquire specific things?

A year-calendar wherein you can notify daily events. It is located at her place. Furthermore – if you are doing it (referring to her caretaking activity) for a family and are being paid – you have to collect all receipts. That calendar is very important because she has a lot of appointments
like doctor’s appointments, physiotherapy. Etc. She has more appointments than me actually. Because of these it is a must. And that is (using the calendar) satisfactory enough for you?

[38:00] Yes.

[Q12] How did you manage all the extra activities e.g. like doctors’ appointments, medication schedules, paying the bills, going shopping?

[1:02:00] I don’t take care of that. All the doctor’s appointments I take care of. Furthermore, I can freely decide, recommend and also execute the doctor’s appointments which I think are necessary and right. They give me regarding that free rein. That is good. We visited the orthopaedist, the neurologist, in the rehabilitation facility etc. And now she is allowed taking a cure. Some things I really pushed in the right direction and insisted on doing more in these fields. You can’t have the position like: “She has AD, and therefore she has to live with it, nothing will get better!” That’s not the way it should be. Every impulse from the environment is important. I organise visits which are important for maintaining her social contacts.

[39:00] It is very important that she is in contact with persons, e.g. ex-co-workers, she was in touch before. I feel that. Two or three hours with her old co-workers make her mind more alerted than before. In these situations she is also able to talk more. Her brain gets exercised.

[Com8] So you only use a calendar for organizing yourself.

Yes, simple things, e.g. dentist appointments, hair-cutter appointments I use for. Practically, you are responsible for such a person. There has everything to be perfect.

[40:00] Have you ever forgotten appointments and/or tasks related to her?

Yes, that also happened. And then she is very proud, that I actually also forget things) saying: “I always thought AD is not contagious.” She is gleeful but funny in these moments; she didn’t lose her humour at all and I say: “Anne, forgetting is something totally normal.” I forget a lot of things. And when I forget something, it is nothing severe for me. I am only astonished that I forgot something important.

[aQ27] “What did you actually forget?”

E.g. the welfare centre was taking care of her at her place and despite of that I appeared at her house. And I go there and she was already being taken care of.

[41:00] I came although I it was not necessary to come (because the welfare centre) was there.

[aQ28] It wasn’t planned or necessary that you came?”

Yes, it wasn’t necessary. But it is no forgetting, it is a process in my life. My process in my life has totally adapted to her process. Before planning anything here (referring to her house/family and friends), I go first to her place. Or another example, the welfare centre was in the evening there and I still went down to her place for checking if everything is all right. It is a kind of “control addiction” you have. That you can’t go to sleep without knowing about the condition of your patient.

[aQ28]
So once you went there accidently, forgetting about the welfare centre was taking care of her and another time you went to her place to make sure everything is all right?

Yes. As she easily fells, these checks in the evening are very important for me.

That is regarded to the loss of strength in her legs. When this happens she just lies somewhere in a corner. And then I think – she doesn’t know how to use the SOS call – which is there. She could reach there and push the button and then somebody would come, but she sees the device but doesn’t understand it’s meaning.

The medication I give her in my presence. Because when I go and say “Eat your yoghurt at noon and take the medication afterwards.” Which I placed next to I don’t know if she actually took them, even while the yoghurt has been eaten. “Are they for the evening?” If I leave them in the pill dispenser she doesn’t see them, if I leave them next to the meal she doesn’t know when to take them.

Anything more?

The son is not willing to get a crate of water you forgot to buy. Then you get problems (referring to her anger). This is only a small example which maybe sounds childish. But you would expect a different reaction.

I live with her. Or when event of the nature´s lovers, concerts you are taking her with her. And that is exhausting because it doesn’t go forward. And you have consistently watch out for her; is she ok, does she need to go to the toilet, does she know the way. You have to ask somebody walking with her, etc. One wants that she distraction but that really takes it out of you.
What is/was your relationship with the person you know that has/had dementia?

My name is Tania and I’m the daughter of Celia, the patient we are referring to.

What type of dementia has/had your ______?

There exist suspects that the patient (Celia) has AD, but this disease can’t be yet scientifically confirmed by only using exams. We can only be sure of the presence of the disease by observing the patient for a long period.

When was it diagnosed?

The patient has been already sick (referring to AD) many times which made us lightly suspect.

Since October 2010 until now (December 2010) she manifested more frequently imaginations and fantasies which made us believe that there really exists a strong possibility of having AD.

What were the first signs that something is/was wrong?

During the times we lived together she affirmed some things that were not true. And we had doubts about these if these were true or not. For example she defended that somebody had a certain attitude with her. And we insecurely didn’t know whether that was true or false. When those attitudes (referring to Celia) repeated we realized that’s something was wrong.

How is the stage of the disease / situation of the patient in the beginning?

In reality she is assisted by a nurse team (consisting of two nurses). I do visit her periodically.

How is the stage of the disease / situation of the patient today?

After she was being examined by the geriatrician he did change her medication. And then she presented a slightly improvement of in her condition.

What changed in the life of your ______ after diagnosed with dementia?

Our relationship became more equilibrated. Because we were on an extreme conflict before due to the things she used to say.

What changed in your life and daily routine, and the ones of people around your ______ after she/he was diagnosed with dementia?

There was more dedication; the visits were more frequent and the manifestation of affection was more intense.

Can you describe some of the everyday situations and problems you had to face while taking care of your ______.
Once upon a time I visited her. She reported me that in the previous evening, she visited a city far, far away going there by bus. And she was the companion of somebody that didn’t want to go there (to the city) and therefore she was very nervous about it. And she wanted me to explain/find why the person didn’t want to go over there.

Try to remember **delicate situations** where things went not the way they should. Maybe you can provide me some examples. What happened exactly in these situations and what could have prevented these?

As I understand not much about nursing. **In one of the Sundays I was with her, she started to say Goodbye (in terms of dying) and it was time to go and asked her to call my Dad.** At the time I didn’t give much importance but then through her expressions and voice I was noticing that she was becoming paler and I went to call my Dad. When my father arrived – he too – was convinced that it was a “Goodbye”. She became gentler, excused herself for something bad eventually happened. She called my Dad her love. She held his hands and asked to lie with her on the bed and hug her because she was going. And he did it. The nurse and I were stunned with the situation. And I asked the nurse to check the pressure (referring to blood pressure).

And the nurse noticed it was dropping. And I said to the nurse “Call your superior, do something!” And only one measure was taken, which was the lifting of the legs. And all became normal again. The next day the scene was repeated. And I already knew what to do. If I would know how to measure the pressure, I could deal with the situation by myself.

**Was the patient autonomously using any Assistive Technology** (e.g. Phone, Wheelchair, Medication scheduler, Calendar)?

Firstly - in order to improve the socializing is to report all the daily situations to her a notebook diary (traditional one) is a constant object in our daily lives. Secondly – we improved the box of medicine in order to not mix the pills and control the times (when to take them).

Have you used any kind of Assistive Technology specifically targeted at dementia?

Yes, on the weekends. In order to help the nurse who stays with her, always one member of the family stayed with her. I was in control of the medicine/pill box. And I was obligated to do the annotations (notifications of the amount and time she took the medicine).

How did you manage all the extra activities (doctors’ appointments, medication schedules, paying the bills, going shopping...) that came along with the disease of your ______?

Our main interest is her well-being and that she feels happy. We stimulate new activities in order to achieve that, like going out with the wheel-chair just to see new faces, the ocean, to visit the family, meet friends, and go to the hairdresser. All that stimulates her joy (well-being).

Have you ever **forgotten appointments** and/or tasks related to the dementia patient?

I forgot a very important factor. After a long crisis which made us practically conclude that she had AD, she asked where she was during that time. And I used to tell her the things and she didn’t remember. And I conclude that she deleted from her memory everything she disliked. She only registers the things she is interested about. Therefore, I think that the best way to help someone with AD is to stimulate the memory in a creative way, with games, reading
something and review it afterwards with questions. Take her out to a trip and then make her
to make a trip report. Taking care that she didn’t notice she was the centre of attention.
[Sto]
What is/was your relationship with the person you know that has/had dementia? (Parental
My name is Alexandra Braga. I am her (Celia’s) daughter, the last one of six children.
Celia has AD.

When was it diagnosed?
The disease was diagnosed in June of 2010 when she was getting memory failures and confused names and we observed that she wasn’t with normal sanity.

What were the first signs that something is/was wrong?
We observed that she was very confused with the names, the dates, the places and she told stories about her past with mixtures of reality and dreams.

Right, she was hospitalized for ten days and the doctor told me that she had signs of AD.

How was the stage of the disease / situation of the patient in the beginning?
She was in her bed for three months without moving. She talked very little and was very sad. When she started to talk, we noticed that she had difficulties making the phrases. Every time she talked about her past she mixed lucid times with moments of forgetting.

How is the stage of the disease / situation of the patient today?
Now she is a little better. But sometimes she still forgets things. In the last medical examination she confused the dates. She confuses the dates of Christmas, Easter, and birthdays.

What changed in the life of your ______ after diagnosed with dementia?
In the beginning she became more aggressive. And then she changed the behaviour. And now she is calm. Still, she isn’t as normal as she used to be.

What changed in your life and daily routine, and the ones of people around your ______ after she/he was diagnosed with dementia?
Well, the first thing was a recommendation by her doctor, that we always told her the truth.
My mother has two controllers (referring to the nurses), one in the morning and one in the night. She was controlled in her alimentary dose of the medicine she takes. Everything related to her was done in special terms in order to not make her feel alone and making us secure that
nothing wrong with her can happen. In the beginning she was very afraid of falling. Things were very difficult.

Can you describe some of the everyday situations and problems you had to face while taking care of your ______.

Once upon a time she forgot about me. That was one of the most difficult phases for me. She didn’t remember me. She looked at me with strangeness and distrust. Like a stranger. She became stubborn, she only wants to do what she wants and eat whenever she wants. She complains about pain that we don’t know if they are real or not. And that make things difficult, because not everything can be done in her way.

Try to remember delicate situations where things went not the way they should. Maybe you can provide me some examples. What happened exactly in these situations and what could have prevented these?

Yes, because she was very stubborn. She wanted to get up after three months on bed and she “unlearned” how to walk. When we were careless she got up and she fell. In one of those falls she broke her knee and things were even more difficult for five months more.

Is there something to prevent such happenings?

The only thing she had to do was to wait for us. And she didn’t want to wait and call for us. So she learnt how to lie with easiness. That made things difficult; it was “in desperation”.

Was the patient autonomously using any assistive Technology (e.g. Phone, Wheelchair, Medication scheduler, Calendar)?

Yes, we control the medicine by daily boxes. The nurses also have a diary notebook registering everything that happens with her. All her food was made following a menu. Everything she does and eats is annotated during the day.

Have you used any kind of Assistive Technology specifically targeted at dementia?

Yes, everything. It’s my turn to take care of her. I used the same methods as the nurses (referring to the notebook).

How did you manage all the extra activities (doctors’ appointments, medication schedules, paying the bills, going shopping…?) that came along with the disease of your ______?

Everything extra is done in the same way as normal things. We bring the nurses, the medicine boxes for making our lives easier.

Have you ever forgotten appointments and/or tasks related to the dementia patient?

This kind of disease is a very difficult one. It’s very complicated to socialize with the patient. We need better medical support, better instructions, things that facilitate us how to work with her humour and daily life.
What is/was your relationship with the person you know that has/had dementia? (I live with her (Celia). I am away only one half of a day on an each week. I am her companion.

What type of dementia has/had your _____? Her doctor said she has AD.

When was it diagnosed? She was diagnosed on September 2010, when I started to work with her.

What were the first signs that something is/was wrong? She confused people and had lapses of memory.

How is the stage of the disease / situation of the patient in the beginning? She accepted me well. She didn’t adapt very well with the other nurse that worked with her at night. But with me she adapted with ease. She had problems confusing things, e.g. she confused orders. I had all the pills controlled for her at night.

How is the stage of the disease / situation of the patient today? Now she is very different. She doesn’t have the memory lapse anymore. Sometimes she wakes up at the night and tells things about losing things. But then I call her attention and she notices that she was dreaming and she becomes normal again.

What changed in the life of your _____ after diagnosed with dementia? It changed the way of socializing with her. It was given more patience to her, affection and basically it was that.

What changed in your life and daily routine, and the ones of people around your _____ after she/he was diagnosed with dementia? For me it wasn’t a significant change because I was used to work with AD people. But when her family went to visit her I had to change my habits with her. For example not to make too many questions. We have to have more patience with her and be more attentive in what she says. Correct the true and false things; make her understand things; showing the wrong things with patience.

Can you describe some of the everyday situations and problems you had to face while taking care of your _____.
For example sometimes she doesn’t want to get up from the bed. She thinks she can’t perform the task. She complains that she is not in the condition to perform daily tasks. But then she tries out and when she manages to do the things she becomes confident and happy. She feels accomplished.

Try to remember **delicate situations** where things went not the way they should. Maybe you can provide me some examples. What happened exactly in these situations and what could have prevented these?

Once upon a time I was walking with her and suddenly she felt weak and tired and asked me to go pick up a wheelchair. And I explained to her that I couldn’t pick up the wheelchair without letting her by herself because I was afraid that she would fall. But she ordered me to do so, because she said she would be able to stay by herself. But then when I went to pick up the wheelchair, she made a backward fall. I was very worried and upset about the situation. I think, we need to be stricter and not letting her do all the things she wants to do.

Was the patient autonomously using any **Assistive Technology** (e.g. Phone, Wheelchair, Medication scheduler, Calendar)?

We use the medicine/pills separated in proper boxes. We have also the diary notebook with annotations about everything she does. She also has “exercise balls” to perform some exercise with the hands. She has word games to exercise the brain.

Have you used any kind of Assistive Technology specifically targeted at dementia?

I use all the mentioned one’s (referring to the previous answer) and some more like card games.

How did you manage all the **extra activities** (doctors’ appointments, medication schedules, paying the bills, going shopping…?) that came along with the disease of your ______?

I take her out of the bed to go for a bath and then I help her dressing nicely to go for a walk. When she wants to go to her daughter, we go by car. She walks a lot in the corridor making different things to distract herself, e.g. chatting, taking her to the beach.

Have you ever forgotten appointments and/or tasks related to the dementia patient?

I think there should be more different kinds of activities for her to avoid spending so many time in bed and participating more in things that incentive her to activate more the brain. She always has a companion not to be alone.
What is/was your relationship with the person you know that has/had dementia?

My name is Bruno Braga. I am her husband. We are married for more than 60 years. We had a normal and calm life. We have a good relationship with our children. In respect to our relationship I have nothing to complain only to thank. It’s very good.

What type of dementia has/had your _______ ?

I have to say the following: After a strong crisis she was hospitalized for two times in a general weak state. The doctor’s had tested her and perhaps she suffered from another memory related disease like PD in which she was started being treated. And after another brain exam they intended that she perhaps had AD.

When was it diagnosed?

More or less after the half of last year. (referring to June 2010) after all those crisis and exams she was submitted to. And that was the situation when we decided to take her to the geriatrist. Informing him that the previous doctor suspected that she had AD. The doctor suspended the medicine (that wasn’t necessary to his opinion) the previous doctor gave her.

What were the first signs that something is/was wrong?

Sometimes she changed from conscious to unconscious periods. She didn’t answer very well to the questions we asked her. And then the doctor asked her the birthday time, what week, year and day (he made a total of five questions) and she only answered one correct.

How was the stage of the disease / situation of the patient in the beginning?

We reached the conclusion, that we were lost the notion of her situation because she suffered from period crisis. Sometimes even with hospitalization without positive results regarding the disease. She stayed with the same treatments and without any good results. She remained unconscious and delirious sometimes. The doctors thought the situation was getting worse; changing from PD to AD disease. And then we concluded that it could be true, because in reality she was out of her mind and only said nonsense.

How is the stage of the disease / situation of the patient today?

Desperately, we tried to change from a doctor specialized in neurology to a geriatrist. Then the geriatrist suspended the medicine. And after the suspension – especially one that was a sedative – she went back to normality – little by little. And the talking was improving and she remembered the dates of things. And then we suspected that should be wrong about the doses of meds (referring to the pills/medication).

What changed in the life of your _______ after diagnosed with dementia?

She was in a state of total depression and with the medication the geriatric doctor gave her and also with a lighter diet and well elaborated she started slowly getting better. She never realized at the end that she had A. Not even when the neurologist was affirming it she never realized it. And we would avoid telling her about the disease so that that would not worsen the state of the disease.
What **changed in your life** and daily routine, and the ones of people around your ______ after she/he was diagnosed with dementia?

After the exams the doctors made that showed that she might have AD, we were all desperate because we all knew AD is a terrible and uncontrollable disease and requires a great level of care. So I was also in a very depressed state because I had realized that would be her end. The disease was getting worse by the day and I was scared because they went from the essential tremors diagnose to A. I thought she was in an irreversible state. And as I was dead worried we started sleeping in separate rooms so that we would sleep more peaceful environment, but I was always worried at all times she would have another crisis, this and that would hurt, and these symptoms would worry us all…. So we were in a very exasperating situation but with the new doctor and the change in medicines we started realizing she was getting better.

Can you describe some of the **everyday situations and problems** you had to face while taking care of your ______.

Our psychological state was deeply affected however we tried to accept the situation and work around it in the best way possible and continued using the medication that the doctor had given her. But every time she would say some nonsense we tried to agree with her still. She was answering unconsciously so we would just agree with her. And we would never let her feel that we knew the situation she was going through.

Try to remember **delicate situations** where things went not the way they should. Maybe you can provide me some examples. What happened exactly in these situations and what could have prevented these?

To the extent that we understood that the new diet was favouring her recovery each time she would go from a conscious to an unconscious state we would try to make her feel that we understood her problem and would answered accordingly to her question even if that was an unreasonable one... and of course our relationship with her become obviously very difficult to us... also because we were always predicting the worse and we only restarted gaining some hope when she started recovering.

Was the patient autonomously using any **Assistive Technology** (e.g. Phone, Wheelchair, Medication scheduler, Calendar)?

Yes. After the appointment with the geriatrics doctor, we hired a specialized nurse and she organized a treatment scheme in which she included all the daily medicine placed in each of these holes “Monday, Tuesday…. Sunday”. Every week the medicine is repeated according to the doctors’ prescription. Some are taken daily and other every other day. Besides that she was put on a diet based on vegetables, vitamins and at the end more substantial. Slowly she started showing sign of being recovering. Earlier she was not even able to walk but present day she is again able to, if with help, walk almost almost as before… she only says she is very tired when her muscles… as she is not making many exercises and her locomotion system is impaired, she has difficulties moving and feel more tired than usual. But she is getting better by the day… This notebook here does the following: shows the schedules, for e.g. at 7:00 she takes XX and XX at 9:00; she takes XX and XX and XX at 14:00; she takes XX and XX and XX and at 20:00; she takes XX and XX before she goes to sleep.

Have you used any kind of Assistive Technology specifically targeted at dementia?

For a long time I, myself, was taking care of the medication. I was doing and separating the medicines according to the doctors’ prescription. Then sometimes when her night caregiver was sleeping with her, she had insomnia, she has lots of insomnia, she still has insomnia, and
she would take a medicine named XX. We suppose that maybe she took a very big dose of XX, twice the necessary dose, and that would keep her in a very unstable even drugged state. When this medicine was suspended, especially this one, she started getting better and those moments of unconsciousness started vanishing. [Q13]

How did you manage all the extra activities (doctors’ appointments, medication schedules, paying the bills, going shopping…) that came along with the disease of your _____? For some years… she has been a sick person. I plan for the morning all the things I need to do outside. All the appointments, getting exams from the lab… I always know what was prescribed to her. In the afternoon, not to be affected by her behaviour; to maintain my health state, I’m well in terms of health, but not to get worse, in the afternoon, I practice bocce. I sleep until 15 and then I play bocce until 18. During that time the nurses stay with her… My life has that routine… in the morning I take care of the problems with the bank, the labs but I try to give her a complete support so that she misses nothing. [aQ1]

And when it is necessary to take her somewhere? Well, I drive myself the car to that place. I’ve been driving her always. There was a period she had two pulmonary oedemas at 2 o’clock in the morning, but more than 4 years ago and we took her to the hospital and she was treated and the situation was overcome. [Q14]

Have you ever forgotten appointments and/or tasks related to the dementia patient? Of course, after Celia started getting seriously ill and her situation got worse my worries increased and I can say that I’m in a permanent watch (my mote from surveillance) state even if I’m sleeping on a separate room I always worry that someone calls me to tell me she is not doing well or something like that. Lately it is not like that it hasn’t been happening and she has been sleeping reasonably well. Our personal relationship, at least for myself, I hope nothing but that the situation doesn’t get worse and that I accept her current state as it is now, and if possible improving step by step her situation either if it is essential tremors or Parkinson which is not likely or even worse A… and this way we try to manage the situation and maintain the doctors we have and I believe that now we’ve found the right path with the geriatrics doctor… nowadays, as a man, I feel handicap from the simple pleasures of life: being able to go out, to travel, go somewhere with her, etc… but I love my wife so much that with around 60 years of marriage I think I have the duty to accept every situation that comes which is related to her either as a result from disease or anything else.
What is/was your relationship with the person you know that has/had dementia?
It’s my mother-in-law and we have a very close relationship.

What type of dementia has/had your ________?

I would have to check it up, but she was in Klingenmünster in the hospital and there they diagnosed a double AD disease but I don’t remember the exact formulation anymore.

If it possible to deliver that later, I can give it to you because Helmut has the documents with him in his folder. So yes – as I said – it is a double form of AD.

When was it diagnosed?
I can’t tell you exactly. At the age of 73 – now she is 81 – with 73 she recognized it herself and also her relatives and her siblings.

Then I went to the doctor who said because he doesn’t know her he can’t assess it. And then it took roughly three to four years wherein she was kind of latent feeling good and bad and we recognized that something is wrong and one can say three to four years later it was obvious. And then it was clear that she has AD due to her constant forgetfulness and restlessness. And then I went to the doctor and he confirmed it.

What were the first signs that something is/was wrong?
I have to think to delineate it correctly.

Her restlessness and dramatic anxiety state – she not exclusively has AD due to the occurrence of an aging-related depression, she hided everything, forgot everything, things claimed, people recognized who visited her. Or there were people at her place which already died ages ago. But the most severe things at beginning were always losing the keys and hiding everything. Hiding the food, forgetting about the time you are supposed to eat. But the restlessness and paranoia were the worst. And when she claimed the first time she did fell and wasn’t able to get on her feet and furthermore claimed she were unconscious. Then she was hospitalized because they thought she had a stroke.

This happened three to four years later (referring to the time the AD was been confirmed). From that moment on she needed help. While being in the hospital it was diagnosed she had an eye stroke which could be associated with the disease.

How is the stage of the disease / situation of the patient today?
As today it is that far that she is unable to speak – while being affected from that disease you are regressing to the state of a baby. She can’t communicate with others; she is bedridden, unable to turn herself, not even able to remove the bedcover herself. She is being feed and needs a catheter, indeed she is vegetating.

By how she has caring level 3. She can’t sit independently – nothing works at all - the whole locomotors system is being affected. Just the same as being a baby where you first lie on the ground, then sit and after finally start walking, but only backwards. It is burdensome.
[Q6]
What changed in the life of your ______ after diagnosed with dementia?

[06:00]
There is no exact moment where you have been informed. You know, it is so stealthy. And somehow it evolved. There is just no exact point in time where you can define: „Now she has it“ (referring to AD).” It was a stealthy process and as time progressed you understand that this is the way it happens. I always was at the doctor and she always received meds – even medications which were still in the test stage – which increased the amount of brain cells significantly but it had a disadvantage: Sometimes the cells are depleted to such an amount, that the plummet collapse is abrupt. But we were informed about that.

[07:00]
[aQ1]
So what actually changed e.g.?

She couldn’t run her household anymore; she was a very tough woman. She didn’t know anymore when to eat something, when to drink, couldn’t go shopping herself, didn’t make her bed, hid everything. We only were searching all day long. She had delusions of persecution; we found her silverware underneath her bed. Her false teeth were hid; she always had this paranoia. All the people were there getting her pillows; everything was hid. Remains of food in the cabinets, it was extreme.

[08:00]
That was three to four years ago but personally the most severe and squall during these days as well as today is that the affected people are noticing that have the disease, that something is wrong with them. That fear they have, it is a tremendous fear and panic, and for me always the central point was calming them down. E.g. this was a sentence she said a lot of times:” Birgit (referring her), I live in another world.” And I always responded:” And how is this world Anna? Is this world sinister?” And then she replied:” No, it is not sinister.” And then I said:” Then you don’t need to be upset. Everything is ok then. You don’t need to be afraid, everything is fine.” Or she simply claimed wrong things while others always insulted her for that. It was terrible.

[09:00]
She couldn’t wash her silverware, she couldn’t do the housework, she couldn’t do the laundry, she neglected herself.

[aQ2]
Was there a husband she was living with?

The father-in-law dyed 30 years ago. So she was living in her own house.

[aQ3]
And then mentioned signs started to show, it was impossible for her to live there anymore?”

It was still possible – luckily - due to my brother-in-law who built his house next to hers. His children then moved into the grandma’s house because there was a lot of space available. But that was connected to certain family circumstances, he had a new partner which brought her children in the house, so the space in the grandma’s house was used by the own grandchildren. Actually that was good because she was not alone.

[10:00]
In Klaus’s (referring to the husband of the interviewee) family a big kinship is existent and there are in a lot of aunts and so on. There were always people surrounding her.

[Q7]
What changed in your life and daily routine, and the ones of people around your ______ after she/he was diagnosed with dementia?
Although a lot of people came it was difficult, because everybody handles the disease different. And that is the big problem.

During that, there was a very important broadcast in the TV I saw wherein a clinic for dementia patients was shown allowing them to be and behave freely as they are. If they did something which wasn’t right or hid something somewhere, it was said: “That is ok, you can do that.”

Regarding our grandma the problem was that there were a lot of people surrounding her and insulted her. And then she went as high as a rocket (referring to a German proverb meaning the state of being quickly very upset), so there was always a high stress potential. And I always campaigned myself saying: “Everything is ok what you are doing.” When somebody was insulting her similar to: “How is it looking today at your place here?!?” Indeed, there was pure chaos. I always said it is ok: “You kept your household appropriate so many years and now you are not able to do it as you did. That is all right.”

For me it was always most important calming her down up until today by saying: “Everything you are doing is all right. There is nothing wrong with you.” And regarding that she had terrible angry outbursts because she was being corrected. Or when she was telling a story like: “Somebody was standing outside and came and tried to sell her something or this or that person was here.” She was always being corrected. I only listened to it because the people (referring to AD affected people) are experiencing this. They tell about what they are actually experiencing. So I don’t need to correct them or say: “That is wrong.” I only listened to it and replied: “Ah, ok, this is what you experienced now.” So never correct the people.

Did you work during that time?
I am in employment, yes. I don’t live at grandma’s place but we drove there very often.

And as I said, there were always people around her (referring to: taking care of her). And then we slowly started with the welfare center! That they stop over at her place. At the beginning I went for shopping and put the groceries in the fridge because she didn’t want shopping herself anymore. After a certain time, I noticed that she doesn’t get anything out of the fridge at all and thought: “Doesn’t she eat at all?” She also lost a lot of weight. Then we started to order meals on wheels for lunch and somebody joined her for checking up if she is actually eating. During evening I came and brought the dinner. So I didn’t shop for dinner and put it in the fridge anymore. According to that, the steps got worse again and again. I’d cut the food in little pieces similar as with children, sat next saying: “Now you drink again.” “Now eat your bread.” And so on. I always gave her instructions but in a calm sound: “Look, now you can take one more.” Always offering:

and not forcing or dictating it to her. Just giving help and staying with her, washing the clothes and so on. Everything needs to be taken care of regarding the household.

It was being handled inside the family and you also contributed yourself and then at a certain moment in time you took the help of the mobile nursing service?
Yes, because it didn’t work anymore. At beginning they came three times a day for washing her. She refused being washed form her own daughter-in-law (referring to her).
And I want to add, washing, cleaning the windows, there she was very peculiar. That wasn't being taken care of. And the most important this was always searching stuff. False teeth; that were a catastrophe: Every day the false teeth were gone. Or the keys were gone. Then we made a necklace for her neck so she doesn't misplace it anymore. And then everywhere stashing the food and facing the danger of pinworms. Regardless where: At impossible locations. Shoes away, everything was hid. That was the most extreme in the beginning.

(17:00)

Did you equally share the caretaking within the family and kinship?

No, my husband and I did the most. As it became too much for us (referring to the husband and her) the same as the other were overstrained, I took the help of the welfare center additionally, because she also became incontinent. That was also an enormous problem which is associated with that disease. And so on and so forth. Washing the body is connected with a lot of exertion of force, e.g. when she is sitting in the bath tub, so we took the help of the welfare center, because it was always smelly and so on. Not only taking care of the housework she didn't do anymore, also taking care of her personal hygiene either.

[18:00]

Can you describe some of the everyday situations and problems you had to face while taking care of your ______?

It was difficult for me because the people always say things, e.g. telling other that she didn't get any food for days towards the relatives. Saying that: “She called me and said that only yesterday, I brought food to her;” For me that was an enormous psychological strain: Because I was exerting and doing so much while knowing on one side it's not her fault but on the other side she was badmouthing about me, e.g. saying: “She doesn't get food from me, she gets no fresh clothes, and so on.

[19:00]

That was a very strong burden for me. And – as I said – the environment; everybody was meddling but nobody wanted to do something. And – as mentioned – her paranoia as a chief point where calming was the most important task:” Now, just stay calm. Everything is OK. Sit down.” That was my biggest work, steadying her.

[Com1]

Mainly the psychological burden besides of the examples you just gave me.

Yes and – as I said – it was a complete chaos and the people – it is a big family as I mentioned – accused e.g.: “How does it look here today?” I always said: “Leave her free. Today it simply is not as tidy as usually.”

[20:00]

I tidied up when I came, but as soon as I was away the searching started. Like maniacs, the whole day they are only searching and hiding. That time was most extreme.

[IQ6]

Try to remember delicate situations where things went not the way they should. Maybe you can provide me some examples. What happened exactly in these situations and what could have prevented these?

I can answer to this question; we are still talking about that these days. She never had situations wherein she’d get up to something dangerous. She never left a tap open, she never turn on the stove so there was no need for us being afraid. We don’t know about any single case where she scooted away.

[21:00]
But she told us about one or two situations at night – we don’t know whether if that is true or not. She said it was quite a situation – wherein she went out wearing her nightgown and a man who was entering the village by car asked her where she was heading to and finally guided her back to her house.

As today we can’t tell; that one did not notify us, she told that herself. But we don’t know if it is true. But – as time went by – she often stood next to the entrance door when she was confused and opened the door screaming in the yard “Help!” Because she didn’t know where she was. That was an even worse stage. And then the neighbors called and so on and forth.

[22:00]
Then one drove there and asked what is going on. Then at one time she didn’t find the toilet in her house anymore. Then she did her “business” (German proverb referring to the toilet break) at all possible places. That was also not nice.

Regarding serious, very dangerous things, you remember something?

No, she didn’t do anything like that. We often talk about that she never got up on something during in this time. Something dangerous, not; or I didn’t notice anything.

Is / Was the patient autonomously using any Assistive Technology (e.g. Phone, Wheelchair, Medication scheduler, Calendar)?

[23:00]
Another important point: I have on Thursdays my day off where I don’t work and there I wrote it down regarding the phone.

[24:00]
At the beginning she always called. And I made a tally sheet. It was on a Thursday; 25 calls, every time the same. Because apparently she saved our number; and then she called here always and told me the same about what she just did or what she would like to have. Two minutes later the next call. Exactly the same; and I said: “Ok.” And that was on a single day. I actually wrote it down: 25 times. And that with the phone was certainly a phase of one year until that was also done; until she couldn’t phone anymore. But real telephone terror, wherein she constantly called regarding the same reason.

[25:00]
Did she take any medication?

Yes, yes. Right away she received that medicament which was -being said- for increasing the cells.

Did you monitor it or used any kind of pill dispenser or did she take it herself?

We gave it to her. You couldn’t rely on that (referring to giving her the responsibility for taking the medication). It would have been too dangerous. Eventually she would have taken all in at once. We monitored that. The tablets when the stored on top of an – for her unreachable – cupboard. And we gave the medication to her daily on a regular schedule. Later then, the welfare center took care of that.

Did she watch TV on her own during that time (referring to the early stage)?

Good that you mention it. I would have forgotten telling you about. A certain time she watched TV but stopped relatively fast; because she always claimed –

and we promoted it to calm her down, that she sits and watches TV – that it wasn’t interesting anymore as these were things from a long time ago. Very early, even earlier than watching the TV, she wasn’t interested anymore in reading the newspaper which was always very important
regarding the obituaries and so on. It was in a very early stage where this interest was being abandoned. No gazette – as it is usual in our environment – she didn’t do it. And TV – we would be pleased if she would - or she usually liked going into the church to the service; “No, stop that nonsense, turn it off.” She couldn’t handle it herself anymore (referring to the TV).

No interest, zero. It went away relatively fast.

[27:00]

The only thing we did – and I thought that was proper - we have a cassette recorder – and she was singing in the local women’s choir and they recorded a tape some time ago. For calming her down – she liked to sing, even until last year in her bed – I sometimes turned on the cassette recorder so she was able to sing along songs. Because that is something which is not getting lost; or children’s songs which she’d sing and was feeling well in that moment. And she recognized all of the lyrics; she knew everything; but TV and newspaper in a very early stage.

[28:00]

Which is also very important for these people – I don’t know if that is important for you – is that everything needs to be on its place, always. You can’t bring new things in a house, e.g. three, four years ago we recognized – also connected to the disease – that she started having problems with walking. The dementia patients are kind of groping; such very little steps they do. She had her sleeping room upstairs and I’d put her sick bed simply in the living room so the she didn’t need to sleep upstairs. We rearranged that all. It took certainly half a year; she always thought she is somewhere unfamiliar. They can’t match things at all. If something is being relocated they can’t orientate themselves. Always the same rhythm in the everyday life is what I tried to establish as long as possible.

[29:00]

And that everything stays on the same place because if you relocate anything they become strongly confused; it takes weeks and months until they are able to orient themselves.

[Q11]

Have you used any kind of Assistive Technology specifically targeted at dementia?

[30:00]

I have to say that most of the things I took care of because I was always responsible – since I was being married – for driving her to the doctor. And this was mainly our responsibility. It there give away too much responsibility to others, you are getting confused. Most things we did. The others were mainly there for visiting her. But the all the things associated with caring, the organization, the therapy; that was all taken care of by my husband and me. Or the arrangements with the welfare center or everything related with the doctors; as I said, the others only stepped back or simply visited her. Because there are a lot of people in her age; she had two sisters during that time which looked after her and were there for talking but everything around my husband and me took care of.

[31:00]

And as long as Nadine or Sandra (referring to her daughter’s) came sometime and helped a lot and visited her but everything else (referring to her husband and her) we mainly did.

[Q12]

How did you manage all the extra activities (doctors’ appointments, medication schedules, paying the bills, going shopping…?) that came along with the disease of your _____?

My husband has the general power. He did take care of things.

[aQ11]

Was there a necessity for organizing yourself, e.g. the usage of a calendar?

Exactly, we separated it. My husband took care of the financial responsibilities and the other things I wrote down and made the calls.

[32:00]
I always – in the certain quartile of the year when you paid these ten euros I caused to give me the doctor’s assignment automatically. So she always had to be introduced to the neurologist for getting the medication. You couldn’t just call asking for the medication. I only received them for the time of 3 months. In that period you had to go there and the doctor checked and did an electroencephalogram every six months and said:” Ok, I prescribe the medication again.” You couldn’t call and say:” They are empty, please sent the prescription or I come and get the medication.” That was not possible. Then she has problems with the eyes, ophthalmologist; gynecologist and all these things I always drove her there with the car.

300 [33:00]
301 And that became more and more difficult lately because her walking became more and more poor.
302 [34:00]
303 So you did all that yourself and just organized things in your head?
304 Exactly, I have my own plan and calendar and made notes. As time went by I got used to it more and more. I planned weeks ahead my things because Thursdays, e.g. is my day off so on Thursdays, I was mainly with grandma on tour.
307 [35:00]
308 Have you ever forgotten appointments and/or tasks related to the dementia patient?
309 To be fully honest I can tell you that I never forgot anything. Good, as time went by we had the help of the welfare center. I always have my paper notes and – as I said – I know what I need to buy. For example tonight, I go to her place – she gets now in the evenings a warm soup which I spoon her. The medication I don’t take care of but I look into the cupboards as I shop for everything. You have to imagine: She gets breakfast, in the morning she gets her cake. Then I have to look that there is some instant coffee there. The welfare center takes care of that.
316 [36:00]
317 That her milk is there; then she wants jam. During the day, she gets tea. Then she gets juices which are diluted with water; that these are there. At noon she gets a pudding. Than I have to check that fruit is there. I was shopping today; then I need to have detergent there; we put the clothes in the washing machine; that softener is there. That everything is there, that the whole process works, the whole apparatus. Then I check has the laundry been made. Depending on that I hang up or down the clothes, and then I put them in the wardrobe. Then all the toiletries have to be there. Shampoo; conditioner; diapers I gave away to the welfare center. They organize that. Then ointment, then wet wipes – I know that sounds disgusting but that’s reality.
325 [37:00]
327 Than what else do I do...? I am busy. That works. And if I actually don’t notice something I have asked the welfare center to put a notice there saying:” This and that is running low. But then I have a couple of days for run so I don’t need to go shopping the same day. And they, e.g. – my husband gives the welfare center usually a certain budget, I think 200 Euros – they go shopping then; they also can carry the insurance card and can go to the pharmacies if they need something. Across the street is the family doctor; there they also automatically ask for prescriptions.
333 [38:00]
335 She has a catheter. Every four to six weeks a doctor has to come and has to clean that. I also gave that away; you can’t do that yourself. They from the welfare center do that. Yes – it’s a lot of organization. I have the support – as I said – that I get a note or are being notified but that I forgot a doctor’s appointment e.g. no. I am a well-organized person; I write down a lot, I have my lists and my things. That works pretty well.
340 [Q13]
So you are self-organizing your responsibilities to an extent you never forgot anything?
Eventually I forgot a trivial thing but I am now not aware of forgetting something.

Honesty, indeed, once I was claiming from the relatives – she needed diapers quite early - that
I didn’t empty the diaper bin:” Three days the bin hasn’t been emptied (High tone in voice
saying this).” Since ever the welfare center didn’t do that and I had to do this. And I forgot that
once.

I would like to add something, maybe you didn’t notice it. What always was important for me
is that you offer these people in moments they actually are paranoid – they don’t know where
they are; they have in fact very confused states – something, if these are only children’s songs
or something like that. Maybe that sounds idiotic but you can’t image how calming that can
be. Giving the feeling of being safe and being home; that is very important; calming the
people.

But that was for me very, very important; that the people find themselves again. I was visiting
a presentation – when dementia affected people are being relocated in a care center – that all
is new for them. The referent (a doctor) was saying:” You have to imagine it the following:
“When they are moving to the care center it´s similar taking a kid in a foreign country, placing
it on an tree and that kid’s starts panicking because it’s not used to the environment and
doesn’t understand the language and doesn’t know where to go. That’s what happens for the-
se people.”” You can’t estimate the dementia patients being on the same level. There
situations of high lucidity. That happened rarely; and then always the states of confusion. And
always calming them down.

It is a huge burden. For us, it was a very big burden. Now it is easier. It sounds terrible. She is
now in a stage wherein it is more comfortable for us. She can’t anymore... you are feeling -
indeed - a certain pressure regarding that she gets up on something or that she runs away. She
never did it.

And then, a year ago, she actually fell and broke her hip and from that moment on she didn’t
learn walking again and everything became worse. But that this thing works every day, I am
under pressure. As I said – this morning I was shopping. Later at five, she gets meal on wheels.
The soup she can’t eat completely, so she gets it microwaved for dinner. And later the welfare
center comes – they come by six times a day – and wash her and so on and forth. But that is
certainly... it needs to work. You never should forget. We can’t go into holidays for more than
eight days in a row;

and even more, for me it’s the mother-in-law; for my husband it’s his mother. And he is
attached very close to his mother. And that was a very “tough” woman – as these country-
women were in the past – being able to cook and bake very proper and so on... being clean.
And seeing her vegetating like that, not being able to move or speak – that is a very big bur-
den. And for her it was always an important topic; she never wanted to go in a care center.
I always said: “I try to maintain and that as long as possible.” I can’t promise that to one hundred percent. So far it works. But it is going to continue we don’t know. I wish that she doesn’t need to go there. No idea, how it will continue.

There is always a pressure: I have to work. And if I don’t work; we were skiing during new years and I need to plan everything, e.g. at work I have my paper sheet with me for days in front of so I don’t forget anything and are able to time everything. Ok - we tell them (referring to the welfare center) and they have money is something would miss, they could buy it – but it is a huge apparatus which always is turning in my head. You have to keep up continuously that it works as it works right now.
What is / was your relationship with the person you know that has/had dementia?

It’s my mother.

What type of dementia has/had your ______?

It was always being said: AD referring to the doctor.

When was it diagnosed?

The first time she was at the doctor six years ago. That means she was 75 years old. There we recognized that the memory is declining. She also repeated in a relatively short time a lot. We weren’t used to that. Then we went directly to “Kandel” (referring to the name of a village next to the hometown of the patient) and they directly said it is a starting dementia. And then she was being examined regularly, she was getting Aricept (referring to a medicament) and then it was being said: “in 20 percent of cases it can help.” One thought at the beginning it goes along a bit better.

but that didn’t last long and one felt that it gets even worse.

What were the first signs that something is/was wrong?

She noticed herself that something is wrong with her. As it was progressed she said: “I am living now in my own world.”

How is the stage of the disease / situation of the patient today?

As today she is bedridden. She is lying in the bed not picking up anything. Can’t actually speak.

Yesterday evening she tried to say something to me but she doesn’t make it.

But she seems pleased. And for me the calming thing is to know that she doesn’t know about her situation and is only living in the here and now, not living in the future, not living in the past. She is living in the present and that’s it.

“So she can’t remember yesterday...?"

No, no. That is over. She can’t talk. It’s over, AI that maybe has been accelerated due to a hip fracture. That happened one and a half years ago, no two years ago at the end of May, 2009. Then after that, it started with the confinement in bed. And then there has the will been lost.

What changed in the life of your____ after diagnosed with dementia?

For her it was severe that she couldn’t help anymore. She was always with my brother in his agriculture. There she always helped. He cultivates that cabbage and that was always during winter the work needed to be done. And that was simply not doable anymore. Although one tried to; it didn’t work anymore. At that point she noticed herself that nothing works anymore. That was what strained here. She can’t work anymore. That was her problem. She always worked in earlier days. It was her everything and not being able to work anymore was like: “Oh my god, working, working.” That was the most severe thing for her. And then I had to say that in fact it doesn’t work anymore because the cabbage needs to be harvested and handled in a proper way.
[05:00]
And that was not possible anymore. And what she actually did – that was very weird – some-
day she hid everything, the usual things. And one of my nephews who lived with her was al-
ways being suspected of stealing from her. Then it started and she said he has to go into ther-
apy, he is taking everything. Then at a certain moment we hoaxed her that he is in therapy for
stopping the continuous suspicion of the kid. Then she always replied: “It became better.” And
we responded: “Yes, it became better.” “Why couldn’t she work anymore?” She couldn’t do
the job. Cleaning the cottage heads. It didn’t work anymore. She was not able to clean the
cottage heads to a level you could resell them. And that stage was also sometime passed. That
was – in fact – her work she did. And that was not possible anymore.

[Q2]
“Caused by motor issues?”

Exactly from the motor. She didn’t recognize where to cut off a certain part of a cabbage head
or differentiae if a cabbage was proper or not.

(06:00)
She couldn’t do it anymore; They usually cleaned the cabbage during winter and that she
couldn’t do anymore.

[Q6]
What changed in your life and daily routine, and the ones of people around your _____ after
she/he was diagnosed with dementia?

Well ok, we started caring of the mum on a substantial higher amount. As today, this is still the
case. Well ok, since she is an invalid we had to take care around all these things like subsidizes
regarding the level of care, the mobile nursing service and all that stuff. And after that – thank
god – we had this general health care proxy. Due to that, all that bureaucracy and paperwork
and so on and forth I could take care of. Thanks god I have to say. If not, we would have im-
posed a legal guardian which we wouldn’t want eventually. And then we significantly went
more outside.

[07:00]
As today, the situation is that we prepare every second day the dinner for her. Because some
things she always denied on: First, she never wanted to move into a care center. That was the
first thing, she preferred to stay home. And the second thing is that we reached an agreement
with my brother and his children bringing one day the dinner and the other day Birgit and me
and Laura – if she is at home – doing it. I wanted it like that, that always somebody of the
family takes care of that. The mobile nursing service could have also done that.

[aQ7]
“Would you say that you neglect your job or your family due to that?”

Well Ok, no. Due to that I live in Offenbach (hometown of the patient as well as the family) it is
not a big affair to spent 2 hours during the week for that. I can’t say that I neglected something
else for that.

[aQ3]
“Could you arrange that?”

Yes, yes. It was problem-free I have to say.

[08:00]
Can you describe some of the everyday situations and problems you had to face while taking
care of your _____?

These are such things like – it is crazy and hard to understand that somebody who is so ill is
finding such hideouts. Once she hid the false teeth inside the lavatory cistern. So that is crazy.
And she suspected my nephew doing that. As I said, the false teeth she hid due to fear of being
stolen from my nephew. There were other things. Once she said she was gone during the night
and somebody brought her back. But we never found a person. And besides of that we could 
rely on that she’s not scooting away during then night.

You could leave her alone insofar that she was sleeping alone in her bedroom. Anterior my 
nephew is living with her. What also changed; I have to add that; did completely forget about:

In former times she was sleeping on the second floor and she is sleeping on the first floor having 
effectively her room there and the kitchen. We did that already a couple of times in the 
past. So we moved within the house; I wanted to add.

“So her psychological problems, her paranoia and fear of being stolen as well as hiding behav-
ior were the main changes?”

Exactly, yes. She was always being suspicious. She also became a little aggressive – also against 
me. Against me she was little aggressive; against me brother she was more aggressive. He was 
a different type compared to me. But towards me, she also became aggressive sometimes. She 
also scolded me, for example. What she also did; that was strange –

telling stories from a very long time ago: She was telling me a couple of times about her father 
during the war who wrote an essay about the Wehrmacht and was complaining about the she 
– as a girl – had to write this. So her father wrote it. Such things she started to talk about. As 
they’d play tricks and so on. Talking a lot more about the past weirdly; nothing worked. You 
hear that more often; the “old” memory works indeed. And she was talking about that; she 
was – in fact – very fluent about these old topics, how it was during these times. It was in fact 
very interesting I have to say.

Try to remember delicate situations where things went not the way they should. Maybe you 
can provide me some examples. What happened exactly in these situations and what could 
have prevented these?

There was nothing, bizarrely, nothing. Regarding that aspect bizarrely nothing. Somehow she 
stopped; she stopped cooking. In former times she liked cooking and baking. She didn’t do that 
anymore, bizarrely. In this regard I never had any concerns that something happens. The only 
thing which happened was – as I said – that hip fracture when she fell. But I can’t define what 
happened. I only know; you can’t even imagine: Sunday, we always brought her for eating to 
our place. Once – that problem with the hip fracture was already there but the doctor didn’t 
diagnose that – we even dragged her to us. That happened with pain, but somehow it worked.

Is / Was the patient autonomously using any Assistive Technology (e.g. Phone, Wheelchair, 
Medication scheduler, Calendar)?

Phoning was still possible at the beginning. At beginning when it started, she always called us. 
She knew our number. And she was able to make the call. Sometimes she also called during 
the night. She was able doing that; calling in the night. What she was not able doing anymore 
was watching TV. When it started she didn’t watch any TV; nothing. She used to sing. You not-
tice that e.g. on Christmas where we playback a Christmas cassette besides of some folk music 
too. You feel that she listens to that and even tries sometimes to sing along.

But as I said, she would have liked doing that but is not able anymore. But interest in reading 
the newspaper; that was over. She stopped early. And I would say that earlier she liked watch-
ing TV but suddenly she reduced that;
[AQ5] Why do you think she'd stop watching TV?

Nothing was interesting for her anymore I would say. Simply no interest; I was actually surprised. I thought it would distract her – but no – it totally not interested her, honestly. Very honestly.

[Q10] Have you used any kind of Assistive Technology specifically targeted at dementia?

[14:00]

We gave them to her. We had a box – as I said – and we took care of this so that she took her medication.

[aQ6]

Did you buy anything when it started, e.g. a calendar?

No...well the appointments with Kandel we registered for us but not for her. Always when the appointments were, we knew we have to get there early and she needs to be dressed and ready and so on and forth. Besides of that we have the advantage that right across the street is the family doctor residing who simply came over sometimes. Just across the street. If something was up we called him and he came over. I also have to say that the mobile nursing service is taking good care of the medication; they look after the prescriptions and getting the medications as well and so on. Earlier we did that. The only thing we did was taking such a box where the days and weekdays are written onto and what she gets. That was actually the only thing regarding that aspect.

[Q11]

How did you manage all the extra activities (doctors’ appointments, medication schedules, paying the bills, going shopping...) that came along with the disease of your...?

That goes as simple as this: The nursing service is bringing her the breakfast and the lunch. For breakfast she gets cake and they simply write a letter if something is missing. Although we check ourselves if something is missing, e.g. the water which you can actually see; but if something and we don’t notice they write a note. Yesterday e.g., there was a note saying: “Please shop cake.” That is the way it works; very simple. They make an awesome job in my opinion.

[16:00]

Have you ever forgotten appointments and/or tasks related to the dementia patient?

Regarding the medication essentially not. Once we squandered with the day because Nadine broke her toe. So we forgot to drive to mum and give her dinner.

And the second we forgot which was indeed a trifle. There was a bank transfer from Herxheim – they bring the food – where I forgot to pay the invoice. So I received a reminder but besides of that there was nothing. I can’t remember now.

[17:00]

[Com1]

“So we are done.”

(Talks freely now...) It is yet a bizarre disease. Understanding that; one can’t figure it out. That the memory is decreasing; that is even ok but that we forget everything and not noticing anything and only live in the here and now, that is impossible to figure out. And that the language doesn’t work anymore; that decreased in the last time a lot and went down rigorously and now you don’t understand anything. Yesterday I noticed she wants to say something. At the moment she has sore points and apparently she is in pain but she is unable to say it. It is like that. Honestly, one can say every day is one day to much because that is no life. She is lying in
the bed, the legs are bent doesn’t move; we can place her inside there in the morning and tonight we see she didn’t move one centimeter.

It hurts seeing that; emaciated. You can’t sit her in the wheelchair; nothing. Now she is getting in place - they have to be two – when they care here and cleaned here. But it is... it is... crazy.

What you also think; it is being said that more and more are getting this. Then you start thinking when you are being affected too.

Every evening hurts when I have to enter. But it’s the mother. That’s something different. Even that was a stupid situation but yesterday apparently she had stool as I entered. Normally I don’t care if something smells but when I enter there I have to throw up. Even half an hour after, I feel sick. I don’t understand why, but it is like that. It’s only with the mother like that.

Yesterday evening, I entered; I smelled it and I could have thrown up. I always say she is the poorest woman from town.
### 12.1.3 Interview coding

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<th>Caregiver-side [CH; Emo; For; ATP]</th>
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<td>S2_3 25-26 ESS</td>
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**Table 12.1:** Patient-side and caregiver-side interview analysis
<table>
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<th>ATP; ATC</th>
<th>No</th>
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<tr>
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<td>ATP</td>
<td>TV - passive</td>
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<tr>
<td>S2_47</td>
<td>169-172</td>
<td>ATP; ESS</td>
<td>TV - passive</td>
</tr>
<tr>
<td>S2_48</td>
<td>173-177</td>
<td>ATP; ESS</td>
<td>TV - passive</td>
</tr>
<tr>
<td>S2_49</td>
<td>182-183</td>
<td>ATP</td>
<td>Phone - active</td>
</tr>
<tr>
<td>S2_50</td>
<td>183-185</td>
<td>ATP</td>
<td>Phone - active</td>
</tr>
<tr>
<td>S2_51</td>
<td>187-191</td>
<td>ATP; ESS</td>
<td>Computer - active with support</td>
</tr>
<tr>
<td>S3_16</td>
<td>118-128</td>
<td>ESS; ATP</td>
<td>Kitchen - active</td>
</tr>
<tr>
<td>S3_31</td>
<td>218-224</td>
<td>ATP; Oth</td>
<td>Phone - active</td>
</tr>
<tr>
<td>S3_37</td>
<td>246-247</td>
<td>ESS; Oth; ATP</td>
<td>Phone - active</td>
</tr>
<tr>
<td>S3_38</td>
<td>248-252</td>
<td>ATP; Oth</td>
<td>TV - active</td>
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<td>S3_60</td>
<td>395-396</td>
<td>ATP</td>
<td>TV - passive</td>
</tr>
<tr>
<td>S3_61</td>
<td>402-413</td>
<td>ATP; Oth; ESS</td>
<td>TV - active</td>
</tr>
<tr>
<td>S3_62</td>
<td>415-419</td>
<td>ATP; ATC</td>
<td>TV - active</td>
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<td>S3_76</td>
<td>488-494</td>
<td>MSS; Emo; ATP</td>
<td>Emergency call - active</td>
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<td>S6_9</td>
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<td>ATC; ATP</td>
<td>Cognitive and motor games - active</td>
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<td>210-222</td>
<td>Ch; ATP; ESS; Emo</td>
<td>Phone - active</td>
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<td>S8_34</td>
<td>236-241</td>
<td>ATP; ESS</td>
<td>TV - passive</td>
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<td>S8_36</td>
<td>244-247</td>
<td>ATP; ESS;</td>
<td>TV - passive</td>
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<td>S8_37</td>
<td>249-254</td>
<td>ATP; Oth; Music</td>
<td>Music - passive and active</td>
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<td>138-140</td>
<td>ATP</td>
<td>Phone - active</td>
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<td>140-141</td>
<td>ATP</td>
<td>TV - passive</td>
</tr>
<tr>
<td>S9_26</td>
<td>141-145</td>
<td>ATP; Oth</td>
<td>Music - passive and active</td>
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<td>S9_28</td>
<td>149-152</td>
<td>ATP; TV - passive</td>
<td>Lost the ability</td>
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**Table 12.2:** Patient-side informative and assistive technology.
<table>
<thead>
<tr>
<th>S1_10</th>
<th>63-68</th>
<th>ATP; ATC</th>
<th>Food plan</th>
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<td>ATC</td>
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<tr>
<td>S2_52</td>
<td>193-196</td>
<td>ATC</td>
<td>Phone; Calendar for appointments</td>
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<tr>
<td>S2_53</td>
<td>199-201</td>
<td>ATC</td>
<td>Poster Medication plan</td>
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<tr>
<td>S3_62</td>
<td>415-419</td>
<td>ATP; ATC</td>
<td>Time switch Eventually necessary</td>
</tr>
<tr>
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<td>431-443</td>
<td>ATC</td>
<td>Calendar for appointments</td>
</tr>
<tr>
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<td>ATC</td>
<td>Calendar for appointments</td>
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<td>S4_8</td>
<td>73-83</td>
<td>ATC; Ch</td>
<td>Notebook diary Medicine box for medication daily recording of the activities</td>
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<td>S4_9</td>
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<td>Emo; Ch; ATC; Oth</td>
<td>Wheelchair for going out</td>
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<td>S5_11</td>
<td>74-83</td>
<td>ATC</td>
<td>Notebook diary Medicine box Food plan</td>
</tr>
<tr>
<td>S6_9</td>
<td>66-75</td>
<td>ATC; ATP</td>
<td>Notebook diary Medicine box Physical and cognitive stimulation</td>
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<tr>
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<td>79-84</td>
<td>ATC; Ch;</td>
<td>Notebook Medication plan</td>
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<td>90-92</td>
<td>ATC Notebook Medication plan</td>
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<td>229-234</td>
<td>ATC; Ch; Oth</td>
<td>Medicine box Unreachable for the patient</td>
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<td>Ch; LSS; ATC;</td>
<td>Calendar for appointments for the patient and the caregiver</td>
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<td>309-315</td>
<td>For; ATC; Ch;</td>
<td>Paper notes Post it’s Shopping, Meals</td>
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<tr>
<td>S9_29</td>
<td>154-162</td>
<td>ATC; ESS</td>
<td>Medicine box for appointments Medication plan</td>
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<tr>
<td>S9_32</td>
<td>166-168</td>
<td>Ch; ATC</td>
<td>Medicine box Medication plan</td>
</tr>
<tr>
<td>S9_33</td>
<td>170-177</td>
<td>ATC; Ch;</td>
<td>Post it’s For little tasks, shopping e.g.</td>
</tr>
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</table>

**Table 12.3:** Caregiver-side informative and assistive technology
12.2 Usability tests

12.2.1 Subject instructions

Welcome

Hello, I am Phil and I welcome and acknowledge your participation for this session 😊 Thank you!

What is it all about – Aim of this project?

I am working on a project that aims at designing a user interface to support early and middle stage dementia patients and their caregivers in their everyday life. I developed an application which allows caregivers to display simple information on the TV in the house of the patient by a Tablet or a Smartphone. This system in order to improve it, I would like to have your help trying it in order to understand if tasks are understandable and easy to perform.

Thank you for participating and contributing to actual research!

What happens with your data and the results?

The results and outcome of this session will be used to understand to improve the application. Of course, your personal data will not be delivered to third party and the results will be treated with confidence.

How is it going to happen?

This session is composed of three parts:

1) I will give you a short introduction to the functionalities, the concept lying underneath and the possibilities this system proposes to caretakers & relatives as you and of course dementia patents.
2) You are invited to test the user interface I designed by performing three tasks I prepared for you!
3) Third and last, I will conduct a short interview with you about your experiences with the interface you tested by assessing e.g. your opinion about the usefulness of this system.
How long does this take?

In total you should expect this evaluation not to take more than 60 minutes of your time.

Before starting I want to express that you can ask questions, interrupt the test or make a break and deny the participation all the time for the case you feel uncomfortable or any other reason.

Final words

Please keep in mind that we are not testing your performance and skills.

You are testing the system for giving us information if we are doing things right or wrong.
12.2.2  Tasks

**Task 1:**
*Let’s start by adding your profile to the application:*

Add yourself as a caregiver to the application and type in your name and take a photograph of yourself.

**Task 2:**

*Now you can try to edit the “Working Activity”:

Try to exchange the current picture of the Working Activity with the other one you will find in the library.

**Task 3:**

*Great! You already added yourself as a caregiver to the system and also successfully edited the “Working Activity”:

Try to imagine now the following situation: You have to go to out of the house to work for the next 2 hours. To show that information on the TV tablet try to

- set yourself in the caregiver screen;
- set the working activity;
- and set the time (2 hours) you are out of the house
### 12.2.3 Detailed task results

<table>
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<tr>
<th>Abbreviation</th>
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<td>[EC]</td>
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<tr>
<td>[EN]</td>
<td>Experimenter note</td>
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<tr>
<td>[S]</td>
<td>Subject</td>
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<tr>
<td>AA</td>
<td>Add Activity</td>
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<tr>
<td>AD</td>
<td>Add Caregiver</td>
</tr>
<tr>
<td>AM</td>
<td>Add Message</td>
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<tr>
<td>AP</td>
<td>Add Picture</td>
</tr>
<tr>
<td>AT</td>
<td>Add Time</td>
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<tr>
<td>ATV</td>
<td>“Access TV” Button</td>
</tr>
<tr>
<td>BACK</td>
<td>“BACK” Button</td>
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<tr>
<td>CA</td>
<td>Change Activity</td>
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<td>CAM</td>
<td>Camera</td>
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<td>CANCEL</td>
<td>“Cancel” Button</td>
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<td>CC</td>
<td>Change Caregiver</td>
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<tr>
<td>CP</td>
<td>Change Picture</td>
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<td>CT</td>
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<td>Change to Caregiver</td>
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<td>CTT</td>
<td>Change to Time</td>
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<td>EDIT PIC</td>
<td>Edit Picture</td>
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<td>Edit Time</td>
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<td>Library</td>
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<td>REDO</td>
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<tr>
<td>SS</td>
<td>Start Screen</td>
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<td>TOUCH “…”</td>
<td>Touch “Caregiver / Activity / Time”</td>
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<td>Take Picture</td>
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**Table 12.4:** Coding of the usability tests
<table>
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<th>Subject Sees</th>
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<th>Subject comments</th>
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<td>1</td>
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<td>ATV</td>
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<tr>
<td>2</td>
<td>MM</td>
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<td>IN</td>
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</tr>
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<td>4</td>
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</tr>
<tr>
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<td>CP</td>
<td>TP</td>
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</tr>
<tr>
<td>6</td>
<td>TP</td>
<td>TAKE</td>
<td></td>
</tr>
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<td>7</td>
<td>RP</td>
<td>SAVE</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>AC</td>
<td>SAVE</td>
<td>[S]: “What is “choose”? There is no relationship between this label and the buttons on the right.”</td>
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<tr>
<td>9</td>
<td>CC</td>
<td></td>
<td>SCENARIO SUCCESS</td>
</tr>
</tbody>
</table>

| Scenario 8C1 |  |  | |
| 1 | SS | ATV |  |
| 2 | MM | CA |  |
| 3 | CA | TOUCH | “is working” |
| 4 | HA | EA | [S]: “Is this a title?” (Label “Change Activity”) |
| 5 | EA | PHOTO |  |
| 6 | CP | LIB |  |
| 7 | LIB | TOUCH | “Briefcase” |
| 8 | EA | SAVE |  |
| 9 | CA | | SCENARIO SUCCESS |

| Scenario 9C1 |  |  | |
| 1 | SS | ATV |  |
| 2 | MM | CC |  |
| 3 | CC | TOUCH | “João” |
| 4 | HC | CTC |  |
| 5 | CC | BACK |  |
| 6 | MM | CA |  |
| 7 | CA | TOUCH | “is working” |
| 8 | HA | CTA |  |
| 9 | CA | BACK |  |
| 10 | MM | CT |  |
| 11 | CT | TOUCH | “2 hours” |
| 12 | HT | CTT | [S]: “I am feeling I have added something. There is no time in the title (“change time”). Maybe it should be “How much time will you take.”” |
| 13 | CT | | SCENARIO SUCCESS |

Table 12.5: Detailed task results of caregiver 1
<table>
<thead>
<tr>
<th>Screen sees</th>
<th>Subject Button</th>
<th>Subject comments</th>
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<td>6</td>
<td>CP</td>
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</tr>
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<td>7</td>
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</tr>
<tr>
<td><strong>Scenario 8C2</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>SS</td>
<td>ATV</td>
</tr>
<tr>
<td>2</td>
<td>MM</td>
<td>CA</td>
</tr>
<tr>
<td>3</td>
<td>CA</td>
<td>TOUCH “is working”</td>
</tr>
<tr>
<td>4</td>
<td>HA</td>
<td>EA</td>
</tr>
<tr>
<td>5</td>
<td>EA</td>
<td>NAME TO “work”</td>
</tr>
<tr>
<td>6</td>
<td>EA</td>
<td>PHOTO</td>
</tr>
<tr>
<td>7</td>
<td>CP</td>
<td>LIB</td>
</tr>
<tr>
<td>8</td>
<td>LIB</td>
<td>TOUCH “Briefcase”</td>
</tr>
<tr>
<td>9</td>
<td>EA</td>
<td>SAVE</td>
</tr>
<tr>
<td>10</td>
<td>CA</td>
<td>SCENARIO SUCCESS</td>
</tr>
<tr>
<td><strong>Scenario 9C2</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>SS</td>
<td>ATV</td>
</tr>
<tr>
<td>2</td>
<td>MM</td>
<td>CC</td>
</tr>
<tr>
<td>3</td>
<td>CC</td>
<td>TOUCH “Conceição”</td>
</tr>
<tr>
<td>4</td>
<td>HC</td>
<td>CTC</td>
</tr>
<tr>
<td>5</td>
<td>CC</td>
<td>BACK</td>
</tr>
<tr>
<td>6</td>
<td>MM</td>
<td>CA</td>
</tr>
<tr>
<td>7</td>
<td>CA</td>
<td>AA</td>
</tr>
<tr>
<td>8</td>
<td>AA</td>
<td>CANCEL</td>
</tr>
</tbody>
</table>

**Table 12.6**: Detailed task results of caregiver 2
<table>
<thead>
<tr>
<th>Screen</th>
<th>Subject sees</th>
<th>Hits Button</th>
<th>Subject comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>9</td>
<td>CA</td>
<td>TOUCH</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>“work”</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>HA</td>
<td>CTA</td>
<td>[EN]: Subject was thinking for a while.</td>
</tr>
<tr>
<td>11</td>
<td>CA</td>
<td>BACK</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>MM</td>
<td>CT</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>CT</td>
<td>TOUCH</td>
<td>“2 hours”</td>
</tr>
<tr>
<td>14</td>
<td>HAT</td>
<td>CTT</td>
<td></td>
</tr>
<tr>
<td>15</td>
<td>CT</td>
<td>SCENARIO SUCCESS</td>
<td></td>
</tr>
</tbody>
</table>

**Table 12.7:** Detailed task results of caregiver 2 (continuation)
<table>
<thead>
<tr>
<th>Screen</th>
<th>Subject sees</th>
<th>Hits Button</th>
<th>Subject comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scenario 7C3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>SS</td>
<td>ATV</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>MM</td>
<td>AC</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>AC</td>
<td>IN</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>AC</td>
<td>PHOTO</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>CP</td>
<td>TP</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>TP</td>
<td>TAKE</td>
<td>[S]:“Didn’t I took it yet?” [EN]: Paper mock-up problem</td>
</tr>
<tr>
<td>7</td>
<td>RP</td>
<td>SAVE</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>AC</td>
<td>SAVE</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>CC</td>
<td>SCENARIO SUCCESS</td>
<td>[S]: “Am I finished?” [EC]:“Yes.” [S]: “I am missing the confirmation.”</td>
</tr>
<tr>
<td>Scenario 8C3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>SS</td>
<td>ATV</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>MM</td>
<td>CA</td>
<td>[EN]: Subject reviews the task and says: “You don’t want me to change the activity; you want me to change the picture of the activity.” [EC]: “Yes.”</td>
</tr>
<tr>
<td>3</td>
<td>CA</td>
<td>TOUCH “is working”</td>
<td>[EN]: Subject thought for a while.</td>
</tr>
<tr>
<td>4</td>
<td>HA</td>
<td>EA</td>
<td>[EN]: Strange face expression of subject.</td>
</tr>
<tr>
<td>5</td>
<td>EA</td>
<td>CP</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>CP</td>
<td>LIB</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>LIB</td>
<td>“Briefcase”</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>EA</td>
<td>SAVE</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>CA</td>
<td>SCENARIO SUCCESS</td>
<td></td>
</tr>
<tr>
<td>Scenario 9C3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>SS</td>
<td>ATV</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>MM</td>
<td>CC</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>CC</td>
<td>TOUCH “Vera”</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>HA</td>
<td>CTC</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>CC</td>
<td>BACK</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>MM</td>
<td>CA</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>CA</td>
<td>TOUCH “is working”</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>HA</td>
<td>CTA</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>CA</td>
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<td></td>
</tr>
<tr>
<td>10</td>
<td>MM</td>
<td>CT</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>CT</td>
<td>TOUCH “2 hours”</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>HT</td>
<td>CTT</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>CT</td>
<td>SCENARIO SUCCESS</td>
<td></td>
</tr>
</tbody>
</table>

**Table 12.8:** Detailed task results of caregiver 3
### Scenario 7C4

<table>
<thead>
<tr>
<th>Screen</th>
<th>Subject sees</th>
<th>Hits Button</th>
<th>Subject comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>SS</td>
<td>ATV</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>MM</td>
<td>AA</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>AA</td>
<td>CANCEL</td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>MM</td>
<td>AC</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>AC</td>
<td>PHOTO</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>CP</td>
<td>TP</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>TP</td>
<td>TAKE</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>RP</td>
<td>SAVE</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>AC</td>
<td>IN</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>AC</td>
<td>SAVE</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>CC</td>
<td><strong>SCENARIO SUCCESS</strong></td>
<td></td>
</tr>
</tbody>
</table>

### Scenario 8C4

<table>
<thead>
<tr>
<th>Screen</th>
<th>Subject sees</th>
<th>Hits Button</th>
<th>Subject comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>SS</td>
<td>ATV</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>MM</td>
<td>CA</td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>CA</td>
<td>TOUCH</td>
<td>&quot;is working&quot;</td>
</tr>
<tr>
<td>4</td>
<td>HA</td>
<td>EA</td>
<td>The edit was not noticed in first... and subject asked: &quot;First change to what?&quot; and then was mentioning: &quot;EDIT&quot; and &quot;CHANGE&quot; are the same.</td>
</tr>
<tr>
<td>5</td>
<td>EA</td>
<td>CANCEL</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>CA</td>
<td>AA</td>
<td></td>
</tr>
<tr>
<td>7</td>
<td>AA</td>
<td>CA</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>AA</td>
<td>PHOTO</td>
<td></td>
</tr>
<tr>
<td>9</td>
<td>CP</td>
<td>LIB</td>
<td>&quot;Briefcase&quot;</td>
</tr>
<tr>
<td>10</td>
<td>LIB</td>
<td>&quot;Briefcase&quot;</td>
<td></td>
</tr>
<tr>
<td>11</td>
<td>AA</td>
<td>IN</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>AA</td>
<td>SAVE</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>CA</td>
<td><strong>SCENARIO SUCCESS</strong></td>
<td></td>
</tr>
</tbody>
</table>

### Scenario 9C4

<table>
<thead>
<tr>
<th>Screen</th>
<th>Subject sees</th>
<th>Hits Button</th>
<th>Subject comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>SS</td>
<td>ATV</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>MM</td>
<td>CT</td>
<td>[EN]: Confusion of subject; weird face expression</td>
</tr>
<tr>
<td>3</td>
<td>CT</td>
<td>TOUCH</td>
<td>&quot;2 hours&quot;</td>
</tr>
<tr>
<td>4</td>
<td>HT</td>
<td>EDIT</td>
<td></td>
</tr>
<tr>
<td>5</td>
<td>ET</td>
<td>SAVE</td>
<td></td>
</tr>
<tr>
<td>6</td>
<td>CT</td>
<td>TOUCH</td>
<td>&quot;2 hours&quot;</td>
</tr>
<tr>
<td>7</td>
<td>HT</td>
<td>CTT</td>
<td>[EC]: Tip solve this screen: &quot;CHANGE&quot;</td>
</tr>
<tr>
<td>8</td>
<td>CT</td>
<td>BACK</td>
<td>[EC]: Tip to confirm the change.</td>
</tr>
</tbody>
</table>

[EN]: Confusion of subject; weird face expression
[EC]: Tip solve this screen: "CHANGE"
[S]: "Is it in the definitions?" [EN]: The task description had a similarity with the settings description [EC]: “Maybe the BACK button?”

**Table 12.9:** Detailed task results of caregiver 4
<table>
<thead>
<tr>
<th>Screen</th>
<th>Subject sees</th>
<th>Hits Button</th>
<th>Subject comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>9</td>
<td>MM</td>
<td>CA</td>
<td></td>
</tr>
<tr>
<td>10</td>
<td>CA</td>
<td>TOUCH</td>
<td>“is working”</td>
</tr>
<tr>
<td>11</td>
<td>HA</td>
<td>CTT</td>
<td></td>
</tr>
<tr>
<td>12</td>
<td>CA</td>
<td>BACK</td>
<td></td>
</tr>
<tr>
<td>13</td>
<td>MM</td>
<td>CC</td>
<td></td>
</tr>
<tr>
<td>14</td>
<td>CC</td>
<td>TOUCH</td>
<td>“Preciosa”</td>
</tr>
<tr>
<td>15</td>
<td>HC</td>
<td>CTC</td>
<td></td>
</tr>
<tr>
<td>16</td>
<td>CC</td>
<td>SCENARIO</td>
<td>SUCCESS</td>
</tr>
</tbody>
</table>

**Table 12.10**: Detailed task results of caregiver 4 (continuation)
12.2.4 After questionnaire

Questionnaire

Subject: #

Age   Gender   Relationship to the dementia affected person

1. The layout of the application makes it easy to understand the various tasks it enables you to perform…
   - Always
   - Most of the times
   - Sometimes
   - Never

2. The organization and the content of the application are clear…
   - Always
   - Most of the times
   - Sometimes
   - Never

3. The way the content is presented enables you to know what to choose and how to perform a specific task…
   - Always
   - Most of the times
   - Sometimes
   - Never

4. The application was easy to use…
   - Always
   - Most of the times
   - Sometimes
   - Never

5. The application was pleasurable to use…
   - Always
   - Most of the times
   - Sometimes
   - Never

6. The application is going to improve the quality of life of your affected relative…
   - Always
   - Most of the times
   - Sometimes
   - Never

7. The application is going to enable your affected relative to feel safer…
   - Always
   - Most of the times
   - Sometimes
   - Never

8. The application is going to enable your affected relative to feel calmer…
   - Always
   - Most of the times
   - Sometimes
   - Never

9. The application is going to help you and the other caregivers to improve the quality of life of your affected relative…
   - Always
   - Most of the times
   - Sometimes
   - Never

10. The application is going to help you and the other caregivers to manage around your affected relative needs…
    - Always
    - Most of the times
    - Sometimes
    - Never

11. The application will enable you to feel less concerned about your grandmother safety…
☐ Always ☐ Most of the times ☐ Sometimes ☐ Never

12. What did you like the most in the application?

13. What did you dislike the most in the application?

14. What would you improve in the application?

Thank you. Your participation was very valuable to me and I am very grateful for your help. This will enable me to develop a better system.
### Table 12.11: Questionnaire coding

<table>
<thead>
<tr>
<th>Answer</th>
<th>Coding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Always</td>
<td>3</td>
</tr>
<tr>
<td>Most of the times</td>
<td>2</td>
</tr>
<tr>
<td>Sometimes</td>
<td>1</td>
</tr>
<tr>
<td>Never</td>
<td>0</td>
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</table>

### Table 12.12: Questionnaire results

<table>
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<th>S1</th>
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<th>S3</th>
<th>S4</th>
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</thead>
<tbody>
<tr>
<td>Q1</td>
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<td>2</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Q2</td>
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<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Q3</td>
<td>2</td>
<td>2</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Q4</td>
<td>2</td>
<td>2</td>
<td>3</td>
<td>3</td>
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<tr>
<td>Q5</td>
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<td>3</td>
<td>3</td>
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<td>Q6</td>
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<tr>
<td>Q7</td>
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<td>2</td>
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<tr>
<td>Q8</td>
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<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Q9</td>
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<td>3</td>
<td>3</td>
<td>3</td>
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<tr>
<td>Q10</td>
<td>1</td>
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<td>3</td>
</tr>
<tr>
<td>Q11</td>
<td>0</td>
<td>3</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

### Table 12.13: Questionnaire results (continuation)

<table>
<thead>
<tr>
<th></th>
<th>S1</th>
<th>S2</th>
<th>S3</th>
<th>S4</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q12</td>
<td>Transmit my location to the patient even if he forgets, he will have access to it.</td>
<td>Utility it has for the CG. Interesting improves the quality of the life of the patient</td>
<td>The advantage of leaving the patient at home calm.</td>
<td>Being able to define an activity. Being able to define a caregiver.</td>
</tr>
<tr>
<td>Q13</td>
<td>Indicate the title in the screen of adding information [EN]: AC, AA Confusion between editing and adding.</td>
<td>Interpretation of the content is not always easy.</td>
<td></td>
<td>Has a lot of questions and steps.</td>
</tr>
<tr>
<td>Q14</td>
<td>See Q13.</td>
<td>I don't know but if I would like to change something, see Q13.</td>
<td>After each function display a message saying if it had success or not. About the TV: Use messages with recorded sound</td>
<td>Be faster.</td>
</tr>
</tbody>
</table>
Rechtlicher Hinweis


Der Verfasser dieser Arbeit stimmt einer Veröffentlichung der Ergebnisse durch das Institut zu und wird diesbezügliche eigene Veröffentlichungen nur in Abstimmung mit dem Institutsleiter und dem betreuenden Mitarbeiter vornehmen.

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Declaration of Authorship

I certify that the work presented here is, to the best of my knowledge and belief, original and the result of my own investigations. I ensure to have used no other resources than quoted.

______________________________
Unterschrift / Signature

Ort, Datum / Place, date