Needs-based enabling- and care technology for people with dementia and their carers
The studies presented in this thesis were conducted at the Department of Psychiatry and the Department of Neurology/Alzheimercenter, VU University medical center, within the EMGO Institute for Health and Care Research (EMGO+, www.emgo.nl), Amsterdam, the Netherlands.

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Needs-based enabling- and care technology for people with dementia and their carers

ACADEMISCH PROEFSCHRIFT

ter verkrijging van de graad Doctor aan
de Vrije Universiteit Amsterdam,
op gezag van de rector magnificus
prof. dr. V. Subramaniam,
in het openbaar te verdedigen
ten overstaan van de promotiecommissie
van de Faculteit der Geneeskunde
op donderdag 12 april 2018 om 13.45 uur
in de aula van de universiteit,
De Boelelaan 1105.

door

Bart Jaco Johan Hattink
geboren te Heemskerk
promotor: prof. dr. R.M. Dröes

copromotoren: dr. F.J.M. Meiland

        dr. A.W. Lemstra
“The baby boomers are getting older, and will stay older for longer. And they will run right into the dementia firing range. How will a society cope? Especially a society that can't so readily rely on those stable family relationships that traditionally provided the backbone of care?

It seems that when you have cancer you are a brave battler against the disease, but when you have Alzheimer's you are an old fart. That's how people see you. It makes you feel quite alone.”

-Sir Terry Pratchett
(in memoriam 1948-2015)
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CHAPTER 1

General introduction
Introduction: Dementia and Alzheimer’s Disease

Dementia, described in the Diagnostics and Statistics Manual (DSM-V; 2013) as a ‘major neurocognitive disorder’ since 2013, is a progressive, neurodegenerative disease that affects and diminishes functioning in multiple cognitive domains. According to the DSM-V, dementia can be suspected when people show A. Evidence of significant cognitive decline from a previous level of performance in (one or more of): 1. Learning/memory; 2. Language; 3. Executive functioning; 4. Complex attention; 5. Perceptual-motor skills; 6. Social cognition; and when B. these cognitive deficits interfere with independence in everyday activities, C. these cognitive deficits do not occur exclusively in the context of a delirium, and D. these cognitive deficits are not better explained by another mental disorder (e.g. depression or schizophrenia). There are over 50 different diseases causing dementia, of which Alzheimer’s disease is the most common form, making up an estimated 60 to 80% of the cases (Alzheimer’s Association).

In Alzheimer’s disease, neurofibrillary tangles are formed by pathological conformation of hyperphosphorylated tau protein which damage neurons/brain cells. Amyloid plaques are extracellular aggregates of amyloid-beta 1-42 (Scheltens, 2015).

Other prevalent types of dementia are vascular dementia, the second most common form making up about 10% of all cases, caused by brain damage from impaired blood flow to the brain and typically characterized by a slower speed of thought and confusion (Loeb et al., 1985), and frontotemporal dementia, characterized by brain damage in the orbitofrontal and temporal lobes of the brain, usually leading to behaviour and/or personality changes (Wu et al., 2016). Additionally, abnormal characteristics of more than one type of dementia can exist, which is known as mixed or multifactorial dementia. Alzheimer’s disease usually begins with memory impairment, and is frequently misdiagnosed as normal (“age-related”) forgetfulness. In later stages however, people become increasingly unable to perform tasks, beginning with relatively complex tasks like cooking, but eventually are unable to perform basic tasks, such as maintaining personal hygiene or eating. [Hope et al., 1999, Lyketsos et al., 2000].

Prevalence of dementia in the Netherlands

According to the Dutch Alzheimer’s Society, the Netherlands currently has 270,000 inhabitants with some form of dementia. By 2040 this number is expected to have doubled to over 500,000; and in 2055 a peak of 690,000 cases is projected. This is mainly because of the aging population: Age is the major risk factor for developing Alzheimer’s Disease (prevalence increases from 5-10% at 65 years to around 45% at 95 years and older). Because of better care for people with dementia, and an increase in healthy lifestyle (eg. not smoking), the incidence of dementia may reduce over the coming years (Alzheimer Nederland, 2016).

Both the rising number of people with dementia and the growing discrepancy between health care professionals needed and the available working population, will put a highly significant strain on the health care system in the future (World Alzheimer’s Day report, 2015). Although there are some drugs on the market, which can temporarily slow down symptoms of dementia, they cannot cure dementia. Considering the long development time of drugs to treat diseases, a cure is not expected for at least the next 15 years.

To care for this growing number of people with dementia in accordance with the current standard of care, nearly 25% of the total working population should be working in elderly care in 2030 (CBS, 2009). However, because of the greying population, the percentage of people working will in fact decrease...
from 68% today to 53.5% in 2030 (CBS; 2016). With an expected age-related decline in the workforce, the world-wide ratio of potential working people to people with dementia is estimated to decrease from 63:1 in 2000 to 27:1 in 2050 (Prince et al., 2013). In the Netherlands, this ratio is expected to change even more dramatically from 43:1 in 2010 to 16:1 in 2050 (Alzheimer Nederland, 2016).

Impact of dementia on caregivers and society
This means that the majority of care in the future will also have to be provided by spouses, children, other family members or friends; the so-called informal caregivers. Informal carers generally provide this unpaid care in addition to obligations of their own such as a job, family and children. An estimated 70% of community-dwelling people with dementia are cared for by informal carers (Alzheimer Nederland, 2016). They experience great burden, both psychologically and practically (Schneider et al., 1999) because of the continuous care task, potentially leading to conditions like depression and social isolation (Smith et al., 2011; Hiel et al., 2015). Overburdening of the informal carer is the leading cause for admission of the person with dementia into long-term care facilities, leading to high care costs to society (World Alzheimer Day report, 2011).

Since there is no way to cure, prevent or effectively treat most forms of dementia yet, the majority of dementia-related costs (75 to 84 percent) involves institutionalization in nursing or care homes (Hurd et al, 2013). In 2014 in the Netherlands, the total care costs of dementia amounted to 5 billion, which is almost 5% of the total national care costs. Dementia puts a heavy burden on people, both on those suffering from the disease, and on those around them. In the Global Impact of Dementia Report, diseases are classified on ‘disability weight’ by consensus among experts. Dementia is rated among some of the most disabling diseases, along with AIDS, blindness and Down Syndrome, and below schizophrenia, severe depression, migraine, quadriplegia and terminal stage cancer (Alzheimer’s Disease International, 2015).

Needs of people with dementia and their carers
Until a decade ago there was a great lack of research into the experienced needs of people with dementia themselves (generally only informal and professional carers or other proxies were interviewed on the needs of the person with dementia). Research has been done into this by Hancock et al. (2006), Orrell et al. (2008) and Miranda-Castillo (2013). The largest study to date into this has been done by van der Roest et al. in 2009 van der Roest who conducted a large study among 230 community-dwelling people with dementia and 320 carers in the Netherlands. They identified a host of needs, some of which were indicated to be largely met, others to be (partly) unmet. Most of the interviewed persons indicated they needed help with household activities (69.9% of people with dementia; 92.6% of carers); handling food (90.3% of people with dementia; 81.3 percent of carers), memory problems (57.1% of people with dementia; 87.7% of carers), and handling money (52.2% of people with dementia and 86.2% of carers). Memory problems, information about their disease process and course and how to deal with it, and company (of others) were most frequently indicated to be unmet. Informal carers indicated household activities, memory problems, and managing money as the most common needs. They also mentioned memory problems, information about the disease process, course and how to deal with it, and company as needs domains that were most frequently unmet.

To meet the needs of both people with dementia and their carers efficiently, it is necessary to develop new methods to support them. One promising method is the use of care technology, which has been found in earlier research (eg. Lauriks et al., 2007) to be promising for fulfilling unmet needs of people with dementia and their carers.
For lack of a cure, current interventions for people with dementia and others involved focus on helping people deal with the symptoms and consequences of the disease, with the ultimate aim to improve their daily functioning and quality of life. As such, innovative care and support approaches are developed to help promote people with dementia's independence for as long as possible and maximize their quality of life. The emergence of enabling and care technology, as well as other eHealth solutions, is considered a very promising innovative field for these aims and has been found to be beneficial to improve quality of life of people with dementia and their caregivers (Meiland et al., 2017; Bateman et al., 2017; Martines-Alcalá et al., 2016). Care technology for dementia is supported as good practice by Alzheimer Nederland, mentioning it specifically in the Dementia Care Standard 2012 as a solution with great potential to allow people with dementia to live in their own homes longer and in better health (Alzheimer Nederland, 2012).

Care technology can encompass a wide range of different means and technologies to assist people with dementia, and everyone else around them, in their daily lives. This can differ from low-tech solutions (e.g. simple sensor-based automatic nightlights or simple apps to enable easy communication) to high-tech solutions such as advanced behavior monitoring and large-scale online platforms for communication or learning. Additionally, technology can differ between consumer-grade ‘everyday technology’ (e.g. the sensor-based nightlights, which are easily available), and specific, purpose-designed technology.

The technology can consist of different application forms such as: Internet-based websites (e.g. information provision, web-based health-communication and online education, also known as E-learning), Health communication tools (increasingly also offered through mobile web/technology, which is also known as mHealth – mobile eHealth) which can, for example, remotely connect patient and doctor, saving them travel time and stress, or which can help to connect people with dementia with family and friends through a video connection - Skype and Facetime are very popular commercial examples. Two forms of technology gaining in popularity in recent years are home automation and robotics. Home automation (often called ‘domotics’ – a combination of domus (home) and robotics/informatics), which automate certain functions of the home, such as closing curtains, switching off certain appliances, or maintaining the temperature of the home. This can also be used, sometimes in combination with other sensor technologies, to enhance safety in the home. Robotics can range from robots doing tasks in the home (e.g. heavy lifting, opening doors or vacuum cleaning), or even as companions, for example in the form of robotic pets (e.g. ‘Paro’, a robotic pet seal that is found to be beneficial in improving quality of life, and reducing overall stress and agitation; Joranson et al., 2016).

Besides helping to keep healthcare efficient and affordable, eHealth might aid in increasing the accessibility of care and making the delivery of healthcare more efficient for professionals, and more easily available for people with dementia. Within the broad scope of technological solutions that are available, several domains of support for people with dementia can be identified.

**Domains of support by enabling / care technology; and how care technology can solve unmet needs.** Based on reviews by Fleming & Sum (2014) and Meiland & Witte (2015); enabling and care technology can be distinguished for six domains of support:
1. (ADL\textsuperscript{1}-) independence
2. Safety and security
3. Leisure and lifestyle
4. Communication and telehealth;
5. Carer support; and
6. Information support.

Care technology may provide solutions for the frequently mentioned barriers to the use of support services (Brodaty et al., 2005; Forbes et al., 2006), such as their (perceived) inadequacy, not matching individual needs, long waiting lists, not being informed about services, high costs and reluctance of people to use services (Peek et al., 2016).

On the different domains of support, care technology can help in a variety of ways:

**Domain 1**, Independence: several solutions/devices/etc. have been developed to enhance an independent lifestyle may help people maintain an independent lifestyle through, for example, prompts and reminders. This can be done through an agenda that sends reminders when it is time for an appointment. It may help to enhance daily activity level, and mood (Lancioni et al., 2010). Besides, it may also help guide people with dementia through complex tasks that they would have been unable to perform otherwise. In addition, memory-aiding devices can help on the important domains of reminding/coaching of food preparation and/or other household activities (when tailored to such activities). One example of a computerized device designed to support memory and independence in daily life (ADL), called COACH, was assessed in a single subject research design study conducted by Mihailidis et al. (2008). This device uses artificial intelligence to autonomously guide six older adults with severe dementia through the activity of handwashing using audio and/or audio-video prompts. Results showed that patients were able to complete ADL activities better when using this device. Another example of technology helping people with dementia to be more independent was described in a study on the use of a computer-based prompting device, in which 11 community-dwelling people with moderate cognitive impairment were involved (Bewernitz et al., 2009). Subjects were guided through tasks by (simulated) smart machine-based prompting. The authors reported that, given appropriate machine-delivered messages, subjects completed tasks better across three self-care tasks.

**Domain 2**, Safety: a diverse range of devices promote the safety of the person with dementia. These can be simple, low-tech tools, such as plugs that stop the flow of gas when one leaves on the stove. However, these can also be high-tech tools, such as GPS for tracking someone’s location when they leave the house, or a system for the detection of falls in the home. The care technology can meet the important and frequently indicated need of safety, through non-intrusive systems that require as little interaction as possible. Fall detection systems, for example, can range from wrist-worn alarm devices (which require a degree of input from the person with dementia, and as such are prone to be forgotten) to fully automated systems, which can detect falls through wireless systems and can report emergencies automatically. These devices and systems could be used in nursing homes to supplement surveillance by staff (Niemeyer, 2014), thereby relieving stress in care staff. Additionally, outdoor safety and

\textsuperscript{1} ADL – Activities of Daily living
independence can be increased through GPS-surveillance technology, both by preventing or monitoring wandering behavior (Pot et al., 2012) and by monitoring fall risk (Gietzelt et al., 2014).

**Domain 3, Leisure:** a variety of software and devices is available which allow people easy or efficient access to leisure instruments, activities, and self-management (Martin, 2013), for example, computerized reminiscence tools, easy to use music players, or digital photo albums. Music (Riley et al, 2009) and art (Leuty et al., 2013) can be easily enjoyed through touchscreen and app-enabled devices, and are found to be useful and enjoyable for people with dementia. Another example are games which can be played on a tablet (Astell et al., 2016). Especially simple, relatable games (e.g. computerized versions of old card games or board games) are found to be enjoyed by people with dementia (Gronewoud et al., 2014). These tools can be used by people with dementia themselves, but can also be used together with informal carers or others. Care technology can greatly benefit people with dementia on the needs of daytime activities and social contact, both frequently indicated to be unmet needs. Additionally, care technology can help with daily leisure activities such as physical exercise and maintaining an active lifestyle (Lancioni et al., 2015; Nauta et al., 2013); group-based reminiscence activities (Lazar et al., 2014; Pringle and Somerville, 2013); social contact through video-communication (Verwey et al., 2015); and even to promote physical exercise, known as exergaming, in which physical exercise is motivated by gaming elements, such as stationary bikes that have a screen to simulate cycling through familiar surroundings. Pilot studies into exergaming have found it to be beneficial for both physical (e.g. aerobic capacity) and cognitive health (e.g. cognitive functioning and neuroplasticity) (Anderson-Hanley et al., 2012, 2016; Barcelos et al., 2015).

**Domain 4, Communication and telehealth:** some devices are meant to improve or simplify communication with others, for example a photophone, which allows people to call by touching a photo on a touchscreen. Another example is video calling, in which people can contact each other with a video-connection, allowing them to see each other while calling. Video calling can also be used by people with dementia and carers to contact their physicians, known as video consulting, which is gaining in popularity, and which in the Netherlands is currently reimbursed like a regular consultation by health care insurances. Videoconsultation can also help on the unmet needs of social contact and, to a lesser degree, safety. By offering people an easy means to contact family members it may reduce social isolation (Moyle et al., 2014). Additionally, family members can use communication tools to communicate with their family member with dementia. In the nursing home, for example, video-communication can be used to reduce agitation in people (van der Ploeg et al., 2016). Besides contact with family members, communication tools can be used for remote diagnosis and contact with physicians or hospital specialists, helping people with dementia to save travel time and costs, as well as potentially helping remote and/or underserved hospitals (Kim et al., 2016; Catic et al., 2014; Tso et al., 2016).

**Domain 5, Support for carers:** different technological means help carers deal with their care task. This support is offered directly, for example, through E-learning in which carers learn to better deal with the consequences of dementia and their care task, or indirectly by supporting the person with dementia in the mentioned domains (e.g. through using safety tools in domain 3, knowing the person is safe in their home is likely to alleviate carer stress), or it can encompass a broad range of other caregiver support means, such as support networks (Bass et al., 1998); offering remote interventions for carers (Finkel et al., 2007); or offering online support groups (Marziali et al., 2011). Care technology can help, among other things, to reduce stress, and experienced burden among caregivers (Marziali et al., 2011).
Besides, eHealth can be especially helpful to support otherwise hard to reach groups, separated by, for example, geography or language (Blusi et al., 2014; Chiu et al., 2009).

Domain 6. Information: many different means of support aim to inform people with dementia, their carers, and professionals, about dementia, the course of dementia, and how to deal with it. Examples include informative websites, online guides (e.g. Alzheimer Nederland’s ‘Alzheimer Assistant’), extensive online courses on how to deal with dementia (such as the STAR course (Dröes, 2013) described elsewhere in this thesis). Offering information through technology-based means fulfills the frequently indicated need for information about the disease. This can be offered through, for example, online remote psycho-education (Lewis et al., 2010; Pot et al., 2015; Cristiancho-Lacroix et al., 2015) or online intervention groups (Zheng et al., 2017). It can help to increase knowledge about dementia, can reduce stress, and increase overall well-being (Verkaik et al., 2015).

Personalization
While ‘older’ technology offered more or less the same experience for any user (e.g. showing the same website without any choices in content, language or preferences), modern and more advanced technology has many possibilities to be specifically tailored to each user. This is especially apparent in the current development of so-called “Web 2.0” content, which focuses heavily or entirely on user-generated content. Websites that are rich in Web 2.0 content, such as Facebook, YouTube or Wikipedia, are able to offer a substantially different experience for every user. The possibility to offer personalizable solutions for people with dementia, informal caregivers, or person with dementia-caregiver dyads offers great promise for the future of healthcare.

This is of importance in the development of care technology, since people with dementia can have different and varying needs, have different capabilities to utilize support, and have different preferences. The technology described in this thesis has, for the greatest part, many different possibilities for personalization.

How to study and evaluate the technology?
Generally, technology can be evaluated on usability and effectiveness. Usability is defined by the International Standards Organization (ISO, Geneva, Switzerland) as “the effectiveness, efficiency, and satisfaction with which specified users can achieve goals in particular environments.” Usability can be further distinguished into User friendliness/ease of use, and usefulness.

1. User friendliness / Ease of use
In most studies into care technology, usability focuses mainly on how easy it is for users to operate the technology, how much instruction they need in order to properly operate the technology, and how many errors they make when operating the technology.

2. Usefulness
Usefulness is the extent to which users judge a website, application or other technology to fulfill their specific needs. It determines, among other things, whether a technology helps users to be more effective, be more productive, and whether it gives them control over things in their lives (Lund, 2001).
3. Effectiveness

Effectiveness describes the degree to which a person using certain technology achieves the goal it is intended for. It can be studied using pre/posttest measures on those domains the technology aims to support. Correlations for these items suggested that these perspectives influence each other, and that improvements in Ease of use improve ratings of Usefulness and vice versa (Lund, 2001). Very little research has been done into the usability of technology, especially for people with dementia and their carers. Several studies report benefits for users, but often these studies are of low quality, making it also important to carry out more research into the effectiveness of technology for people with dementia and carers (Meiland et al., 2017).

Aim and outline of this thesis

The main research question this thesis attempts to answer is: ‘Are needs-based enabling/care technologies that aim to support people with dementia and/or their (in)formal caregivers experienced as user-friendly, useful and effective, and what could be recommended for their further improvement and development?’

To study this, we developed and researched several different care technology solutions for dementia care, and attempted to answer the following subquestions:

1. How do users (people with dementia, informal carers, care professionals) experience the user-friendliness of the intervention?
2. Do users experience the intervention as useful? If so, in what sense?
3. Is the care intervention effective in achieving its aims?

Chapter 2 details the development process of the ROSETTA technology, through prototyping and design workshops with people with dementia and their carers. The ROSETTA enabling & care technology system aims to support on the domains of memory and safety, social contact and leisure activities, for both the person with dementia and their informal caregiver, through an integrated system of sensors, cameras and a touchscreen device. The system offers three functionalities: a safety system, in which sensors and a camera detect potentially dangerous situations (e.g. falls) and warn help when necessary. Secondly, the sensor system can also detect gradually occurring changes in behavior (e.g. more frequent wandering at night; less use of the kitchen) and send alerts to informal or professional carers. Finally, it contains both a fixed touchscreen device placed in the home, and a mobile device persons can take with them during the day, which could be used for contact with others, for agenda reminders, and for help in dangerous situations (in which the person with dementia calls a family member by pushing one button, and the position of the device can be located using GPS). The main aim of this research was to study the user-participatory development process for such an integrated multimodal system, to ensure it meets user needs and demands in different stages of the disease.

Chapter 3 describes the pilot study conducted to evaluate the user-friendliness, usefulness and impact of the first prototype device of the ROSETTA technology. To this end the system was installed in the houses of participants in the Netherlands, Germany and Belgium. The systems were installed according to the needs and wishes of participants (i.e. matching the severity of their dementia and preferences), and they lived with the system installed for a period of 1 to 5 months. Using standardized questionnaires, these participants were tested pre- and posttest on, among other things, caregiver burden,
sense of competence and needs. Additionally, they gave their opinions on the user-friendliness and usefulness of the system in semi-structured interviews and weekly diary-notebooks.

Chapter 4 describes the development of the dementia simulator, Into D’mentia, that aims to provide insight into the world and experience of people with dementia to informal caregivers, to enhance their empathy and understanding. Here we first performed a literature survey, to inventory the experience of people living with dementia, based on interviews containing quotes of people with dementia. These quotes were categorized according to three perspectives, focusing on different domains of experiencing dementia: quality of life; adaptation-coping; and problem areas in daily life. Using the collected and categorized quotes, these experiences were discussed during focus groups with people with dementia and informal carers, to determine which domains they recognized most in their life. A selection was then made of experiences to be simulated/implemented in the Into D’mentia simulation.

Chapter 5 describes a pilot study evaluating the effect of the Into D’mentia dementia-simulator on the empathy and understanding of informal and professional caregivers, as well as a study into the user-friendliness and usefulness of the simulation. Using sensors, interactive content and video projections, Into D’mentia lets caregivers experience a day in the life of someone with dementia in 25 minutes, followed by a half-day group training. To this end, a pretest-posttest one-group design with informal and professional caregivers was conducted, using standardized questionnaires and semi-structured interviews.

Chapter 6 describes the STAR elearning: To assist informal carers, professionals and volunteers in gaining skills and information needed to care for people with dementia, an online e-learning course called STAR (Skills Training And Re-skilling) was developed in cooperation with dementia experts. The course is divided into 8 different modules, covering topics such as “What is dementia”; “Living with dementia”; “The emotional impact of dementia”; and “Taking care of yourself as an informal carer”. These modules are available at basic, intermediate and advanced levels and include text, video, exercises and tests. Using online questionnaires, the effect of STAR on knowledge about dementia, on empathy and understanding, and on user-friendliness and usefulness was evaluated in a Randomized Controlled Trial across two countries.

Chapter 7 describes a study into the Digital Alzheimer center: To assist people with dementia and carers visiting the VUmc Alzheimer Center (a memory clinic specialized in diagnosis and research) who generally live outside of the Amsterdam area and for whom traveling to the hospital might be a burden, an online web portal, the Digital Alzheimer Center, was developed. This Digital Alzheimer Center offers people with dementia and carers information about their condition, practical tips and support, and allows them to view their personal appointments and securely contact their carers. It also offers the opportunity to contact peers (other people with dementia and caregivers). Through questionnaires, interviews and observations during use of the platform, the Digital Alzheimer was evaluated on user-friendliness and usefulness.

Finally, Chapter 8 provides a General Discussion, which addresses the main findings of the research chapters, as well as the methodological issues that were encountered. It also discusses the scientific and societal impact of the findings. Additionally, it provides recommendations for future research and development.
References


CHAPTER 2

ROSETTA: Designing domotica


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ABSTRACT

Background: In the European ROSETTA project three separate, previously developed, ICT systems were improved and integrated to create one modular system that helps community-dwelling people with mild cognitive impairment and dementia in different stages of the disease. The system aims to support them in daily functioning, monitor (deviations from) patterns in daily behaviour and to automatically detect emergency situations. The study aimed to inventory the end users’ needs and wishes regarding the development and design of the new integrated ROSETTA system, and to describe the to be developed ROSETTA system.

Methods: Qualitative user-participatory design with in total 50 persons: 14 people with dementia, 13 informal carers, 6 professional carers, 9 dementia experts, 7 care partners within the project, and 1 volunteer. In the Netherlands user focus group sessions were performed and in Germany individual interviews. Dementia experts were consulted by means of a questionnaire, an expert meeting session, and interviews.

Results: Persons with dementia and informal carers appreciated the following functionalities most: help in cases of emergencies, navigation support and the calendar function. Dementia experts rated various behaviours relevant to monitor in order to detect timely changes in functioning, e.g. eating, drinking, going to the toilet, taking medicine adequately, performance of activities and sleep patterns. No ethical issues regarding the use of sensors and cameras were mentioned.

Conclusion: The user participatory design resulted in valuable input from persons with dementia, informal carers and professional carers/ dementia experts, based on which a first prototype ROSETTA system was built.

Keywords: dementia, mild cognitive impairment, psychosocial interventions, qualitative research, services.
Introduction
The global population ages rapidly and the prevalence of dementia is expected to increase dramatically to 115 million people in 2050 (Prince and Jackson, 2009). Additionally, with the expected decline in workforce, the ratio of potential working people to people with dementia will decrease from 69:1 in 2000 to 27:1 in 2050 (Health council of the Netherlands, 2002; Wancata et al., 2003). The major challenge is therefore to provide adequate care for the growing number of persons with dementia, of which 70% will live in the community, often taken care of by informal and professional carers. Therefore, the importance of the role of Assistive ICT technologies will increase in dementia care. They may support persons with dementia in coping with the disease and improving their quality of life (Lauriks et al., 2007; Topo, 2009), reduce caregiver burden (Gilliard and Hagen, 2004; Beauchamp et al., 2005; Smith and Toseland, 2006; Van Mierlo et al., 2012) and improve the caregiver’s self confidence (Lewis et al., 2010). Additionally, they may reduce professional carers’ anxiety (Blackburn, 1988) and improve their work satisfaction (Engström et al., 2005). Assistive technologies may enable elderly people with progressive chronic disabilities to stay in their own homes safely for a longer period, and subsequently reduce health care costs.

It is important that assistive technologies are developed that adequately meet the needs of the persons with dementia and carers. Drawbacks of current assistive technologies are that they often aim to support single needs instead of multiple needs in various stages of the disease, they are often developed without involvement of the target group of persons with dementia (Wilkinson, 2002; Bharucha et al., 2009). They are also often initially designed for younger people, usually with nonprogressive, traumatic injuries (Span et al., 2013), which makes it questionable whether persons with dementia can use them, and whether they will accept them.

In the ROSETTA project a user participatory design was adopted to develop an integrated system, which combines three previously developed assistive technology systems and is, in close cooperation with the target groups, adjusted to their needs and wishes. The three previously developed systems are the COGNOW Day Navigator (CDN) (Meiland et al., 2010), the EMERGE system (Storf et al., 2009) and the Unattended Autonomous Surveillance system (UAS) (Jans et al., 2009). The CDN supports people with dementia in the early stages of impairment in the unmet need areas of memory, social contact, daily activities, and safety (Van der Roest et al., 2009; Meiland et al., 2010). People with dementia use a touch screen computer which offers reminders for activities, a picture dialling system, radio and music button, activity support (e.g. preparing coffee) and safety warnings (e.g. front door is left open), and they have a mobile device with partly the same functionalities on it and a navigation service to help them find their way home. In the ROSETTA project the CDN was further developed and called the Elderly Day Navigator (EDN). The EMERGE system has been developed to support elderly people with monitoring, prevention and emergency response by employing sensors to monitor activities of daily living and vital data (Storf et al., 2009). The UAS system provides a fully automatic detection of emergencies (including falls and wandering) for independently living elderly by using an ambient sensor network (Jans et al., 2009). The functionalities of these systems described above are also proposed in other studies that included persons with dementia, informal and professional carers in the design process. For example in studies by Jones (2004); Sixsmith et al. (2007); Wherton and Monk (2008); suggested technologies with a focus on prompting and monitoring daily activities, support in leisure activities, social contact and participation, and devices to improve safety. The aim of the ROSETTA project is to combine these three systems into one platform, attuned to the needs of people with dementia.
from the early to severe stages of dementia, and their informal carers. The aim of this article is to provide insight into the methods used in the participatory design process, by describing the methods for assessing user needs and wishes as well as the results of this process that contributed to the development of this integrated ROSETTA system.

**Methods**

**Design**

A qualitative, user participatory, research design was adopted with different types of workshops, semi-structured interviews, and expert consultations throughout the development process. Participants and setting The study was executed in the Netherlands and in Germany where the full ROSETTA system was field-tested. Convenience samples were recruited throughout the development process: for an overview see Table 2.1. Prior experience with assistive technologies was not required. Persons with severe dementia did not participate in the workshops or interviews. Information on their needs, wishes and abilities were collected via dementia experts and care partners within the project. In the Netherlands separate workshops were conducted with community-dwelling people with dementia, informal carers, professionals and dementia experts. Persons with dementia and informal carers were recruited from two Meeting Centers for people with dementia and their carers in two regions of the Netherlands (Amsterdam and Tilburg), and via an organisation for transmural care. The dementia experts were two professors (Clinical Health Psychology, Chronic Diseases in Elderly care), one Elderly care manager of a Mental Health organization, one care manager of a residential home for elderly, one neurologist, one program manager on innovations in Psychogeriatrics, and three project partners with expertise in dementia (a professor of Psychosocial care in dementia, a health psychologist and an expert in ICT and dementia). In Germany individual semi-structured interviews were conducted with persons with (very) mild cognitive impairments, who were recruited from Westpfalz-Klinikum Kaiserslautern and the Red Cross organisation. Also, ambulant professional caregivers of the German Red Cross participated in a workshop on assessment of mock-ups of the ROSETTA system. The dementia care partners within the project (nine persons from Zorgpalet Baarn-Soest, Christelijke Mutualiteiten, Westpfalz-Klinikum, and VUmc) were repeatedly consulted about the design of the ROSETTA system. In total 50 persons participated in different phases of the development of the ROSETTA system: 14 persons with MCI/dementia, 13 informal carers, 6 professional carers, 9 dementia experts, 7 care partners, and 1 volunteer.

**Table 2.1 Overview participants in different phases of development process**

<table>
<thead>
<tr>
<th>Initial phase</th>
<th>Development phase</th>
<th>Fine-tuning phase</th>
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<tbody>
<tr>
<td>NL workshop</td>
<td>NL workshop</td>
<td>NL workshop in demonstration house</td>
</tr>
<tr>
<td>3 persons with dementia</td>
<td>4 informal caregivers</td>
<td>4 persons with dementia</td>
</tr>
<tr>
<td>1 professional</td>
<td>1 professional</td>
<td>5 informal caregivers</td>
</tr>
<tr>
<td>NL expert meeting</td>
<td>9 dementia experts</td>
<td>NL testing in demonstration house</td>
</tr>
<tr>
<td>GE individual interviews</td>
<td>3 people with (very) mild cognitive impairments</td>
<td>1 volunteer</td>
</tr>
<tr>
<td>Consultation care experts within project</td>
<td></td>
<td></td>
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<tr>
<td>7 care partners</td>
<td></td>
<td></td>
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</tbody>
</table>
Data collection

Users were involved in the initial development phase, in the design phase and in the fine-tuning phase. The data were collected between February 2010 and May 2011. In the initial phase two workshops were conducted in the Netherlands: one with three persons with dementia, and one with four informal carers. Besides these persons, one professional carer working in one of the Meeting Centers participated in the workshop. The workshop was lead by one of the researchers, assisted by another person taking notes. To explain the potential functionalities of the integrated ROSETTA system, a written scenario was developed that described the possible use of these functionalities in real life in relation to, and as means to support, activities of daily life. This scenario was read aloud during the workshops. The different functionalities presented in this scenario were discussed among the participants. Notes were made of all suggestions made by the participants. To help people recall their habits and need(s) of support during a normal day, time-specific pictures from waking up until going to sleep were shown in a PowerPoint presentation. At the end of the workshop participants were asked to rank the relevance of the proposed functionalities in relation to their needs. Furthermore, participants were questioned about the user-friendliness and if they felt privacy concerns regarding the technology and hardware to be used (e.g. sensors and cameras in the house). In Germany three individual interviews were conducted with people with (very) mild cognitive impairments in which the same scenario and questions were used. In the Netherlands, also an expert meeting was organised. During this meeting, the scenario was read aloud to the experts and they were asked to provide feedback on the relevance of the functionalities. Furthermore, the experts were consulted about the behaviours of persons with dementia they considered relevant to monitor for the Early Detection System (EDS) in order to detect deterioration in functioning timely. For this purpose the Dementia expert team was asked to rate the relevance of monitoring each of the behaviours and need areas as described in the Camberwell Assessment of Needs for the Elderly (CANE) (Reynolds et al., 2000). The CANE is a semi-structured interview to assess (un)met care needs and care use on 24 areas (social, medical, psychological, and (living) environment). Furthermore, the dementia care partners in the consortium received a ‘long list’ with behaviours that may occur in various stages of dementia (based on the Global Deterioration Scale (GDS) (Reisberg et al., 1982)). The dementia care partners rated two things: the occurrence of these behaviours in the mild and the more severe stages of dementia, and the relevance of monitoring this behaviour to detect changes in dementia.

Subsequently, an Excel file was created with the main proposed functionalities of the Elderly Day Navigator (EDN) and EDS. Care partners within the project were independently asked to prioritize these functions in two separate lists: One list with functionalities that are considered useful for people with mild cognitive impairment to early dementia (Global Deterioration Scale 3, 4), and one list with functionalities that are considered useful for people with severe to very severe dementia (Global Deterioration Scale 6, 7). Stage 5 of the GDS would represent a transition phase in which functionalities both from the mild dementia stage and the more severe dementia stage could be useful. The highest ranked functionalities of each list were marked as having high clinical priority.

Based on the results of the user and expert consultations and the technical feasibility, the to be developed functionalities of the ROSETTA system were selected and mock-ups of how these functionalities would look/work were made. These were discussed in a next phase in separate workshops with four different persons with dementia and four informal caregivers in the Netherlands and with five ambulant professional caregivers of the Red Cross in Germany. Notes were made of all feedback suggestions.
After this, the ROSETTA system was further developed and a functioning first prototype was installed in a demonstration house in The Hague. Again a workshop was conducted with four new persons with dementia and five informal caregivers who received a demonstration of the system and could test parts of the system themselves. Participants were asked for feedback on usefulness and user friendliness. Also, privacy issues were discussed. A next adapted version of the ROSETTA system was tested by a volunteer who stayed in the demonstration house for three days, used the ROSETTA system and was monitored by it.

The workshops and interviews were audiorecorded, except for the workshops in the demonstration house (where people walked around to test functionalities). Several project members were present to take notes during these workshops. The workshops lasted 2 hours for persons with dementia and 2.5 hours for informal caregivers. Data were collected to improve the system and to develop the final prototype which was field-tested in a later phase of the project in a controlled study.

Data analyses
Notes were taken at each workshop and interview, and the data were analysed qualitatively by categorizing and summarizing the results. Also, the data in the excel sheets on occurrence of different behaviours in dementia and relevance of monitoring them that were provided by individual experts, were analysed qualitatively and quantitatively and summarised. The results were discussed with the technical partners and were used as input for further development of the ROSETTA system.

Procedure
The study was approved by the relevant ethical committees in the Netherlands and Germany. In Germany, however, this study was restricted to persons with Mild Cognitive Impairment (MCI), because no approval was obtained from the Ethical committee of the Landesärztekammer Rheinland-Pfalz for participation of persons with a diagnosis of dementia. All persons with MCI or dementia and informal carers who participated provided their signed informed consent.

Results
Initial workshop and interviews with participants to assess functionalities
Based on the scenario, several potential functionalities of the integrated ROSETTA system were discussed with persons with dementia, informal and professional carers, and dementia experts. Their opinions regarding these functionalities are presented in Table 2.2. The functionality most often mentioned as relevant and useful by persons with dementia was help in cases of emergencies (with movement sensors). The functionalities most often preferred by carers were support with navigation outdoors and the calendar function. The least preferred functionalities were activity support and picture phone-dialling. Some functionalities were not considered useful, like providing an overview of activities that were performed during the day. Informal carers pointed out several other issues related to using assistive technologies. For example, they stressed that persons with dementia may have difficulties using buttons and they may have vision problems which could affect the usefulness of some proposed functionalities. The carers also wondered if people with dementia would be able to learn how to use new equipment. A major concern of the dementia experts was if people with dementia would take the mobile device with them when going outside and if it would be sufficiently charged.
Table 2.2 Opinions regarding proposed functionalities and use of technology in ROSETTA

<table>
<thead>
<tr>
<th>Support for memory: calendar and reminder for activities</th>
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<tr>
<td>Persons with dementia and carers indicate that this might be useful. It is suggested to list the activities only for one day, otherwise it could be confusing. A calendar function is also indicated to be “comforting” for the carer. Reminders for doing activities are perceived useful for activities like taking a walk, making dinner, measuring blood glucose (person with diabetes), and appointments with physicians. Also, reminders to take keys when leaving the house or to lock the doors are considered useful. Suggestions for which clothes to wear are not considered useful. Some carers worry that the person with dementia may not want to use such a reminder system. One of the persons with dementia indeed resents such a computer system, she says “I am not a machine and do not want to be instructed by one. I have my husband to remind me. He is ‘My living computer.’” After the first round of workshops it was decided to implement the calendar function. Design issues were decided after mock-up workshops and workshops in the demonstration house.</td>
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<tr>
<th>Support for memory: interrupted activities and activity support, giving compliments</th>
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<tr>
<td>One person with dementia mentions he recently forgot to turn off the gas, which made him feel anxious and might have resulted in a dangerous situation. So he would be interested in a reminder for interrupted activities. Another person would like to be reminded that a piece of clothing had been worn several times before and would like to receive a hint to choose something else to wear. Other persons with dementia are not interested in memory support because they feel they do not need it yet or they get help from their spouse. Carers think suggestions to support in activities (e.g. in making coffee) might be useful, but the device would have to be very patient (not give too much cues and reminders). Carers think that the system giving compliments when an activity has been performed successful might be considered too childish by the persons with dementia. Perhaps only a neutral remark like “the activity is finished” should be made by the system. Persons with mild cognitive impairment or dementia vary in their opinions: one person would like a compliment, a voice saying “well done,” one person cannot imagine how it would work, but it might be good, another person reacted “what’s that got to do with the system?”. The dementia experts warn that though the system may conclude that the person with dementia is preparing a meal, it will not know whether that meal has really been eaten. After the first round of workshops interrupted activity reminders and activity support were considered useful, providing compliments was not. Based on the (lower) priority given by participants and technical feasibility, the activity support was not implemented.</td>
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<tr>
<th>Social support/activities: picture dialling and photobook</th>
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<tr>
<td>Though all persons with mild cognitive impairment or dementia still use their normal telephone and address book, some of them think the picture dialling function may be useful. Carers think that seeing a photo of who is calling is very useful. One carer mentions that her relative only answers the phone if he knows who is calling. For being able to start a call, the photos will have to be large and clear enough. Dementia experts suggest showing photos on recognition of the voice of the person with dementia. One carer stresses that her relative is yet well able to use a regular phone. Persons with mild cognitive impairment or dementia also appreciate a digital photo book. They look at photos regularly and think that a digital photo book may even be nicer to look at then a normal photo book and would be used more often. The same holds for a digital life-history photo book. Dementia</td>
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</table>
experts suggest using older pictures when people have become more severely demented. There are some doubts among carers about the digital photo book: persons with dementia are not very used to use a computer, so it will need to be very simple to use. One carer mentions that they have a CD with photos of their grandchildren, which is watched often. Carers think a digital life-history photo book could be nice. One person with mild cognitive impairment would like to have cooking recipes on the screen and a possibility to make a shopping list on the screen. Dementia experts stress that it’s important to offer activity support attuned to personal preferences and abilities.

After the first round of workshops it was decided to implement the picture dialling and photobook function. Design issues were decided after mock-up workshops and workshops in the demonstration house. The voice recognition function as suggested by the dementia experts was at that time discarded due to low technological feasibility (it is difficult to implement it in a robust way).

Support in case of emergency (for instance a fall in the house)

Persons with dementia think this might be useful in the future, they do not need this at the moment. Carers think it might be useful and comforting; one of the persons with dementia falls regularly. They wonder if this detection of emergency situations will be possible in specific rooms and how reliable the detection will be. The proposed functionality detects that persons do not move in areas where movement is normally expected; for example sitting in a chair in front of the television will not be detected as an emergency situation. The question people pose is: if a person has a heart attack while sitting in front of the TV, it is an emergency situation, but will the system detect this? One carer would like to be informed when her relative is away from home for more than 1 hour. Dementia experts consider a fall detection system very useful.

After the first round of workshops it was decided to implement this functionality because of its high priority given and expected implementation feasibility. The functionality of monitoring life-signs (heart attack when sitting and watching TV) was discarded in the development stage due to high costs and low technological feasibility.

Wearing a wireless device

Persons with dementia do not consider this desirable. Carers would not mind a wireless device to be worn by their relatives, but they also think their relatives would not appreciate it.

After the first round (based on the output from the expert meeting) it was decided to refrain from wearing wireless devices.

Outdoor support (navigation, context based suggestions)

Several persons with mild cognitive impairments or dementia think the navigation support would be useful, one mentions that it would ‘save him some soles’. Another person thinks it would be helpful in the future and someone else remarked that it would not be helpful because she doesn't like to go outdoors on her own anyway. This remark is also made by some of the carers. They do think it would be comforting for them to know where the person with dementia is. Especially help in finding the way back home is considered important. To receive a suggestion to visit someone who lives nearby, is not considered useful, though one person would like to have a suggestion for a place to take a break on a longer walk. Dementia experts advice to only provide suggestions for visiting a person if it is known that this person is at home. A professional carer suggests that it might be helpful to receive a warning on the way that a busy traffic point is nearby. Spoken instructions will be
needed because of visual problems of the person with dementia. The dementia experts’ main concern is that persons with dementia will forget to take their mobile device with them. Their suggestion is to at least provide a sound reminder when leaving the house without the mobile device. After the first round of workshops navigation support was added to the list of functionalities to be developed. The context reminders were not included because of lower priority given and because proper implementation was perceived to be less feasible. Warnings of a busy traffic point were also discarded at that time because they were considered out of the project focus. The sound reminder when leaving the house without the mobile device was included in the system after the mock-up workshops.

Monitoring of activities/behaviour

This was not discussed with persons with dementia. Carers felt an overview of activities performed throughout the day would not be useful for the persons with dementia, though one person with dementia keeps a diary to help him discuss events with his daughter. The Dementia experts rated the following activities as useful to monitor: Looking after the home (cleaning), Food (unusual weight increase or decrease, water consumption), Self care (change clothes, number of times showering), Daytime activities, Memory, Mobility (falling incidents), Continence, Physical health, Drugs (right time and dose intake), Psychological distress (wandering), Deliberate self-harm, Inadvertent self-harm (fire), Behaviour (movement patterns), Alcohol, Company (telephone, visitors). After the first round of workshops it was decided to implement this functionality. Budgetary considerations (number of sensors needed to assess behaviour) restricted the number of behaviours that could be monitored (see also table 3 to see which behaviours are monitored). The decisions for that were taken during the development phase. For some of the activities it was also concluded that the technological or organisational feasibility was low. For example the weight sensors were discarded because the necessary sensors (in a chair or in the floor) were relatively expensive and it is difficult to assure that the targeted person is weighed instead of someone else. A scale with sensors has the disadvantage of having to motivate or remind persons to weigh themselves.

Use of cameras

One person with dementia said to accept this if the camera is only turned on when needed. Carers think it might be comforting and it would enable them to leave the home for a while. However, they think it is difficult to decide when it would be the right time to implement this functionality. They think the persons with dementia will not accept it. From the first round of workshops the use of cameras seemed acceptable and feasible. This was confirmed in later workshops in the demonstration house.

Expert opinions on behaviour and activities, relevant to monitoring in EDS

According to the dementia experts in the workshop, fifteen out of the 24 CANE domains of life, were considered relevant to monitor with the EDS (see also Table 2; activities/behaviours). From the ‘long list’ of behaviours in various stages of dementia (based on the Global Deterioration Scale), dementia experts from the consortium rated 20 behaviours as relevant to monitor because it could provide an indication of deterioration in functioning. These were related to memory (e.g., forgetting appointments and phone numbers that are called frequently; forgetting to switch off appliances; forgetting to wash themselves; not remembering where the toilet is; not knowing (anymore) how to finish an activity)
and behaviour related to daily activities (e.g. reduced or higher activity; less watching television; sleeping more frequently or longer; apathy; repeating activities; not eating and drinking enough; trouble getting dressed; not cleaning the house; and not doing groceries. Based on these assessments a list with functionalities of EDN and EDS was made, of which care partners were asked to prioritize the 10 most important ones for the earlier stages of dementia and 10 most important for the more advanced stages of dementia. The highest ranked functionalities of each list were marked as having high clinical priority. This resulted in two series of 11 prioritized functionalities, e.g. various EDN functionalities, like reminders and a calendar, and EDS functionalities like monitoring meal preparation, and bathroom usage. The technical partners rated the feasibility of these functionalities and the required number of sensors for monitoring this. Based on all this information, the ROSETTA system was designed and mock-ups were made.

Results on assessment of mock-ups of the ROSETTA interfaces
Persons with dementia, informal carers, professional carers and care partners rated the userfriendliness of the interfaces in ROSETTA. Remarks were made regarding some of the icons used (not clear and familiar enough), the amount of information provided on a screen (e.g. how many days visible in the calendar, how many contacts visible in the address book of the picture dialling function), the content of information provided (e.g. day and date added in the calendar, photos in the address book together with (sur)name, phone number), formulation of reminders (short and in a nice, non-demanding, tone) and multimodal presentation of reminders (text, pictures, voice). Preferences did vary between people with dementia and that is why it was suggested to provide the possibility to individually adjust the layout based on personal preferences. A description of the integrated ROSETTA system with the different functionalities is provided in Table 3, a photograph of the Elderly Day Navigator screen is provided in Figure 1. The first prototype was then developed and shown to persons with dementia and informal carers in the demonstration house. There were some critical comments regarding the EDN user interface, e.g. the size and layout of pictures, way of presentation of days in the calendar, and the wish to be able to choose between digital and analogue clock. These comments were used as input for further refinement of the system, though not all comments could be taken into account due to budgetary constraints. The participants did not report privacy concerns with regard to the cameras and sensors during these sessions. Subsequently the prototype was used by a volunteer who stayed in the demonstration house for three days. This resulted in several suggestions for improvement regarding the technical performance of the ROSETTA system. The final prototype in the ROSETTA project was tested in a controlled trial of which the results will be described in another article.

Discussion
This article describes the participation of persons with MCI or dementia, informal carers and dementia experts in the development of an integrated multimodal assistive technology solution to support community dwelling people with mild to severe dementia in their daily life, as well as their informal and professional carers. Previously developed systems were used as a starting point to develop the integrated system. Most of the suggested functionalities were appreciated by the participants. The most preferred functionalities were help in cases of emergencies (with movement sensors), outdoor navigation support and a calendar function. These functionalities are also proposed or developed in other assistive technology projects (Ikarashi et al., 2002; Gilliard and Hagen, 2004; Van Hoof et al., 2010) and relate to some needs of persons with dementia with regard to orientation problems, safety and the need for support in structuring the day. Some functionalities were not considered useful, like providing an overview of activities the person with dementia has performed during the day. Also activity support
was given less priority, in contrast to for instance the study by Sixsmith et al. (2007) where the wish-list of technology consisted of various types of support for activities. Informal carers expressed doubts about whether their partners would be able and willing to use assistive technologies. Apart from one person with dementia who did indeed resent technology, most participants with dementia were interested and receptive to new technologies. The dementia experts rated various behaviours as relevant to monitor with the aim to detect changes in functioning. Most of these behaviours were related to memory problems (forgetting appointments, forgetting to switch off appliances) and performance of activities (eating/drinking, repeating activities). A previous review showed that, in agreement with our expert assessment, many devices were developed in the last decade to compensate for symptoms in dementia, mainly for memory impairments, and that they proved to be useful, although it should be noted that the study designs were mostly rather weak (Lauriks et al., 2007).

Table 2.3. Description of the integrated ROSETTA system with the three subsystems

<table>
<thead>
<tr>
<th>Integrated ROSETTA system</th>
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<tr>
<td><strong>Devices</strong>: video home terminal (touch screen), mobile device, sensors, actuators, cameras, a Domotica Access Point (DAP) and a server.</td>
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</table>

**Elderly Day Navigator (EDN)**

This touch screen supports persons with mild cognitive impairment (MCI) to moderate dementia in their daily functioning in four areas: memory, social contact, daily activities and safety. To support memory the touch screen provides reminders that can be entered remotely by informal or professional carers. The screen also shows an agenda with the planned time to start these activities, an analogue clock and the current date. To support social contact there is a picture dialling function on the screen with a photo address book. To support activities, a person’s own collection of digital photos can be shown on the screen. And finally, there are several functionalities to promote feelings of safety, such as safety warnings on the screen (“you left the fridge door open, please close it”), a Help button, which enables easy telephone contact with a relative. The Help button on the mobile device may also be used to ask informal caregivers to direct them in finding the way home using the navigation support on a website that shows the location of the person with dementia and the path he has followed. The persons with MCI/dementia and/or informal carers may choose which functions of the EDN they want to use.
**Early Detection System (EDS)**

The Early Detection System (EDS) software records the daily pattern of living of the persons with MCI/ dementia for several weeks by analysing signals from the sensors in the house. In case of two-person households, the daily patterns of both persons are monitored together. After this period the software can:

- Automatically indicate whether there are significant changes in the day-to-day pattern of living.
- Generate graphs/indexes that offer a summary of the day-to-day pattern of living and reveal slowly occurring changes in it. These graphs allow professional carers and informal carers to monitor the status of the person with dementia, and to decide on the need for follow-up actions. To help analyse these graphs coloured markers are displayed: green markers indicating no changes in daily patterns, yellow markers for mild changes in daily patterns and red markers for significant changes in functioning.

The EDS focuses on sleep-wake rhythms, mobility inside and (time a person spends) outside the house, meal preparations, personal hygiene and number of reminders and emergency alarms. The persons with dementia and/or informal carers may choose which activities they want to have monitored.

**The Unattended Autonomous Surveillance system - Advanced Awareness and Prevention System (UAS-AAPS)**

This subsystem is able to detect emergency situations and generate alarms to care organisations. By using movement sensors and cameras in the house, emergency situations are detected, such as fall accidents and wandering in the house. In emergency cases, a message is pushed forward on the video home terminal and the mobile device, and the person with dementia is asked to confirm whether he is safe or not. When he is unsafe or when there is no response from the person with dementia, an SMS will be forwarded to the professional carer, who then can assess the situation via the speak-listen unit and the camera in the home of the person with dementia and decide whether help is needed.

*Figure 2.1. Elderly Day Navigator screen with agenda function activated.*
The use of different user perspectives (e.g. persons with dementia, informal and professional carers) in the development phase of assistive technologies has been proven valuable (Orpwood et al., 2004; Wherton and Monk, 2008). Also, in the ROSETTA project complementary feedback was provided by the different participants and it was considered useful to also involve persons with dementia, since they provided relevant feedback for the selection and the technical development of the system. This supports the expectations expressed in a recent review in which it was pointed out that persons with dementia are still hardly involved in the development of assistive technologies, but that this will probably happen more frequently as their involvement clearly has added value and may improve the acceptability of assistive technologies (Span et al., 2013).

Though research on assistive technologies for people with dementia is growing, there are still few products available to support persons with dementia effectively and to enable them to live longer independently (O’Keeffe et al., 2010). More research is needed to understand the opportunities and limitations of assistive technologies for people with dementia and to provide insight in how to effectively match the characteristics or functional requirements of assistive technologies with the biological, psychosocial and emotional features and needs of people with dementia (LoPresti et al., 2004; Topo, 2009; O’Keeffe et al., 2010; Meiland et al., 2012).

This study had several limitations. The sample size was rather small and consisted of convenience samples, and the sample in Germany could not include persons with a diagnosis of dementia (due to ethical regulations), where therefore persons with Mild Cognitive Impairment were included instead. Strengths of our study are that different types of users were included (participants with dementia, informal carers and dementia experts) and that the users participated in several phases of the development process: the initial phase of choosing functionalities and establishing priorities, the design phase and prototype testing in a demonstration house.

Our study contributes to scientific research by providing insight into the development of technological solutions that are adapted to the needs and wishes of the target group. Focus groups, interviews, and testing with a prototype of the assistive technology to be developed proved to be useful methods to collect relevant data that could be used for further development of assistive technology. The user needs were assessed mainly by means of focus groups and workshops or group interviews. A potential drawback of this method is that people may not express their own needs and wishes but go along with what is expressed by the more dominant participants in the group discussion. However, an advantage of this method is that discussion may be stimulated and more ideas and wishes for assistive technologies may come up. Separate workshops for people with dementia and for carers were conducted to provide an atmosphere where people could express themselves freely; e.g. where persons with dementia were not overruled by carers, and informal carers were able to also express negative aspects of caring without offending their relative.

The proposed ROSETTA system is expected to have several advantages compared to existing assistive technologies: it is a modular system, of which modules can be used or switched off dependent on the specific phase of the disease and wishes of persons with dementia. The ROSETTA system is beyond the state of the art by integrating different systems that usually are offered as a single system (Lauriks et al., 2007), making it difficult and expensive to offer a multifunctional solution, and by focusing more on automatic surveillance and alarm systems instead of the traditional alarm systems that need to be
worn around the neck or that have a relatively high number of false positive messages that do not relate to a real emergency situation.

From a societal point of view, the ROSETTA system will provide an alternative solution to satisfy the needs of the growing number of people with chronic diseases, like dementia. Due to the progressive nature of the disease, people with dementia who live at home have an increasing need for help from their family and professional caregivers. Family carers often feel unable to help and support their care-recipients and thus carry a heavy burden. Therefore, both the person cared for and the carer need increasing support with the progression of the disease. About 70% of dementia patients are eventually transferred to long-term care settings (Health council of the Netherlands, 2002). The overall societal challenge is to postpone, or avoid this admission as much as possible. As soon as proven effective, further implementation of (modules of) the ROSETTA system will be promoted as a useful, personalisable, multifunctional assistive technology solution to support the growing number of elderly people with chronic disease like dementia in different stages of the disease.

**Conflict of interest**

None.

**Description of authors’ roles**

FM carried out part of the research and wrote the paper, BH, MdB, TOM, PE, SF, and ISC assisted in data collection and reviewed the paper, JvdL co-designed the study, assisted in data collection and reviewed the paper, AJ and IK co-designed the study and reviewed the paper, RMD co-designed the study, supervised the research and reviewed the paper. Acknowledgments The project is funded by the EU (AAL project) and national (governmental) institutes of participating countries. Additional funding was received from Foundation Vita Valley.
References


CHAPTER 3

ROSETTA: Evaluating domotica


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Abstract

**Purpose:** This research aimed to integrate three previously developed assistive technology systems into one modular, multifunctional system which can support people with dementia and carers throughout the course of dementia. In an explorative evaluation study the integrated system, called ROSETTA, was tested on usefulness, userfriendliness and impact, with people with dementia, their informal carers and professional carers involved. The ROSETTA system was installed in participants’ homes in three countries: The Netherlands, Germany and Belgium.

**Method:** Controlled trial with pre- and posttest measures across three countries (randomized controlled trial in Germany; matched groups in the Netherlands and Belgium). Participants completed questionnaires for impact measurement and participated in semi-structured interviews regarding usefulness and userfriendliness of ROSETTA.

**Results:** All participants agreed that ROSETTA is a very useful development. They did not rate the user friendliness of the system highly. No significant effects were found on impact measurements.

**Conclusion:** All participants found ROSETTA a very useful development for future care, and would consider using it. Since ROSETTA was still in development during evaluation, a discrepancy between expectations and actual functioning of ROSETTA existed, which may explain the lack of findings on the impact of the system and the low appreciation of user friendliness.
Introduction

Our ageing society will cause a significant increase in persons with age-related physical and cognitive impairments of which dementia forms the biggest threat. This will result in a major burden on public health care. Dementia is a neurodegenerative disorder, characterized by a progressive decline in cognitive ability, with a combination of symptoms including impairment of memory, speech, action, perception and reasoning. This is often accompanied by changes in personality and behaviour. In its early stages, dementia usually begins with memory impairment and can often be misdiagnosed as normal forgetfulness. In later stages however, people with dementia increasingly become unable to perform tasks. This begins with relatively complex tasks, like cooking, yet eventually people become unable to perform even the most basic tasks of daily life, such as maintaining personal hygiene or eating. [1,2]. Dementia may be preceded by Mild Cognitive Impairments (MCI), in which people suffer impairment in a single cognitive domain, such as memory or language, but they experience no consequences on daily activities [3]. People with MCI are at a greater risk of developing dementia: it has been estimated that annually, 6 to 15% of people with MCI develop dementia [3, 4, 5].

When people become unable to perform tasks in their own home, they need intensive support to maintain independent living. Since professional care is limited and expensive, this support is generally provided by spouses, children or other family members. These non-professional caregivers are known as ‘informal carers’. An estimated 70% of community-dwelling people with dementia are cared for by informal carers [6]. Providing this care poses a great burden on them and frequently leads to conditions like depression and social isolation. Overburdening of the informal carer is the leading cause for institutionalization of the person with dementia [6].

Another major concern is the global increase of dementia prevalence: Since the main risk factor for dementia is age [7] (prevalence increases from 5-10% at 65 years to around 45% at 95 years and older [7]) and the global population is aging rapidly, the prevalence of dementia is expected to increase dramatically [8]. Additionally, with an expected decline in workforce, the world-wide ratio of potential working people to people with dementia will decrease from 63:1 in 2000 to an estimated 27:1 in 2050. In the Netherlands, it is estimated that this ratio will change even more dramatically from 43:1 in 2010 to 16:1 in 2050. [6,7,9]

To support both informal and professional carers in their care tasks, assistive technologies are becoming increasingly important. They support persons with dementia in dealing with the disease and improving their quality of life [10-12] and allow them to stay in their own homes safely for a longer period [13]. Assistive technology can help to reduce the burden of informal caregivers [14-18] and improve their confidence [19]. Professional carers may also benefit from including assistive technology into their daily practice, as it can give them more time for their care tasks [20], reduce staff anxiety [20], and improve work satisfaction [21]. The technologies may be very simple, like calendar clocks, to more advanced technologies like GPS-tracking systems, monitoring with sensor-based environments, and telecare services [11,12].

Four main domains of support by assistive technology (AT) can be distinguished: 1) prompts and reminders; 2) leisure; 3) communication and 4) safety [22]. Generally, many earlier developed systems
support only a single one of these domains, resulting in people being forced to purchase several systems if the need support in more than one domain. Also, many assistive technologies are developed without involvement of the target group of people with dementia [23] and are often initially designed for younger people, usually with non-progressive, traumatic injuries [24]. This makes it questionable whether they could be used by persons with dementia, and if these users would readily accept them. For categorizing AT for people with dementia, all symptoms and consequences of the disease should be taken into account. Thus, attention should not only be paid to compensations for cognitive and physical symptoms, but also to e.g. abilities to participate in (re)creational activities and in society [25, 26].

In the ROSETTA project a fully-integrated multifunctional modular system was developed, which, if needed, can address all previously mentioned domains to support persons with dementia, informal carers and professional carers in the subsequent stages of the disease. The integrated ROSETTA-system was designed to enable the combination of three previously developed assistive technology systems, i.e. the Cogknow Day Navigator [26,27,28], the EMERGE system [29] and the Unattended Autonomous Surveillance system (UAS) [30]. Though highly complex, this combination of systems was expected to offer the best possible support for the longest period of time, i.e. from the early stages of dementia (all three systems) until the more advanced stages (Emerge and UAS). Additionally, all of these systems were previously tested in European research studies, and were evaluated positively by users.

The three systems were adjusted to the needs and wishes of the target groups by means of a user-participatory design process, where people with dementia and carers, as well as dementia experts, were involved in all steps of the design process. In workshops, users could indicate both their support needs and their preferences for the ultimate lay-out and design of the system.

In the ROSETTA project the three adapted and integrated subsystems were called the Elderly Day Navigator (EDN), the Early Detection System (EDS), and the Unattended Autonomous Surveillance – Advanced Awareness and Prevention System (UAS-AAPS) (web overview: www.aal-ROSETTA.eu).

These subsystems aim to help people with MCI and dementia in performing the daily activities they indicated to be of importance. Examples that were given during workshops are: reminders about activities to be done during the day; support in recreational activities and social contacts; and increasing feelings of safety by monitoring behaviour patterns (thus allowing for early detection of changes in care needs) and by autonomous surveillance with sensors and smart cameras to detect potentially dangerous situations.

The integrated ROSETTA system was evaluated during a field test pilot on usefulness and user friendliness of the system, ethical issues in using the system, and on its impact on autonomy and quality of life of persons with dementia and on the feeling of competence and quality of life of their carers. Finally, among professional carers, it was rated on usefulness and user friendliness. In this article, we will report on this evaluation study.
Methods and Materials

Design
The study was initially set up as a randomized controlled trial (RCT) among people with MCI and dementia and their carers in the three countries: The Netherlands, Germany and Belgium. However, many prospective participants indicated they specifically wanted to be in the experimental group, and if not they would not participate at all. This made recruitment for an RCT within the timeframe of the project not feasible in the Netherlands and Belgium. Therefore, at second instance, it was decided to change the design in those two countries into a pretest-posttest control group design with matched groups. Matching criteria were severity of MCI/dementia and having a one or two person household. Other intended matching criteria were: relationship between caregiver-care receiver (spouse, child, etc.), age and gender of the person with dementia. In Germany, the RCT design was maintained. In the section ‘population and setting’, differences between the sample which participated in the RCT and in the pretest-posttest control group design are described. For the evaluation of the usefulness and user friendliness of the ROSETTA system among professional caregivers a one group post-test only design was used.

Ethical approval
The ethical boards of the participating research organizations in Germany and the Netherlands approved the study. In Belgium, external ethical approval of the study was deemed unnecessary by the Belgium partner (insurance and care) organization, as they considered the implementation of the system as part of the home care they provided.

Population and setting
Participants in the Netherlands were recruited among clients of Zorgpalet Baarn-Soest (home care section). Belgian participants were clients of Christelijke Mutualiteiten (Belgian health insurance company and care provider). Participants in Germany were selected through the German Red Cross and the Westpfalz Klinikum’s (academic hospital in Kaiserslautern, institute for anaesthesiology & emergency medicine).

The evaluation of ROSETTA was performed with in total 42 persons with either mild cognitive impairment (MCI) or dementia (19 in the Netherlands, 11 with MCI in Germany and 12 in Belgium), and 32 of their informal carers. Among these participants, the 11 persons with dementia in Germany were randomized to the experimental or control group (ne=5; nc=6), while the 31 persons with dementia in the Netherlands and Belgium were matched on a group level (ne=15; nc=16). The low number of participants was mainly due to the restricted budget for this project and the high costs of a full ROSETTA system, which did not allow for a large number of participants to get a system installed. Six professional home-care workers that during the intervention period as care providers had been using the ROSETTA system at a distance (3 in the Netherlands, 1 in Germany, and 2 in Belgium) participated in the evaluation of the usefulness and user friendliness of the system. For the recruitment of participants the following inclusion criteria were applied:

General inclusion criteria for all countries:
Included were participants with Mild Cognitive Impairment (MCI) or dementia living in the community and their informal carers. Other general inclusion characteristics included a maximum of 7 rooms in a
one story-house with a maximum size of 180 square meters and a maximum of 5 exterior doors. The house had to have the possibility for installation of wireless broad-band internet access (if not available already), since all signals of the ROSETTA system were transmitted wirelessly and uploaded through an internet server. In all countries, both one- and two person household were recruited for the study. In two person households, the decision to install EDS or not was based on the wishes of the informal carer. EDN was not offered to those with more severe dementia (Global Deterioration Sale (GDS) >5) [31], because they would likely not be able to learn how to independently utilize this system.

Specific inclusion criteria for the Netherlands:
Severity of dementia: mild, intermediate or severe (GDS 3 to 7).
Use of ROSETTA: All functionalities (EDN/EDS/UAS-AAPS) of the ROSETTA system.

Specific inclusion criteria for Belgium:
Severity of dementia: Intermediate or severe (GDS 5 to 7).
Use of ROSETTA: Focus was exclusively on the UAS-AAPS system, since fall- and wandering detection are most relevant in the intermediate and severe stage of dementia.

Specific inclusion criteria for Germany:
Severity: Mild Cognitive Impairments (GDS 1 to 3). Due to German regional ethical laws regarding medical research with people, people with a diagnosis of dementia were not allowed to participate, therefore in Germany only people with a diagnosis MCI were included.
Use of ROSETTA: All functionalities (EDN/EDS/UAS-AAPS) of the ROSETTA system.

Professionals: All professional home-care workers that had used at least one subsystem of the ROSETTA system in the houses of people they cared for, were invited to participate in an online survey. This was done through the involved care organization in each country.

Intervention
The ROSETTA system was installed in the homes of the persons with mild cognitive impairment or dementia in the experimental group. After installation, participants received a training explaining how the system works. The effective usage period varied from half a month (which was the case for one participant, recruited as replacement for a drop-out) to eight months. Average use was nearly four months. This relatively short average period of usage was caused by three issues: First, some participants dropped out just before installation of the system was finalized in their homes; in their place, new participants had to be recruited. Second, it took quite some time to plan installation dates with informal carers, since the installation usually involved two full days of technicians visiting the home of the person with dementia, this shortened the intervention period. Third, technical issues often involved ordering replacement parts, which took up a large amount of time during which the system did not work. For installation of these replacement parts, it was then again necessary to plan a new installation date. The full ROSETTA system consisted of the following three subsystems designed to support people throughout the disease process, and on different need domains:

1) The EDN (Elderly Day Navigator): this subsystem supports persons with mild cognitive impairments to moderate dementia in their daily functioning in the areas of memory, social contact, recreational activities and feelings of safety. This support is provided through a video home terminal (touch screen)
and/or a mobile device. To support memory, the touch screen provided reminders for activities (for example “you have an appointment with the doctor at 10:00 am”). These reminders were configured remotely by informal or professional carers and were shown in an agenda containing all programmed activities and the time they were planned. Furthermore, an analogue clock and the current date were shown. To support in social contact there was a phone with a photo address book (see Figure 3.1 and Figure 3.2). The screen of the EDN was always switched on, so that people could always glance at it to view information, and to promote that they did not forget to use it.

![Figure 3.1. Example of photo address book.](image)

![Figure 3.2. Screenshot of the help function on the mobile device.](image)

To support in a recreational activity, a person’s own collection of digital photos could be viewed on the screen of the video home terminal (which could be uploaded remotely by informal carers). Finally, EDN offers several functionalities to promote feelings of safety. One of these functions is receiving safety warnings on the screen, such as “you left the fridge door open, please close it”. Another safety feature is a Help button, which enables direct telephone contact with a relative (a list of relatives which will be contacted sequentially through this button can be set up during installation) (see Figure 3.2). If this relative does not answer the phone, the message ‘Try another number?’ will be displayed on the screen, allowing the user to call the next person in line to help. The final number to be called is usually a professional care organization, available 24/7. The Help button on the mobile device could also be used when persons with dementia had lost their way outside. In that case informal caregivers could help them find their way home: through GPS technology, the informal caregivers were able to see on a webpage where the person with dementia was and which path they had followed. This information
could be used to guide the person with dementia home safely. The persons with MCI/dementia and/or their informal carers could choose which functions of the EDN they wished to use in their homes.

2) The Early Detection System (EDS) software: this subsystem records the pattern of behaviour in daily living of the persons with MCI/dementia by analysing signals from sensors in the house. In case of two-person households, the daily patterns of both persons are monitored. Within the ROSETTA system, EDS analysed the sleep-wake rhythm, mobility in- and outside the house, meal preparations, personal hygiene and the number of (emergency) alarms. The persons with dementia and/or informal carers were invited to choose which activities they wanted to have monitored. In the first two weeks after installation, the EDS software established a baseline through data from the sensors. After this baseline assessment, the software:

- Automatically warned carers if there were significant changes in the day-to-day pattern of living.
- Generated graphs/indexes that offered a summary of the day-to-day pattern of living and revealed any (slowly) occurring changes in it.

These graphs allowed professional carers and informal carers to monitor the status of the person with dementia, and to decide on the need for follow-up action. To help analysing these graphs, coloured markers were displayed: green markers indicated no changes in daily patterns, yellow markers indicated mild changes in daily patterns and red markers indicated significant changes in functioning. The EDS system is designed to enable further personalisation with additional sensors to register more activities and behaviours.

3) The Unattended Autonomous Surveillance system - Advanced Awareness and Prevention System (UAS-AAPS): this subsystem is able to detect emergency situations and generate alarms to care organisations. By using movement sensors and cameras in the house, emergency situations such as fall accidents can be detected. In emergency cases, a message was displayed on the video home terminal and the person with dementia was asked to confirm whether he was safe or not. When the person was unsafe or when there was no response from the person with dementia, a message was forwarded to the professional carer, who then could assess the situation via a speak-listen unit as well as via a still image from the camera in the home of the person with dementia and decide whether help was needed. Because of privacy concerns, the camera of the system only activated when the motion detectors did not register movement for a specified time (by default set at 20 minutes). When activated, software analysed the camera feed and decided if the person was motionless in a ‘safe zone’ (eg. sitting a chair) or in an ‘unsafe zone’ (eg. on the ground). If it was established that the person was in a ‘safe zone’, the camera would turn off again. If, however, no movement was detected and the person was in an ‘unsafe zone’, the alarm would be triggered and carers would be contacted. Analysis of all ROSETTA data was done securely on a local server (the ‘Information Broker’), transmission of data through the internet was encrypted.

Persons in the control group received care and support as usual. This usual care generally consisted of home care for household chores and/or personal care and day care. Some participants received extra care, for example help with food preparation or visits to the general practitioner.
**Measures**

All countries used the same measuring instruments for the selected outcome measures. In the Netherlands and in Belgium the questionnaires were offered in the Dutch language, in Germany the questionnaires were offered in the German language.

Primary outcome measures:
- Usefulness and user-friendliness were measured with self-developed semi-structured questionnaires for both the persons with MCI/dementia and for their informal carers, which covered all aspects of the ROSETTA subsystems and included questions on ethical issues as well.
- Perceived autonomy of the person with MCI/dementia was measured with a scale which included relevant items from the Mastery scale [32] and the WHOQOL-100 [33].
- Quality of Life of the person with MCI/dementia was measured with the Quality of Life in Alzheimer’s Disease scale (QOL-AD) [34]). Informal caregivers filled in two additional questions about their overall judgment of their own quality of life taken from the minimum dataset of the Dutch National Programme for Elderly Care (MDS-NPO).
- The feeling of competence of informal carers was measured with the Short Sense of Competence questionnaire (SSCQ) [35].

Secondary outcome measures:
- Delay of nursing home admission of the person with MCI/dementia was assessed by registering nursing home admissions of participants in the study.
- Care needs were measured by the Camberwell Assessment of Need for the Elderly [36].

Additionally patient and caregiver characteristics were measured to describe the study sample:
- Severity of dementia was measured by the Mini Mental State Examination (MMSE) [37]. This variable was also included as a potentially confounding variable.
- The caregiver management strategy was assessed by means of a Dutch questionnaire on ways of caring for a person with dementia [38].
- Use of services was measured with the Use of Services questionnaire [39].

Other methods used:
At the end of the trial a focus group was performed with informal carers in the Netherlands to evaluate the experiences in using the ROSETTA system and to discuss issues regarding future implementation of the ROSETTA system. The focus group was led by an experienced researcher and was audio-taped for future analysis.

Professionals:
At the end of the trial an online questionnaire was filled in by professionals of the participating care organizations to assess the usefulness and user friendliness of the system (with a.o. items from the USE-questionnaire [40], changes in contacts with clients, bottle-necks, positive experiences and satisfaction in using the system, and the impact on job satisfaction, measured with the Leiden Quality of Work Questionnaire [41]).
Procedure
Recruitment procedure: Participants were selected through care organizations in the three countries. Health care professionals of these organizations sent letters to the potential candidates. In Germany, additionally, an information meeting was organized for potential participants. Participants who were interested to participate in the study were advised to consider participation. After a week a care professional contacted them again. If they agreed to participate, they were invited to sign the informed consent form and an appointment for the first interview (baseline impact measurement) in their own home was made. Professional caregivers who used the ROSETTA system were recruited via the participating care organizations.

Measurement procedure: Pretest measurement took place after signing of the informed consent form and – in the experimental group – before installation of the ROSETTA system. Post test measurement took place at the end of the trial. Measurements and interviews were performed by experienced researchers and interviewers from the respective countries. At the end of the trial the online questionnaire was sent out to professionals and a focus group was organized for informal carers.

Data analysis
Descriptive analyses were performed using SPSS Statistics version 20 to describe baseline characteristics of the study sample and the answers to the structured questions in the semi-structured interview on usefulness and user friendliness. The qualitative data were summarized for the total ROSETTA system and for each part of the system (EDN, EDS, UAS-AAPS). Differences between groups at baseline, and between the drop-outs and the completers of the trial, were tested with relevant tests (such as Chi-square tests, Mann-Whitney U tests and t-tests). To test if participants in the Netherlands, Germany and Belgium could be treated as one homogeneous group in the overall analyses, we tested for differences between countries in background characteristics at baseline.

To study the effect of the ROSETTA system on primary and secondary outcome measures, univariate covariance analyses (ANCOVA) were conducted on the post-test data with pre-test data included as covariates. This strategy of analysis for data with related repeated measures is recommended in small samples [42]. (With data from different clusters, multi-level analyses are generally advised. However, in small numbers of participants within clusters in combination with a small number of clusters, as is the case in our dataset, these analyses are dissuaded.) Levene’s tests of homogeneity were performed to test the assumption of equality in variance among the groups. Personal characteristics that differed at baseline and were related to the outcome variable (and thus potential confounders) were included as covariates in the analysis as well. All tests were conducted two-sided with \( \alpha \leq 0.05 \).

Results
Characteristics of study sample at baseline and drop-outs
In total 42 persons with MCI and/or dementia and 32 informal carers participated in the study. Characteristics of the study population are presented in Table 3.1. Six professional caregivers participated in the online survey assessing usefulness and user friendliness of the system and impact on job satisfaction. These professionals were all home care workers who visited the homes of participants.
Table 3.1. Baseline characteristics of the study population

<table>
<thead>
<tr>
<th>Persons with MCI/ dementia</th>
<th>Netherlands (n=19)</th>
<th>Germany (n=11)</th>
<th>Belgium (n=12)</th>
<th>Total (n=42)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exp (n=9)</td>
<td>Control (n=10)</td>
<td>Exp (n=5)</td>
<td>Control (n=6)</td>
<td>Exp (n=20)</td>
</tr>
<tr>
<td>Age, mean (sd)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Range</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>82,7 (9,4)</td>
<td>78,6 (4,2)</td>
<td>76,2 (5,3)</td>
<td>81,3 (3,0)</td>
<td>80,6 (7,6)</td>
</tr>
<tr>
<td>62 - 96</td>
<td>73 - 87</td>
<td>71 - 82</td>
<td>78 - 85</td>
<td>62 - 96</td>
</tr>
</tbody>
</table>

Sex: male          female

Living, n together alone

MMSE, mean (sd)

QOL-AD

Carers

Age, mean (sd) Range

Sex: male          female

Relation PwM/IC: partner child other

QOL-AD2, mean (sd)

Own QoL, mean, (sd)

Feeling of competence, mean (sd)

---

1 PwM = person with memory problems (MCI/dementia); IC: Informal Carer
2 QoL of person with memory problems, as answered by carer.

The mean age of persons with MCI or dementia was 81 years in the experimental and 78 years in the control group. Half of the participants were male, and half were living together. The majority of the participants in the Netherlands and Germany had (very) mild cognitive impairments; in Belgium all of the participants had severe dementia. This difference reflects the intended selective recruitment of different groups in the three countries. The informal carers in the experimental group had a mean age of 66 years and in the control group 69 years, and those in the experimental group were slightly more often female. Most carers were either partners or children of the person with dementia, 22% had another relationship with the person with dementia. From the persons with MCI or dementia who participated at baseline, eighteen dropped out during the field trial. A flow chart of the participants with
dementia and reasons for dropout is presented in Figure 3.3. The professional carers were all female and varied in age from 26 to 54. They had intermediate or higher professional education (e.g., nursing), sometimes followed by special courses. Most of them gained little or no experience in using the ROSETTA system during the pilot, only in Germany the professional carer gained much experience with the EDN part of ROSETTA.

**Figure 3.3 Flowchart of dropouts of persons with MCI/dementia**

For 24 participants with memory problems (MCI or dementia) pre- and post test assessments of outcome measures were available. Tests were performed to check whether the participants from the experimental and control group who completed the trial were comparable or differed at baseline, and the participants from the different countries could be treated as one homogeneous group or that variables, such as certain background characteristics, had to be included in the effect analyses as potential confounders. Participants from the experimental and control group only differed in gender, it turned out that there were significantly more males in the control group than in the experimental group (see Table 3.2). Between the Netherlands and Germany, participants differed on age and MMSE score, for which was corrected in the analysis by including these variables as covariates.

**Use of the system during the trial**
At baseline, the persons in the experimental group were offered all parts of the ROSETTA system (UAS-AAPS, EDS, EDN), except for Belgium where persons only received the UAS-AAPS system. Not all subsystems were fully working at the moment of installation of the system. Systems could be temporarily switched off, or turned in idle mode in case of multiple false alarms, maintenance or lacking functionality. For participants who used the ROSETTA system, the usage varied from half a month to 8 months. EDN support was available for the full period after installation. EDS was disabled for the majority of the installation time in most houses, though at the end of the field trial it worked well. Due to technical issues with the sensors and camera, the UAS-AAPS system was also not always available. In some participants' homes this system was not activated or it was removed, because some participants did not want the sensors installed. Another participant, for example, decided it took too long before the system was working properly, and removed all technology himself.
Table 3.2. Comparison of experimental and control group at baseline (completers only).

<table>
<thead>
<tr>
<th></th>
<th>Experimental</th>
<th>Control</th>
<th>Test statistic</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age carer, M (s d)</td>
<td>59.22 (12.93)</td>
<td>58.33 (19.68)</td>
<td>$t = 0.11$</td>
<td>0.91</td>
</tr>
<tr>
<td>Age PwM, M (s d)</td>
<td>81.00 (6.00)</td>
<td>76.38 (5.24)</td>
<td>$t = 2.01$</td>
<td>0.06</td>
</tr>
<tr>
<td>MMSE, M (s d)</td>
<td>21.36 (5.78)</td>
<td>21.77 (3.78)</td>
<td>$t = -0.20$</td>
<td>0.41</td>
</tr>
<tr>
<td>Living situation PwM, n (%)</td>
<td></td>
<td></td>
<td>$\chi^2 = 3.55$</td>
<td>0.17</td>
</tr>
<tr>
<td>alone</td>
<td>8 (72%)</td>
<td>5 (38%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>with partner</td>
<td>3 (28%)</td>
<td>6 (46%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>with others</td>
<td>0</td>
<td>2 (15%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Carer sex, n (%)</td>
<td></td>
<td></td>
<td>$\chi^2 = 0.00$</td>
<td>1.00</td>
</tr>
<tr>
<td>male</td>
<td>2 (22%)</td>
<td>2 (22%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>female</td>
<td>7 (78%)</td>
<td>7 (78%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>PwM sex, n (%)</td>
<td></td>
<td></td>
<td>$\chi^2 = 7.24$</td>
<td>0.01</td>
</tr>
<tr>
<td>male</td>
<td>1 (22%)</td>
<td>9 (22%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>female</td>
<td>8 (78%)</td>
<td>4 (78%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiving style, n (%)</td>
<td></td>
<td></td>
<td>$\chi^2 = 2.81$</td>
<td>0.42</td>
</tr>
<tr>
<td>nurturing</td>
<td>2 (22%)</td>
<td>4 (44%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>supporting</td>
<td>4 (44%)</td>
<td>3 (33%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>confronting</td>
<td>0 (0%)</td>
<td>1 (11%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>none</td>
<td>3 (33%)</td>
<td>1 (11%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

PwM = person with memory problems (MCI/ dementia)

Usefulness and user friendliness
Participants were questioned about their opinions on the usefulness and user friendliness of the ROSETTA system and its specific subsystems. It should be noted, however, that participants varied in use of specific systems and duration of usage. Furthermore, participants with dementia were only actively interacting with the EDN subsystem and not with the EDS and UAS-AAPS system as these work automatically without user involvement. As a result of this it was not always clear to participants which functionalities belonged to which subsystems (EDN, EDS, UAS-AAPS). With the EDS and UAS-AAPS the carers were involved when using the EDS web interface and in case of alarms respectively.

Both people with MCI/ dementia (n=10) and informal carer (n=9) judged the overall ROSETTA system to be a very useful development and agreed that systems like this would very likely be necessary to properly support people with dementia in the future. Despite technical difficulties, participants indicated that the system is very useful and that they were happy with it. They were very satisfied with the technical support provided in cases of problems with the system. Three informal caregivers described the system to have had a noticeable impact on the life of their family member with dementia: They indicated that it was “more comforting”, and that it offered “a safer feeling, [like] an extra pair of eyes watching her” and “[feelings of] more security and confidence”. Carers indicated they felt “safer, [they got] more rest at night”, and they experienced “a little less burden”.

Professional carers were ambivalent in their opinions on the system. One carer indicated that she was “convinced this system kept the person with dementia at home longer”, whereas one other indicated that the system “did nothing”. Other remarks about the usefulness of the system as a whole focused on technical issues encountered during the trial, like “[It gives me] more security and confidence, but [there are] so many problems that one can’t rely on it now” or “A good idea, it would have worked if
the system didn’t have this many faults”. This was confirmed during in-between interviews, in which it was indicated that participants thought the system is very useful, but that they could not depend on it and therefore hardly felt safer.

Partly because of the technical issues, the user friendliness of the overall ROSETTA system was not rated very high by informal caregivers or by persons with dementia; the system was experienced as complex and hard to work with. Half of the ten persons with MCI/ dementia indicated at post-test that at some point during the trial, they had doubts about their participation in the study. Reasons for persons with MCI/dementia to doubt were for example, that “the system is too hard to understand”. Informal carers had fewer doubts about their participation, only one expressed doubts because were concerned what the ‘technical people’ would install in their house. Concerns about privacy or whether or not their family member would cognitively be “too good for this” were mentioned occasionally.

During in-between interviews people also indicated that they recognized the importance and usefulness of the system, but had not realized at the start of participation in the study that the development of the system was still ongoing.

EDN (Elderly Day Navigator)

Usefulness: Both the EDN homescreen and mobile device were considered useful by the three carers that actively used them. One of these carers indicated they thought that the EDN was the only thing still keeping their family member at home. Without the EDN, they indicated, their family member would likely be staying in a care home now. Three of the persons with dementia, as well as three carers indicated that the agenda on the EDN screen was the most useful function of ROSETTA. Two persons with dementia and three carers, however, indicated that the EDN was the least useful part of the whole ROSETTA system, and that they didn’t use it.

User friendliness: Regardless of how useful participants considered the EDN, they were generally not positive about its user friendliness. Especially the caregivers expressed difficulties with the system. For example, regarding remote configuration for the agenda and reminders, carers in the focus group said that they had trouble logging into the portal website, and that they had to save three to four times before a single message or reminder in EDN was actually saved. One of the carers in the focus group indicated he had given up trying to access this portal due to technical difficulties, despite being highly motivated to access the system at first. Informal caregivers also did not like the look of the portal; they felt it looked very outdated and complicated. It was experienced as especially frustrating that downtime of the portal website could happen without communication on the reasons for this, or how long it would take before the site was operational again. Informal carers of the participants really wanted to use the GPS navigation features to locate their family members, yet this functionality was most of the time unavailable, either due to technical difficulties, battery problems or reception issues of the mobile device. Informal carers were disappointed this did not work; they indicated it would have given them a great feeling of safety if it had worked since some of the participating people with dementia were known to get lost.

Of those people with dementia who had used the EDN touch screen for some time, 3 out of 7 indicated they had learned how to use it without help. Another 3 out of 7 could use it, but needed help. A major complaint about the home terminal was that the touch screen was both un-intuitive to use for older people who had never used a touch screen before, and that the responsiveness of the screen
was bad as well. This was mainly because the touch screen used an older form of touch screen technology (resistive instead of capacitive) because of economic considerations. Both informal carers and persons with dementia indicated this.

**EDS (Early Detection System)**

Usefulness: Very few opinions on the usefulness of the sensor-based EDS were collected. This is partly due to restricted usage of the system during the trial period because of technical problems, but also due to persons with dementia not realising that (the sensor based) EDS was installed in their home (as the system does not require interaction with users). Most people with dementia were in fact confused as to what exactly EDS registered in their home. The fact that people were not aware of the system confirms that the EDS is indeed unobtrusive. Since EDS did not function fully during the trial period, informal carers had very little opportunity to experience the full usefulness of information generated by EDS. This was confirmed during in-between interviews by three participants, who indicated that they “would look [on the web page with sensor data], but [it] hasn’t worked yet”. Most informal carers considered it especially useful to be able to see the sleeping and eating patterns of their family members – especially to check up if they actually did eat or sleep like they said they did: “Saying they’re doing something is different from actually doing it”.

User friendliness: Most of the user friendliness-related remarks concerning EDS are again related to the ROSETTA-portal site which was judged very user-unfriendly, since it often did not work during the trial, gave errors and required persons to try and log in multiple times. Persons with dementia judged the user friendliness of this EDS system differently than carers, since participants were hardly aware of the system. Most of them noticed the sensors and the camera, but did not mind them, and had no opinion on them.

**UAS-AAPS (Unattended Autonomous Surveillance-Advanced Awareness Prevention System)**

Usefulness: Most informal carers felt UAS-AAPS is a very useful system. One of them indicated that since the installation of the UAS-AAPS system, she turned off her cell phone at night, allowing her quieter nights and better sleep. Besides feeling more pleasant and at ease, persons with MCI/dementia also indicated at the end of the trial period that UAS-AAPS is “useful” (n=7) or “very useful” (n=3) to feel more safe and self-sufficient. During the trial with the UAS-AAPS system, 5 persons clearly had felt safer in their homes, 3 sometimes felt safer and 2 did not feel any safer with the support of the system. Professional carers agree the UAS-AAPS system is very useful to help persons live in their own homes for a longer time.

User friendliness: False alarms were experienced as bothersome, though informal caregivers in the focus group indicated they would “rather get 100 false alarms and 1 actual alarm, than risking missing out on getting the actual alarm.” For persons with MCI/dementia, these false alarms were bothersome as well; people disliked getting phone calls (sometimes at inconvenient times) asking if something had happened while nothing was wrong and they hadn’t even noticed that the system had triggered in the first place.

There were some incidents in relation to detection of falls. On three occasions, twice in the Netherlands and once in Germany, the participant had fallen but the system had not detected these falls. For one of these cases, this was likely because the person continued moving while on the ground, thus triggering the motion sensors and preventing an alarm. Though this (assessing non-movement instead
of detecting a fall) reflects correct functioning of the system, this limitation of the system was not fully understood by the carer who therefore had higher expectations of the system.

**Ethical issues**

EDS: EDS did not raise any privacy concerns for persons with MCI/ dementia, most of who indicated that they never noticed the system. All 10 participants with MCI/dementia who answered this question indicated that the presence of the sensors was ‘not uncomfortable or stressful at all’; nor did it bother anybody if other people would see the presence of the sensors, all 10 indicated this was “not bothersome at all”. This matched with the expectations of people about the system in the first place. The same was true for informal carers: None of the 9 informal carers interviewed at post-test indicated that EDS had been an issue, neither for themselves nor for their family members.

UAS-AAPS: There were minor issues regarding the privacy concerns raised by the UAS-AAPS supervision; most of the participants (both persons with dementia and carers) indicated that they were not uncomfortable at all (n=9) or only somewhat (n=1) uncomfortable with the system in the house. Also during the semi-structured interview persons with dementia indicated they had no privacy concerns regarding the system. On the other hand, most people did seem to have some negative feelings about the camera, more specifically about the red light on it. In most homes, this small light turned on occasionally when assessing suspected cases, which was experienced as somewhat uncomfortable (“Is it filming me now? Can it see me?”). One informal carer that participated in the focus group commented she had noticed that her aunt—who had indicated she had no privacy concerns—had recently started sitting in another chair; the one the camera was not facing (focus group). In the semi-structured interview more persons with dementia commented specifically on this light: “[it bothers me] only when that light turns on “[it] feels strange when the camera suddenly switches on”. Despite this, however, only 1 participant indicated that the camera’s ability to see him was “somewhat bothersome”, the other 9 participants all indicated that the presence of the camera was “not bothersome at all”.

**Impact of (sub) systems on main and secondary outcomes (PwM, carers)**

The results show that overall there were no significant differences in background characteristics between the experimental and control group at baseline, except for the gender of the person with memory problems. There was a trend that persons in the control group were younger (t=2.01, p=0.06). There were differences between the countries: Participants from the Netherlands and Germany differed significantly on mean age and MMSE score at baseline, with the German group being significantly younger and less cognitive impaired (higher MMSE scores). Informal carers’ age and gender did not differ significantly between the countries.

The ANCOVAs, using baseline scores together with age and MMSE as covariates, show that there were no significant differences on primary and secondary outcome measures between participants who used the ROSETTA system and those who received usual care (the control group) see Tables 3.3 and 3.4).
Table 3.3. Analysis of covariance on primary outcome measures

<table>
<thead>
<tr>
<th>Test</th>
<th>Baseline</th>
<th>Posttest</th>
<th>Statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Experimental</td>
<td>Control</td>
<td>Experimental</td>
</tr>
<tr>
<td>QoL-AD (PwM) total (sd)</td>
<td>38.10 (1.90)</td>
<td>33.67 (1.56)</td>
<td>36.10 (6.86)</td>
</tr>
<tr>
<td>QoL-AD (Carer) total (sd)</td>
<td>31.89 (2.05)</td>
<td>29.00 (.96)</td>
<td>30.25 (6.74)</td>
</tr>
<tr>
<td>Perceived autonomy (PwM) (sd)</td>
<td>39.10 (2.37)</td>
<td>38.83 (1.62)</td>
<td>35.80 (8.97)</td>
</tr>
<tr>
<td>Grade for QoL (Carer) mean (sd)</td>
<td>7.89 (.40)</td>
<td>8.00 (.27)</td>
<td>7.06 (.69)</td>
</tr>
<tr>
<td>Feeling of competence (Carer) (sd)</td>
<td>4.13 (.40)</td>
<td>5.30 (.37)</td>
<td>4.13 (1.45)</td>
</tr>
</tbody>
</table>

PwM= person with problems (MCI/ dementia)

Table 3.4. Analysis of covariance on secondary outcome measures

<table>
<thead>
<tr>
<th>Test</th>
<th>Baseline</th>
<th>Posttest</th>
<th>Statistic</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Experimental</td>
<td>Control</td>
<td>Experimental</td>
</tr>
<tr>
<td>MMSE (PwM) total</td>
<td>21.36 (1.74)</td>
<td>21.73 (1.24)</td>
<td>21.40 (3.40)</td>
</tr>
<tr>
<td>CANE (PwM) number of unmet needs (sd)</td>
<td>1.00 (.38)</td>
<td>.31 (.18)</td>
<td>2.10 (2.23)</td>
</tr>
<tr>
<td>CANE (Carer) number of unmet needs (sd)</td>
<td>3.09 (.70)</td>
<td>.62 (.29)</td>
<td>2.18 (.64)</td>
</tr>
<tr>
<td>CANE (PwM) number of met needs (sd)</td>
<td>5.45 (1.02)</td>
<td>5.92 (.74)</td>
<td>7.10 (3.45)</td>
</tr>
<tr>
<td>CANE (Carer) number of met needs (sd)</td>
<td>1.00 (.38)</td>
<td>.31 (.18)</td>
<td>8.30 (5.08)</td>
</tr>
<tr>
<td>Total number of services used (sd)</td>
<td>3.73 (.72)</td>
<td>4.38 (.99)</td>
<td>3.80 (2.39)</td>
</tr>
<tr>
<td>Delay of nursing home admittance</td>
<td>3 participants admitted to nursing home</td>
<td>3 participants admitted to nursing home</td>
<td></td>
</tr>
</tbody>
</table>

PwM= person with memory problems (MCI/ dementia)

Discussion

Overall, users indicate that they find the ROSETTA system a very useful device, one which they think to be likely necessary in the future to provide good care to people with dementia. Some users indicated in the interviews and focus groups that the system had an impact on their lives and their feelings of safety and comfort. Especially the fall detection function of UAS-AAPS and the memory support through the EDN touch screen and mobile device were experienced as supportive. In its current form, the users of the system rated its user friendliness low. It was considered especially bothersome that
the system was hard and unintuitive to use. No significant impact was measured on the selected quantitative outcome measures (perceived autonomy, care needs, quality of life or performance of daily activities, and sense of competence of informal carers), which is most likely explained by the relatively short period of time that the system had successfully worked during the intervention period.

Both people with dementia and their informal carers considered a system like EDN useful to help maintain independence by reminding people with dementia of appointments, which informal carers can remotely set. Earlier research by Cahill et al (2007) confirms that assistive technology like this can help people with dementia maintain independent living and can promote their time orientation [43]. Many people also appreciated the ability of the UAS/AAPS subsystem to enhance feelings of safety. Research also points out that, since accidental falls are one of the leading causes of death in older adults [44], technology that can monitor fall situations is a highly relevant research topic [45, 46]. Rialle et al (2007) for example, also note that technologies aimed at increasing safety for people with dementia and lowering anxiety of informal carers, are among the most appreciated technological developments [47]. This research also confirms earlier research with regard to the overall positive attitude of people with dementia and informal carers towards assistive technology, and the expectation that most will readily accept the use of assistive technology [48, 49] if it can enhance safety and assist in self management and independent living. Moreover, people with dementia and carers who participated in this study also had no ethical or privacy concerns regarding the provided technology. They indicated that, as long as they can rely on the support of the system, assistive technology may help to promote feelings of safety and reduce feelings of burden and stress. This gives hope for future development of technological systems, and adds to a growing body of research evaluating the use of assistive technology, specifically with people with dementia [50, 51].

The ROSETTA study had several limitations, which may have influenced the study results. Firstly, this project was a research and development project in which the development took more time than expected. Therefore, the reliability of the system was not yet entirely consistent during the explorative evaluation research and nearly all users had to deal with unstable or malfunctioning systems, which has affected the results of the evaluation study. It also caused a discrepancy between user expectations and ultimate functioning of the system, which in turn may have caused a more negative assessment of the system: with participants expecting a fully-developed and (near-) 100% functioning system, the level of development of the system could not match expectations, and may have caused participants to rate the system markedly lower than they would have if the system had been already more stable. Secondly, the sample size of the study was small, due to the expensive equipment needed for each participant in the experimental group and the limited budget. Due to the fixed project time and the extended development period, it was not feasible to have persons use the equipment sequentially, which could have allowed for including more participants. Thirdly, it seemed not feasible to maintain the RCT design in the Netherlands and Belgium, what may have caused some selection bias in these countries. To limit bias, we used a matched control group. Finally, since participants could choose which ROSETTA subsystem they wanted to use, this may have biased the results, since those that chose specific systems (eg. using EDS or not) may have been biased towards use of such systems (eg. those uncomfortable with touchscreens may have chosen not to use the EDN).
This evaluation study showed that the ROSETTA system was anticipated very useful by the participants, especially when the major technical problems would be resolved. At the end of the project, the ROSETTA system worked well and some parts of it are currently being brought on the market. It would be therefore recommendable to repeat the impact evaluation study, with the improved version of the ROSETTA system. For future research, it is recommended that end-users with dementia are involved in the design of a new assistive technology device and in the evaluation of its user friendliness and usefulness. Evaluation of the impact of devices on daily life should only be performed when the system meets an acceptable standard of stability and reliability. Unfortunately it happens still too often that impact evaluations perforce start too soon in ICT development projects (see e.g. Jones, 2004 and Meiland, 2012) [27, 52]. The ROSETTA system was developed for people with mild dementia as well as for people with moderate dementia and their carers. Earlier research focused mainly on people with mild dementia, since these are generally more able to learn using new devices [51]. It is encouraging that people with more severe dementia can also be served by assistive technologies and may also benefit from it.

Acknowledgements
We would like to thank all people with dementia and their carers that participated in the workshops, focus groups and the evaluation trial as well as their professional carers who participated in this study.

Declaration of Conflicting Interests
The Authors declare that there is no conflict of interest.

Funding Acknowledgement
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Table 3.5. Summary table

<table>
<thead>
<tr>
<th>What was already known about the subject?</th>
<th>What this study added to our knowledge</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Assistive technology is a useful addition to regular care to allow people with dementia to live in their own homes for a longer time.</td>
<td>• People with dementia and their carers find assistive technology a useful development to support good care.</td>
</tr>
<tr>
<td>• People with dementia and carers mostly desire assistance in their daily lives, for example reminding about activities to be done.</td>
<td>• People with dementia have little privacy or other ethical concerns with being ‘watched’ by assistive technology like software, sensors and camera’s.</td>
</tr>
<tr>
<td>• Carers desire assistive technology to aid with feelings of safety, by monitoring for falls and other dangerous situations. This can reduce their feelings of burden and stress.</td>
<td>• Given that a system works flawlessly, assistive technology can reduce carer stress and burden</td>
</tr>
</tbody>
</table>
References


CHAPTER 4

Into D’mentia: Designing a dementia simulator

Submitted as:
Hattink, B¹, Meiland, F.J.M.², Dröes, R.M.¹ (2018) Experiencing dementia from three perspectives: problems, adaptation and quality of life

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Abstract

Background: This study describes the preliminary research for development of Into D’mentia, a mixed-reality simulation that lets visitors experience a day in the life of someone with dementia. For an accurate representation of the experience of people with dementia, this study aimed to find the most recognized domains of experience.

Method: A literature search was performed for articles containing quotes by people with dementia about their experiences. These were categorized according to three perspectives of: problem areas; adaptation-coping aspects; or quality of life domains (QoL). We investigated in four focus groups with people with dementia and informal caregivers; as well as in a survey among professionals, which experience themes mentioned most in literature were recognized by participants.

Results: Ten articles that met inclusion criteria were found in literature. In focus groups, in particular aspects of adaptation-coping and QoL were recognized. The problem areas of the Dutch National Dementia Programme were recognized to a much lesser extent.

Conclusion and discussion: Most adaptation-coping aspects and QoL domains are well recognized by participants. In part based on experiences described in this study, a mobile dementia simulation was created, which is currently used in practice, and which was evaluated positively on impact and feasibility.

Keywords
Dementia; experience; informal care; quality of life; coping
Introduction

Dementia is a highly disabling, neurodegenerative disease, characterized by, among other things, cognitive impairments and disabilities in daily functioning, as well as changes in behavior. People with dementia gradually develop more severe impairment until they eventually require full-time care and become dependent on others for even their most basic tasks of daily living, such as eating and personal hygiene. This care is usually offered by informal caregivers: family members or friends, who offer this care free of charge and usually in addition to other obligations, such as care for their own family or employment. Offering this care is hard and can be stressful for caregivers (Van der Lee et al., 2014). There currently is no cure, and the disease is progressive, with a usual life expectancy of 7 to 14 years after diagnosis (Tom et al., 2015).

Psychoeducation has been shown to improve the understanding and empathy of caregivers and to support them in their care task (Hattink et al., 2015b). One example of psychoeducation are simulations that aim to help caregivers to experience what it is like to have dementia and specific disabilities. By experiencing the world ‘through the eyes’ of someone with dementia, caregivers are expected to gain more understanding of the behavior of people with dementia, and to therefore be better able to offer care. Earlier research showed that simulations are a good tool to promote understanding (Beville, Virtual Dementia Tour, 2003) and can be beneficial to both the caregiver and the person with dementia (Beville, 2003; Lamm, Batson & Decety, 2007; Schulz & Sherwood, 2008). A shortcoming of the current simulations is that they focus primarily on physical disabilities and neglect the emotional and social consequences of living with dementia, therefore providing a very limited view of what people experience in daily life.

Experiencing dementia

During the 90s of the last century, the focus of research gradually shifted from the dementia patient, who was generally studied from a medical perspective as ‘a collection of symptoms’ to the person with dementia and their experience. Several authors (Woods, 1999; Downs, 2000; McGolgan et al., 2000; Manthorpe et al., 2011) refuted the earlier statement by Zarit et al. (1985) who described informal caregivers as the ‘hidden victims’ of dementia, by stating that the people with dementia themselves are the true ‘hidden victims’, since their experience of the disease is usually ignored. Other work by Cotrell & Schulz (1993) also urged listening to the voices of those with dementia, challenging that the academic community sees people with dementia as ‘objects’ and that the neglect of opinions of people living with dementia themselves causes researchers to miss ‘valuable insight’ into the disease (Cotrell & Schultz, 1993; See also Keady & Nolan, 2003; Dröes, 2006). An important contributor to the research on personhood and experience in dementia is Kitwood, who in 1997 described the concept of ‘person-centered care’ (Kitwood, 1997).

Several authors explicitly paid attention to the perspective of the person with dementia in dementia care. One of the first was Feil (1982) whose “Validation approach” aimed to validate the experiences of people with dementia. Finnema et al. (2005) and De Lange (2004) focused on emotion-oriented care, and other researchers (e.g. Spector (2000), Harman & Clare (2006), and De Boer (2007)) also stressed the importance of seeing the individual with dementia as a person and to consider all their personal qualities.

In literature the earliest exploration started around 1997 following the works of John Kitwood, of the lived experience of dementia. This was done primarily through analysis of written accounts by people.
with dementia (Kitwood, 1997). Although these written accounts obviously provide valuable, first-hand information, they are rare, and they cannot directly be assumed to reflect the general or predominant experiences of persons with dementia. Later approaches explored the experience of people with dementia through (semi-structured) interviews. Although awareness of the importance of interviews for examining their experiences already dates back to the late 1980s (Wilson, 1989), it was not until the mid 1990s and early 2000s that these interviews were actually conducted. In 2000, Gillies performed one of the first substantial interview studies among 20 people with various forms of dementia, which resulted in interesting insights into the actual, lived experience of dementia (Gillies, 2000). Since then elaboration upon interview studies and an increasing focus on the person and their experience, revealed a wide range of experiences of people with dementia, which can be roughly divided into three categories: 1) the problems people experience in daily life, caused by dementia; 2) the manner in which they adapt practically, emotionally and socially to the changes dementia brings in their lives; and 3) how they experience their quality of life and what they find important for their quality of life.

The present study: research questions
In this paper we describe the preparatory study for the development of a dementia simulator that aims to help caregivers of people with dementia to experience what it is like to have dementia, taking into account the practical, emotional and social consequences of the disease. To make the simulation as realistic as possible, i.e. to present an accurate representation of how people with dementia experience living with the disease, we conducted a literature study, focus groups among people with dementia and informal caregivers, and a survey among professional caregivers.

The main research questions of the present study were:

1) What problems do people with mild to moderate dementia experience?
2) What practical, emotional and social adaptation problems do people with mild to moderate dementia experience and how do they adapt/cope in order to maintain a balance?
3) What do people with dementia experience as important for their quality of life?

Method

Design
Using the three experience perspectives (problems, adaptation/cop ing and quality of life) as a framework for our research, we aimed to map generally recognizable experiences of people with dementia that have a high impact on their daily lives and on that of their caregivers. We did this by:

a) performing a literature study searching for written accounts of the ‘voice of those with dementia’ (to qualify, papers had to contain quotes of people with dementia);
b) categorizing these quotes into the three experience perspectives (problems areas, adaptation aspects, QoL domains); and

c) checking if these findings were recognized and confirmed by people with dementia, their informal caregivers and care professionals. We did this by means of separate focus groups with people with dementia and with informal caregivers and a written survey among professional caregivers, in which they were asked if they recognized the inventoried experiences.
d) Finally, we checked with all of them which of the most frequently recognized domains they considered to have the greatest impact on daily life.

**Methods of data collection: Literature review, focus groups and survey**

- Literature study

A literature search in PubMed was conducted for studies written in English, containing quotes by people with MCI or dementia about their experience of living with dementia. Any study that only contained summaries or accounts by others than the person with dementia was excluded. The articles could contain quotes from people with dementia through interviews, questionnaires or writing. The quotes in the studies that met the selection criteria were analyzed by the authors (see Analysis). The PubMed search strategy was performed for articles since 2000 with the following key words: ("Dementia"[Mesh] OR "Alzheimer Disease"[Mesh]) AND ("experience"[Title] OR "views"[Title] OR "qualitative"[Title] OR "perspective"[Title] OR "accounts"[title] OR "fears"[Title] OR "stories"[Title]). The search resulted in a total of 471 articles of which 10 articles contained usable quotes by people with dementia. These were included for further analysis.

**Categorization of inventoried quotes:**

All quotes of people with dementia from the ten articles were categorized using the following three experience perspectives/models:

1) Problem areas of the Dutch National Dementia Programme (NDP; Meerveld et al., 2004). The NDP distinguishes 14 areas/themes in the ‘dementia career’ in which people with dementia and their caregivers may experience problems (the ‘problem areas’). The NDP was developed by the Dutch national Alzheimer organization, in cooperation with the Netherlands institute for health services research (Nivel). The 14 problem areas were based on a) literature study, b) (analysis of) interviews with people with dementia and informal and professional caregivers, c) comparison with care programs and additional literature, d) workshops with professional caregivers in the field of dementia care (housing, welfare, care and treatment) and e) try-outs in two regions of the Netherlands. The problem areas are described in terms of experiences as reported by informal caregivers and together form a more or less chronological path of the dementia experience. This includes, for example, the following themes: ‘the feeling that ‘something is wrong’; ‘being angry, frightened and confused’; and ‘experiencing loss’ (see also tables 1 to 3). We chose the NDP as a model since it was based on the literature, opinions of people with dementia and informal caregivers and was validated by professionals and experts in the field of dementia care, and because it offers a ‘timeline’ of problems experienced when the disease progresses (see table 4.1 for an overview of the NDP problem areas).
Table 4.1. The problem areas mentioned in the Dutch National Dementia Programme

<table>
<thead>
<tr>
<th>Dutch National Dementia Programme (14 problem areas)</th>
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<tbody>
<tr>
<td>1. Feeling that something is not right</td>
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<tr>
<td>(Forgetfulness; no longer recognizes people; can no longer perform certain actions)</td>
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<tr>
<td>2. What is happening and what can be done to help?</td>
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<tr>
<td>(Unknown what help is available; unfamiliar; no referral made after the diagnosis)</td>
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<td>3. Frightened, angry and confused</td>
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<td>(Dejected, no longer interested in activities and world; uncooperative; quickly irritated and irritable)</td>
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<tr>
<td>4. Managing on your own</td>
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<tr>
<td>(Can no longer perform familiar tasks; can no longer drive a car; carer has nobody to ask for help)</td>
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<td>5. Avoiding contact</td>
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<tr>
<td>(Withdrawal; inappropriate social behavior; carer is ashamed of behavior, avoids meeting people)</td>
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<td>6. Physical care</td>
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<td>(Do not look after themselves; can no longer dress or undress)</td>
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<td>7. Dangers</td>
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<td>(Accidents and near-misses (fire, falls); wanders off, gets lost)</td>
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<td>8. Health problems as well</td>
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<tr>
<td>(Medical problems; problems eating or swallowing, constipation; combination of medications)</td>
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<tr>
<td>9. Loss</td>
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<td>(Sad, defiant, frightened; difficulty accepting illness; carer saddened by regression)</td>
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<td>10. It’s all getting too much for me</td>
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<td>(Carer is stressed by care; carer sacrifices own social life; carer receives no support)</td>
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<tr>
<td>11. Forfeiting and losing control</td>
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<tr>
<td>(Carer experiences help as patronizing; carer feels threatened by help; carer feels dependent on help)</td>
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<tr>
<td>12. In good and bad times</td>
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<tr>
<td>(Carer feels duty to care for partner; carer does not acknowledge they are suffering from stress)</td>
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<tr>
<td>13. Breakdown in communication with professional care providers</td>
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<tr>
<td>(Professional and client lack of communication and coordination)</td>
</tr>
<tr>
<td>14. Resistance to admission</td>
</tr>
<tr>
<td>(Resists admission; carer postpones admission; negative perceptions of care or nursing home)</td>
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</tbody>
</table>

Problem areas displayed in bold were mentioned at least six times in the literature and recognized by people with dementia, informal caregivers, and professionals in the focus groups.

2) For the adaptation perspective the Adaptation-Coping model with its seven adaptive tasks was used. This model was developed by Dröes (1991, 2011; Finnema et al., 2000), based on the Stress-appraisal-coping model of Lazarus and Folkman (1984) and the Crisis model of Moos and Tsu (1977). The Adaptation-Coping model explains behavior and mood (disruptions) as the result of the way in which people deal with the practical, emotional and social consequences of dementia (adaptation) and how they cope with the stress this may cause. Examples of the seven adaptive tasks this model distinguishes are ‘dealing with one’s own disabilities’; ‘maintaining a positive self-image’; and ‘developing and maintaining social relationships’ (see table 4.2)
Table 4.2. Overview of the Adaptation-Coping model.

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<th>Adaptation-Coping model (7 adaptive tasks)</th>
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Adaptive tasks displayed in bold were mentioned at least six times in the literature and recognized by people with dementia, informal caregivers, and professionals in the focus groups.

3) For the quality of life perspective we used the list of quality of life domains reported by Dröes et al. (2006). They performed an explorative study, using interviews and focus groups to determine the domains of Quality of Life (QoL) deemed relevant by community-dwelling persons with dementia and people with dementia living in nursing homes and by their professional caregivers. The final list contains 12 domains of QoL (e.g. affect, self-esteem; enjoyment of activities; physical & mental health; see table 4.3 for the full list).

Table 4.3. Overview of the Quality of Life domains

<table>
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<th>Quality of Life domains (12 domains)</th>
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</table>

Domains displayed in bold were mentioned at least six times in the literature and were recognized by people with dementia, informal caregivers, and professionals in the focus groups.
Focus groups
Participants and setting: For the focus groups community-dwelling people with dementia and informal caregivers were invited who participated in the Meeting Centres Support Programme for people with dementia and caregivers in the Northern and Southern parts of the Netherlands (Amsterdam and Tilburg). Separate groups were organized for people with dementia and caregivers. Participants for the focus groups were either selected by the coordinator of the center (this was the case for people with dementia in Amsterdam), or all visitors on a specific day who consented to take part in the focus group were invited to participate (everybody agreed; this was the case with caregivers in Amsterdam and people with dementia and caregivers in Tilburg).

The average age of people with dementia (n=13) in Tilburg was 76.8 years old; the average age of informal caregivers in Tilburg (n=9) was 74.2 years old. No data were collected on the age of people with dementia in Amsterdam (n=5) or of caregivers (n=6). In both Tilburg and Amsterdam all informal caregivers were partners of people with dementia. Five of the people with dementia and caregivers participating in the focus groups formed a couple. Of the other meeting center visitors, either the caregiver or the family member with dementia took part in the focus groups.

Content of the focus groups: All collected themes from the three experience perspectives (problem areas, adaptation aspects, QoL domains) that were mentioned six times or more in the literature, were discussed in the focus groups. Several quotes were used as an example for each of the three experience perspectives. At the end of the focus groups participants were also asked if they had any other experiences they felt were not discussed in the focus group.

Procedure: The four focus groups were held within the meeting centers. In Tilburg, the meeting with people with dementia was in the morning; the one with caregivers in the afternoon of the same day. In Amsterdam, both meetings were in the afternoon, on different days. The focus groups were led by the regular group leader, since people were expected to be most at ease talking to a familiar person. A researcher and a designer were present during these interviews and took notes, but did not get involved in the conversation. The conversations were recorded with an audio recorder for future reference; these recordings were used several times in the analyses to verify the context of quotes.

Survey among professional caregivers
Participants and setting: Researchers (around 20 people) of the Alzheimer center of the VU University medical center that had regular clinical contact with people with dementia as a health professional, as well as coordinators of all 100 Meeting Centers (throughout the Netherlands) were invited via email to participate in the survey, and were encouraged to distribute the online survey to other professionals. In total, 33 professional caregivers took part in the online survey. Their average age was 46.7 years (min 29.5; max 60.91). Among these professionals were Meeting Center managers (n=8); Meeting Center employees (n=6); psychologists (n=5); (research-)physicians (n=4); casemanagers (n=4); social psychiatric nurses (n=2); physical therapists (n=2), a spiritual counsellor (n=1) and a researcher (n=1). On average, they had 15.6 years of experience in geriatric healthcare (min 0.5 years; max 36 years).

Topics of the survey: All experience themes derived from the literature, which were mentioned six times or more were included in the questionnaire for professionals working with people with dementia. Questions focused on the occurrence of the experience themes in the three domains, regardless of whether they were experienced as a problem by people with dementia and the kind of impact they had on the lives of the person with dementia and caregiver according to the professional. Quotes were
used as an example for each of the perspectives and themes. For every perspective open-ended questions were also included where professionals could add additional information (e.g. 'Why do you think this item has a severe/not severe impact on daily life?').

Procedure: The questionnaire was administered through an online survey, giving professionals the possibility to fill in the questionnaire at a time of their choosing.

Analysis
All quotes derived from the literature study were independently analyzed and categorized by two researchers ([anonymized] and [anonymized]; 88% agreement) regarding their representativeness for one of the three mentioned experience perspectives. If authors disagreed at first they discussed the quote until consensus was reached. Results from the focus groups and professional caregiver survey were described both quantitatively, reporting how often certain themes were mentioned or were recognized by people with dementia, informal caregivers and professional caregivers, and how they impacted the lives of people with dementia and informal caregivers, and qualitatively by collecting quotes from the focus groups on the most recognized themes to gain a deeper insight into the themes and further enrich the results.

Results
Below, we describe the findings of the types of experiences retrieved from the 10 selected articles (literature review), categorized according to the three perspectives (problem areas, adaptation aspects and quality of life domains), as well as the results of the focus groups with people with dementia and informal caregivers and the survey among professionals on how they recognized the inventoried experiences within the three perspectives and how these impact their daily lives.

Literature
Only three domains of the NDP were included for further investigation in the focus groups, the other eleven domains were mentioned less than six times in the selected articles. NDP domains included were: ‘the feeling that something is wrong’ (NDP1); ‘being angry, frightened & confused’; and ‘experiencing loss’. With regard to the Adaptation-coping model, all adaptive tasks except for ‘adjusting to care settings’ were included for further investigation. Included Quality of Life domains were: Affect; self-image; attachment; social relations; enjoyment of activities; sense of aesthetics in the living environment; physical & mental health and being useful/giving meaning to life.

Results of Focus groups

A. Recognition of problems encountered throughout the dementia process (problem areas of NDP)
The ‘feeling that something is wrong’ (NDP1) was not widely recognized among people with dementia, to most the diagnosis came as a shock:

“[It came] as a shock, I never expected it. It took me a lot of time to come to terms with it. I cried, a lot.”

To most informal caregivers however, the diagnosis of dementia was less of a shock, most already had the idea something was wrong:

“She couldn’t do certain things. Like use the computer, or take care of financial matters. Or a mobile phone, she never learned how to operate a mobile phone.”
Fourteen (14/33; 42%) professionals recognized this and they all agreed that it is experienced as a problem.

The problem area ‘frightened, angry and confused’ (NDP3) was strongly recognized by most people with dementia:

“I once fell asleep on the couch. When I woke up, I didn’t know where I was. I panicked, it was terrible.”

Informal caregivers also report trouble with this, especially the sudden changes in personality were considered hard to deal with:

“Sometimes things are going along well, until all of a sudden, [it’s like] someone pulls the plug and he’s all confused again.”

Fifteen professionals (15/33; 45%) encountered this. All (15/15; 100%) those who encountered it agreed it was a problem that is experienced as very negative:

“People don’t recognize their house anymore, or their partner seems to be somebody else.”

Finally, ‘experiencing loss’ (NDP9) was strongly recognized, by people with dementia as well as caregivers. They described both the loss of practical things like being able to drive a car or bike; and more abstract things, like losing friends, memory or even their abilities:

“It is a confrontation, when you find out you can’t do certain things anymore.” (Person with dementia)

Fourteen professionals (14/33; 42%) encountered this. Eleven (11/14; 79%) professionals recognized this as a problem:

“People lose their identities and lose touch with themselves and their surroundings. This causes feelings of loneliness.”

B. Adapting to the practical, emotional and social consequences of dementia

Many people recognized the adaptive tasks outlined by Dröes (1991, 2011). All people with dementia mentioned that they used methods to find ways to deal with their own disability (A1). This focused mainly on handling memory impairment, for example the use of reminders and diaries. Caregivers recognized the use of this method of coping, but indicated that people generally did not use these coping mechanisms adequately: “[they are] staring at the agenda for hours” and “losing their diaries all the time”.

Most caregivers tried to help, something people with dementia experienced as unnecessary and as “a confirmation of them not being able to do anything anymore”. 25 (25/33; 76%) professionals recognized this in their practice. Unlike people with dementia, professionals mainly considered this way of coping as having a negative effect: Fifteen (15/25; 60%) of them thought people with dementia experience it mostly as a problem, quoting “becoming dependent is experienced as very difficult by people who used to be very independent, some had management level jobs. The memory loss can be extremely frustrating.”

The second adaptive task that is strongly recognized is maintaining an emotional balance (A2). Most people recognize early dementia especially as frustrating and emotional. Informal caregivers agreed on this and had trouble coping with this:

“She would take 20 minutes to make a cup of coffee. And when I came to help, she’d get mad because I was telling her what to do.”
Professionals agreed on this: 20 of them (20/33; 61%) recognized this, 16 (16/20; 80%) agreed it posed a problem for both people with dementia and their caregivers:

“People don’t tell anybody what is going on. They avoid social contact out of fear they will say something wrong, or have forgotten something important.”

Another important issue that arose is ‘maintaining a positive self-image, and expressing the desire to be respected as a normal human being’ (A3). Most people indicated it is terrible when people treat them differently, or when people talk to their caregiver about them, instead of talking to them directly. Also speaking ‘too childishly’ to people is experienced as very degrading. People mentioned they try to protect themselves from situations that may compromise their personhood by attending less social occasions. Informal caregivers recognize this coping behavior, and indicate that it can lead to increased isolation, since people tend to avoid social situations. Professionals agreed on this, 21 (21/33; 64%) recognized this in their daily practice; 19 (19/21; 90%) of them agreed it is experienced as a problem:

“People literally say they are ‘not crazy’, they don’t want to be treated like they are”.

‘Preparing for, and dealing with, an uncertain future’ (A4) was indicated to be hard for most people. While many learn to ‘live by the day’: “It comes anyway. I live each day”, especially those whose partner is their informal carer expressed a great fear of the future, should they lose their informal caregiver. One participant with dementia had already documented a wish for euthanasia in case she developed dementia. 17 (17/33; 52%) professionals indicated that dealing with an uncertain future is something they recognize among their clients. 17 (17/17; 100%) encountered this, all agreed that people experienced this as a problem:

“At day care, people with dementia may see others who have progressed further in the disease, it is frightening [for them] to see.”

The earlier mentioned enjoyment of the meeting center is the only thing most people recognized about the importance of ‘an adequate care relationship with professionals’ (A6), nothing else is specifically mentioned about the interaction with professionals.

Despite avoiding social occasions, many people indicate that ‘maintaining social relationships’ is very important to them (A7), especially to experience “the feeling that they still count for something”. Nearly all participants indicated that they enjoy visiting the meeting center and enjoy the presence of “like-minded people. You all share the same problem. It creates a sort of connection.”

Losing social contact can be very stressful, 20 (20/33; 61%) professionals indicated they recognized this, of whom 19 (19/20; 95%) agreed that this is experienced as a problem:

“People feel this is a loss, it is often difficult to change this. Others [caregivers or family] don’t understand that you don’t see the whole picture clearly, that you don’t understand if many people speak at once.”

C. Quality of Life (QoL)

On QoL, the participants of the focus groups confirmed seven of the domains found in the literature. ‘Affect’ (Q1) is considered rather important, with people mostly experiencing negative emotions in the early stages of their dementia. However, most realize this will not help in the long run and learn to cope with it. Especially changes in the relationship with the person with dementia were considered of major impact by partners:
“Things don’t go that naturally anymore. It’s gone. That’s bad.”

Ten (10/33; 30%) professional caregivers recognized problems with negative affect in people with dementia in their daily practice. Nine (9/10; 90%) of these indicated it has a mainly negative impact on people’s lives.

Here again, people noted that it is important to maintain a ‘positive self-image’ (Q2). Many people indicated they hated being treated differently, “People keep their distance. Like I have some contagious disease.”; and “People ask my partner how I’m doing, while I’m right there!” This also includes being ‘treated like a child’ with most people hating quotes like “you’re doing so well!” the most. Eight (8/33; 24%) professionals confirmed they recognized this as a problem in their practice.

Regarding the QoL domain ‘social contact (Q4)’, which was discussed together with adaptive task 4, people with dementia indicated that they did indeed value social contact a lot. Professionals also indicated that loss of social contact is experienced as a problem, 17 (17/33; 52%) professionals recognized this; 15 (15/17; 88%) professionals agreed on this, stating:

“It can work positively if a group of friends changes their activities for someone, but more often people with dementia don’t get invited at all. That gives them a sense of no longer counting, of having been cast aside.”

A markedly positive experience for almost all participants is enjoyment of activities (Q5), both general activities, and especially enjoying aesthetics of music, art and nature.

Company of children or grandchildren is greatly appreciated, as is simply going out for a walk, into town or the city (Q6). Especially nature is appreciated greatly by people:

“Nature, all those colors in the fall. I can enjoy that so much.”

This was confirmed by professionals, “It’s not all bad, there are still things to enjoy”, of whom fifteen (15/33; 45%) agreed they noticed this. Of these, nine (9/15; 60%) agreed this is mostly positive.

Of the QoL domain of mental & physical health (Q7) mental health is considered the most important for quality of life. Participants hardly mentioned physical health as important; most physical shortcomings are readily accepted as part of normal aging. Many people did, however, worry about their mental health, mostly about how their dementia would affect them in the future. People expressed fear of not being able to recognize their family members; and of being forced to go to a care home. Professionals agreed people experience this as a problem: Thirteen (13/33; 39%) recognized this from their daily practice and all thirteen (13/13; 100%) agreed this is experienced as negative, stating: “People are afraid of the effects of dementia, of decline and losing control over their lives.”

Finally, being useful to others (Q11) is an experience of major importance, as it provides people with a sense of purpose and self-worth, of ‘still counting’. Informal caregivers mentioned they would often let people with dementia participate in certain tasks, even if they could not do them properly anymore (e.g. letting someone help with the dishes; and then doing all the dishes again afterwards). 16 (16/33; 48%) professional caregivers indicated they recognized this, and all considered the inability to execute the task a negative experience for the person with dementia. One professional said:

“Being useful greatly increases the experienced quality of life for people.”
Discussion
The current study aimed to map the generally recognized experiences of people with dementia, specifically those that highly impact their daily lives, as input for a scenario of the Into D'mentia simulator.

In the selected literature we identified very few quotes that referred to the problem areas mentioned in the National Dementia Programme. The reason for this could be that these problem areas derived mainly from the opinions of informal and professional caregivers of people with dementia, whereas the present study searched for quotes of people with dementia themselves. Of the three NDP problem areas, two (‘frightened, angry and confused’ and ‘experiencing loss’) were well recognized by people with dementia as well as by informal and professional caregivers and were experienced as having an impact on their daily life. The six adaptive tasks of the adaptation-coping model presented to participants were all recognized to be especially important in the daily lives of people with dementia. People with dementia mentioned that ‘dealing with disabilities’ mattered most to them. Informal caregivers and professional caregivers confirmed this; the majority of them identified this as the most important thing for people with dementia. Seven of the presented eight of the 12 domains regarding QoL were well recognized by people with dementia; only ‘Attachment’ was not recognized widely in the focus groups. They especially found it important to ‘still count’, as described in the domain of ‘being useful’. Additionally, many people with dementia indicate a desire to remain useful and active in their communities in order to maintain their social relations.

Our findings regarding the general experiences of people with dementia are in line with recent findings reported in the literature. Regarding the problem area of being ‘frightened, angry and confused’ Peeters et al. (2010) found that dealing with an angry, frightened or confused family member was one of the most important issues informal caregivers desired help on. Regarding our findings on adaptation-coping, more specifically on ‘dealing with disabilities’, the literature mentions that as dementia progresses ‘each person will find their own way of coping with, and reacting and adapting to, the changes that dementia brings’ (Dewing & Keady, 2015). They recommend that caregivers ‘treat the person with dementia as an individual, and value them as such’ (Dewing & Keady, 2015). The adaptation-coping and QoL domain of ‘Maintaining a positive self-image’ is also often mentioned, indicated by both people with dementia and (informal and professional) caregivers. In other research we often find that maintaining a positive self-image is of great importance to people for successfully dealing with dementia (George & Bearon, 1980; Brod, 1999; Ettema et al., 2005). Regarding the QoL domain of ‘being useful’ the literature mentions that remaining ‘involved and active’ is often indicated to be of great importance to people with dementia (Phinney et al., 2007; Gerritsen et al., 2007). Phinney et al. (2007) conducted interviews and observations among community-dwelling people with dementia, and found that ‘the single most important driving force in their lives, was being active’. They indicated that this helped them ‘[feel] a sense of connection and belonging; and retain a sense of autonomy and personal identity’. Clare et al. (2008) studied conversations with people with dementia, and found that a similar domain they describe as “I’m alright, I’ll manage”, was strongly present among people with dementia (Clare et al., 2008).

It is remarkable that most of the themes that were well recognized in this study, concerned areas of adaptation-coping and quality of life domains. In fact, much research finds that people with dementia appear to focus much more on coping with their dementia, instead of experiencing problems. Examples include Preston et al. (2007), who interviewed people with dementia and found that people with
dementia 'actively work to preserve their identity and to cope with difficulties'; and Holst and Hallberg (2003), who found that many people with dementia try to find ways to 'experience living with dementia positively'. On the other hand, it could also be argued that people with dementia actively try to present 'a positive narrative', in which they need to carefully balance their feelings of 'value and worthlessness, struggling to remain someone of value' (Steeman, 2007).

The current study had several limitations. First of all, there may have been a selection bias, since in our study we collected quotes from scientific research literature, which were pre-selected by the original authors as relevant quotes from a larger body of quotes. We cannot be entirely sure if these quotes were fully representative of the experiences expressed by people with dementia in these studies. Additionally, the interviews in these original studies were conducted with different objectives in mind; they therefore focused on selected themes/subjects (e.g. one article focused specifically on 'fears and anxieties'; another focused specifically on the relationship with the informal caregiver). Secondly, since the focus was specifically on publications containing quotes from people with dementia based on interviews with them, other purely descriptive or observational research without quotes was not included in the current study. This limited the study focus to the experiences of people in the milder stages of dementia. Generalizations to the more severe stages of dementia therefore cannot be made based on our findings. Thirdly, in the current research, because of time constraints we only conducted four focus groups. Discussing the different aspects of the experience of dementia with more participants and/or a broader group of participants could have led to other or additional insights.

A strength of the study is that we first conducted a systematic literature search on the experience of dementia as expressed by people with dementia in international scientific research, and that we verified and checked the results for relevance with those involved, i.e. people with dementia, informal caregivers and professionals, in another country, as none of the selected papers from the literature search resulted from research in a Dutch population. In this regard, the study is unique, and adds interesting, cross-country verified insights to the current knowledge about the experience of dementia.

Scientific relevance - It was found that one perspective in particular, i.e. the adaptation-coping perspective, was recognized most by both people with dementia and their caregivers. This underlines its value for describing the experience of people with dementia, and warrants further research into the application of this model in research and practice. Also the majority of quality of life domains were well recognized by people with dementia and caregivers.

Societal relevance – The findings of this study were used to develop a scenario for the Into D’mentia simulator (for more information on the simulator please visit www.intodmentia.com; more information in Dutch at www.intodmentia.nl) in which informal and professional caregivers can experience a day in the life of a person with dementia. Inside the ‘main room’ of this simulator, which looks like an ordinary family kitchen, technology like projectors and sensors simulate the disabilities and social and emotional adaptive tasks people with dementia have to deal with every day. It enables caregivers to experience how they would react and cope with them, and the emotions they evoke in the person with dementia (and in themselves as a user of the simulator). A projected informal caregiver (the daughter of the person with dementia in the scenario) in the living room next to the kitchen allows for experiencing the quality of the interaction with the informal caregiver, and how this impacts the person with dementia. Additionally, a voice projected through speakers worn on the shoulders guides the
participant through the experience, giving recommendations on what to do, and encouraging the participant to reflect on situations that happen in the simulation. The Into D’mentia makes a truly personal experience and understanding of dementia possible, since every individual caregiver invited into the Into D’mentia will cope differently with the disabilities they are confronted with, and will feel touched or stressed by different events in the simulator. Additionally, after the simulation, participants are invited to reflect and elaborate on their experiences in a debriefing and a group session with other participants. The mobile Into D’mentia unit is used throughout the Netherlands. The main target group are informal and professional caregivers, although the Into D’mentia is also used to inform policymakers and other stakeholders who are in some way involved with people with dementia. The main aim is to help people better understand what it is to have dementia. This may contribute to better care for people with dementia and support for their caregivers. Recently, the experience was also adapted as a Virtual Reality experience (called ‘Dementiebril’ or ‘Dementia-glasses’), whose usability is currently being investigated by the Dutch institute for Mental Health and Addiction (Trimbos-institute). Results of a first pilot study into the feasibility and impact of this simulator were positive (Hattink et al., 2015a). The effectiveness of the Into D’mentia simulator is presently being tested in a longitudinal quasi-experimental study (Jütten et al., 2017).

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We would like to thank all the people with dementia and informal caregivers who have participated in the focus groups, and all professional caregivers who have filled in the online survey. The Into D’mentia simulator was developed in collaboration with Minase Consulting BV, De Wever in Tilburg, VU University medical center in Amsterdam, Tilburg University, Ideon in Vlaardingen, Gleijm & v/d Waart in Eindhoven and IJsfontein in Amsterdam. This study was funded by the IAB-4 programme with partial financial support from the Province of North-Brabant, ‘Midpoint Brabant’, ‘Fonds Sluyterman van Loo’ en ‘Stichting RCOAK’.
References


CHAPTER 5

Into D’mentia:
Evaluating a dementia simulator


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Samenvatting

Achtergrond: De meeste Nederlanders met dementie wonen thuis en worden daar verzorgd door mantelzorgers, familieleden of vrienden die deze zorg onbetaald leveren. Deze zorgtaak is zeer belastend, vergroot het risico op een slechtere gezondheid en zorgt voor minder sociaal contact. Veel mantelzorgers geven aan dat zij meer zouden willen weten over het gedrag van hun naasten.

Doel: Het ontwikkelen en evalueren van Into D’mentia, een nagebouwde woonkeuken, waarin bezoekers een dag in het leven van iemand met dementie doorlopen. Tijdens deze “dag” worden door middel van moderne technieken (zoals sensoren en projecties) de beperkingen van dementie gesimuleerd. Deze interventie wordt geëvalueerd op bruikbaarheid en gebruiksvriendelijkheid, en op zijn effect op empathie, attitudes ten aanzien van dementie, coping, belasting van mantelzorgers, persoonsgerichte zorgvaardigheden, en arbeidssatisfactie.


Resultaten: Deelnemers vonden Into D’mentia een zeer bruikbare en gebruiksvriendelijke ontwikkeling. Ze gaven aan dat de simulatie een goede weergave was van een dag in het leven van iemand met dementie en dat zij betere zorg konden leveren door deze ervaring. Ook gaven deelnemers aan dat zij nog vaak terugdenken aan hun ervaringen in de simulator, om gedrag van mensen met dementie beter te begrijpen.

Conclusie: De Into D’mentia biedt een unieke, laagdrempelige manier om mee te maken wat de beperkingen van dementie in het dagelijks leven betekenen. Gebruikers geven aan dat het een bruikbare en gebruiksvriendelijke innovatie is. Into D’mentia lijkt een geschikte methode te zijn om mantelzorgers en professionele zorgverleners te steunen.

Trefwoorden: dementie, technologie, evaluatie, persoonsgerichte zorg, mantelzorg
Abstract

**Background:** Most persons with dementia in the Netherlands live at home, where they are cared for by informal carers such as family members or friends, who offer this care unpaid. Their care task poses a high burden on these informal carers, increasing the risk of health problems and social isolation. Many informal carers indicate they want more information on the behaviour of those they care for.

**Aim:** To develop and evaluate Into D’mentia, a simulation set in a living kitchen in which visitors experience a day in the life of someone with dementia. During this ‘day’, modern techniques such as sensors and projections, simulate the limitations of having dementia. This intervention is evaluated on usefulness and user friendliness, and on its effect on empathy, attitudes towards dementia, coping, carer burden, person-centered care capabilities and care satisfaction.

**Research:** Nine informal carers and 23 care professionals took part in the research into the Into D’mentia simulation. Before and after their visit, they filled in several questionnaires, with, among others, their opinion on the usefulness and user friendliness of this experience.

**Results:** Participants found Into D’mentia a highly useful and user friendly development. They indicated that the simulation offered good insight in the life of someone with dementia, and that they could offer better care thanks to this experience. Participants also indicated that they often thought back on their experiences in the simulation, in order to better understand the behaviour of people with dementia.

**Conclusion:** Into D’mentia offers a unique, accessible way to experience the limitations dementia has on daily life. Users indicate that it is a useful and user friendly innovation. Into D’mentia appears to be a suitable method to support informal and professional caregivers.

**keywords:** dementia, technology, evaluation, person-centered care, informal caregiver
Inleiding

Achtergrond
Onderzoek van NIVEL en Alzheimer Nederland heeft aangetoond dat de zorg voor mensen met dementie een zware taak is voor mantelzorgers: 51% voelt zich tamelijk zwaar tot ernstig belast door het geven van mantelzorg. Vanwege het hoge percentage mantelzorgers dat risico op overbelasting loopt, is het vinden van een manier om mantelzorgers te steunen in hun zorgtaak noodzakelijk. Overbelasting vergroot bij de mantelzorger namelijk het risico op een slechtere gezondheid, leidt tot minder sociaal contact en is de voornaamste reden voor opname van de persoon met dementie in een zorginstelling.

Veel mantelzorgers geven aan dat zij graag meer informatie zouden willen over de symptomen van dementie en bijkomende gedragsveranderingen zodat zij meer begrip krijgen voor het gedrag van hun naasten. Dit kan een positief effect hebben: mantelzorgers die meer kennis hebben over dementie, hebben minder vaak last van depressies en verwacht wordt dat zij ook beter zullen omgaan met hun naasten, omdat zij door hun kennis bijgestelde verwachtingen hebben van de vaardigheden van hun naasten. Bovendien leidt beter begrip van het gedrag van een persoon met dementie tot meer empathie voor hun situatie, waardoor gevoelens van stress bij mantelzorgers kunnen verminderen. Wanneer de mantelzorger begripvoller omgaat met de persoon met dementie, kan dit zelfs achteruitgang in het cognitief functioneren van de persoon mee dementie vertragen.

Ook bij professionele zorgverleners wordt verwacht dat empathie voor mensen met dementie van belang is voor het bieden van goede zorg. Lagere empathie voor mensen met dementie wordt onder professionele zorgverleners bijvoorbeeld gerelateerd aan burnout. Dit idee is zeker niet nieuw: Florence Nightingale suggereerde halverwege de 19e eeuw al dat toekomstige verpleegsters “zichzelf in gedachten in de plaats van de patiënt moeten zetten, om de effecten van het gedrag van zichzelf en anderen op zichzelf te kunnen begrijpen.”

Een manier om meer begrip en empathie voor mensen met dementie te bereiken, is mensen zelf te laten ervaren wat het is om dementie te hebben. In eerdere projecten is geprobeerd dementie, en beperkingen van het ouder worden, te simuleren. De belangrijkste voorbeelden hiervan zijn de simulatie-ruimte ‘Virtual Dementia Tour’ (VDT) (Second Wind Dreams, 2002) en de simulatiepakken AGNES (Age Gain Now Empathy System, MIT, 2011) en GERT (Gerontologic Testsuit, Moll, 2011). In de VDT beleven deelnemers een aantal gesimuleerde fysieke en mentale beperkingen en moeten zij een aantal alledaagse taken uitvoeren. Professionele zorgverleners gaven aan dat deelneme aan de VDT hun mening over het gedrag van mensen met dementie sterk veranderd had. De simulatiepakken simuleren vooral fysieke beperkingen van het ouder worden, zoals verminderde spierkracht door middel van elastieken aan de ledematen, of slechter zien door middel van een wazige bril.

Het Into D’mentia project beoogt met een interactieve simulator waarin men het dagelijks leven van iemand met dementie kan beleven, meer begrip en empathie voor dementie te kweken bij mantelzorgers en professionele zorgverleners. In deze simulator, een mobiele, verplaatsbare cabine wordt met verschillende technieken een normale dag in het leven van iemand met dementie nagebootst: de bezoeker ervaart hoe het is om beperkingen te hebben en krijgt bief van de gevoelens die daarmee gepaard gaan. Voorafgaand aan de simulatie krijgen deelnemers een ‘briefing’ waarin zij voorbereid worden op wat zij kunnen verwachten en na de simulatie vindt een gesprek plaats over hoe zij de simulatie hebben ervaren. Om opgedane kennis te verdiepen en te delen, wordt in de week na het bezoek aan Into D’mentia een groepstraining aangeboden. In deze training worden deelnemers, onder
leiding van een docent, gestimuleerd om na te denken over hoe zij de kennis opgedaan in de simulator in de praktijk kunnen toepassen. Deze training is ontwikkeld in samenwerking met dementie-experts en wordt op locatie aangeboden door trainers van Into D’mentia, die hiervoor speciaal zijn opgeleid en tevens werkzaam zijn in de psychogeriatrische zorg.

In dit artikel wordt de evaluatie van Into D’mentia beschreven. Voor deze evaluatie is een pilotonderzoek verricht waarin primair de bruikbaarheid en gebruiksvriendelijkheid van Into D’mentia is onderzocht onder mantelzorgers en professionele zorgverleners. Daarnaast is exploratief nagegaan wat de impact is van deelname aan de Into D’mentia simulatie en groepstraining op de beleving, empathie, gevoel van competentie, en wijze van coping van mantelzorgers en op de beleving, empathie, belevenisgerichte vaardigheden, attitude en arbeidssatisfactie van professionele zorgverleners.

**Methode**

**Onderzoeksdesign**
Om de bruikbaarheid en gebruiksvriendelijkheid van Into D’mentia te evalueren werden door middel van semi-gestructureerde interviews en een vragenlijst de meningen van mantelzorgers en professionele zorgverleners verzameld. Een eén-groeps pretest-posttest design werd gehanteerd om exploratief de impact van Into D’mentia op beleving, empathie, gevoel van competentie, en wijze van coping van mantelzorgers en beleving, empathie, belevenisgerichte vaardigheden, attitude en arbeidssatisfactie van professionele zorgverleners te onderzoeken.

**Onderzoekspopulatie en –setting**
Aan het onderzoek konden mantelzorgers van mensen met dementie en professionele zorgverleners deelnemen, uit de regio Tilburg en Amsterdam. Met een poweranalyse13 werd berekend dat 64 deelnemers nodig waren om een middeldagelijks effect (Cohen’s d=0,5) te kunnen detecteren (met een power van 80%; alfa=0,05). Rekening houdend met een uitval van 20%, werd daarom gestreefd naar 80 deelnemers. Door vertraging in de ontwikkeling van Into D’mentia en beperkte interesse om aan het onderzoek deel te nemen, is dit aantal van 80 echter niet gehaald. Omdat de Into D’mentia tijdens de onderzoeksperiode in Tilburg opgesteld stond, deden alleen mantelzorgers en professionele zorgverleners uit Tilburg mee.

**Interventie**
In de voor het project ontwikkelde Into D’mentia simulator beleefden deelnemers in een nagebouwde woonkeuken een scenario dat verschillende beperkingen, alsmede de sociale en emotionele gevolgen daarvan, simuleert waar mensen met dementie tijdens een normale dag mee te maken kunnen krijgen. Onder andere geheugen- en oriëntatieproblemen, verwarring, handelingsproblemen, vermenging van heden en verleden en onbegrip door de omgeving worden gesimuleerd en negatieve en positieve gevoelens uitgelokt. De beperkingen worden nagebootst, en de emoties uitgelokt met behulp van onder andere sensoren, videoprojecties waarbij onder andere interactie plaatsvindt met een virtuele mantelzorger en een ‘innerlijke stem’, die klinkt via een speciaal voor deze interventie ontwikkeld speakervest en die de gebruiker door het scenario heen loodst. Doordat de Into D’mentia simulator in een verplaatsbare container gebouwd is (zie afbeelding 5.1), kan de interventie eenvoudig in verschillende regio’s worden aangeboden.
De gehele Into D’mentia interventie bestond uit vier onderdelen:

1. Een intake (5 minuten), waarin de deelnemer de benodigde attributen voor de simulatie kreeg, zoals het speakervest waardoor de ‘innerlijke stem’ klinkt. Ook werden tijdens deze intake de veiligheidsmaatregelen, zoals een noodknoop en nooduitgang, toegelicht.

2. Deelname aan de simulatie (20 minuten), waarin de deelnemer het scenario doorliep in de simulatieruimte.

3. Een nagesprek (15 minuten), waarin de eerste indrukken werden besproken, en waarin de deelnemer - indien nodig - ondersteuning kreeg van een coach.

4. In de week na de simulatie: een groepstraining van een dagdeel met andere deelnemers die de simulatie hadden ondergaan (apart voor professionele zorgverleners en mantelzorgers).

De interventie werd aangeboden in de eigen woonregio van de deelnemers. Deelnemers aan het onderzoek konden kosteloos meedoen aan de Into D’mentia interventie (simulator en training). Nu het onderzoek is afgerond kost een bezoek aan Into D’mentia 250 euro per bezoeker. Dit bedrag wordt voor mantelzorgers in de toekomst mogelijk vergoed door de verzekeraar.

**Meetinstrumenten**

Bij de mantelzorgers werden de volgende achtergrondgegevens verzameld: leeftijd, geslacht, opleiding, relatie tot de persoon met dementie, de periode dat zij zorgden voor hun naaste met dementie en het aantal uren dat zij besteedden aan de zorg. Ook werd de zorgstijl van mantelzorgers in kaart gebracht met de Caregiver Management Strategy vragenlijst (CMS). Bij de professionele zorgverleners werden de volgende achtergrondgegevens verzameld: leeftijd, geslacht, opleidingsniveau, en aantal jaren werkervaring in de zorg.
**Primaire uitkomstmaten**


**Secundaire uitkomstmaten mantelzorgers**

Secundair werd de impact van de Into D’mentia ervaring bij mantelzorgers onderzocht op de uitkomstvariabelen empathie, gevoel van competentie, copingstrategieën en kwaliteit van de relatie. Voor het meten van empathie werd de Interpersonal Reactivity Index (IRI) gebruikt. De IRI meet empathie aan de hand van vier subschalen: Fantasy Scale (verbeeldende empathie; α = 0.78 (bij mannen (M))/0.79 (bij vrouwen (V))); Empathic Concern (emotionele empathie; α = 0.71 (M)/0.75 (V)); Perspective Taking (cognitieve empathie; α = 0.68 (M)/0.73 (V)) en Personal Distress (persoonlijke stress; α = 0.77 (M)/0.75 (V)).

Voor het meten van Gevoel van competentie werd de verkorte Gevoel van competentielijst gebruikt (SSCQ, α = 0.7). De totaalscore werd berekend door de antwoorden op 7 vragen te dichotomiseren, waarbij scores t/m 3 de waarde 0 krijgen, en scores 4 en 5 de waarde 1.

Copingstrategieën werden geïnventariseerd met de Brief COPE (met drie subschalen: Emotion focused strategies (emoti-gerichte strategieën; α = 0.72), Problem focused strategies (probleem-gerichte strategieën; α = 0.84), en Dysfunctional strategies (dysfunctionele strategieën; α = 0.75)).

De kwaliteit van de relatie met de naaste wordt gemeten met enkele vragen uit de Longitudinal Study of Generations over de beoordeling van relaties, zoals “hoe hecht is het contact tussen u en uw naaste?”, en “hoe goed begrijpt u uw naaste met dementie?”

**Secundaire uitkomstmaten professionele zorgverleners**

Ook bij de professionele zorgverleners werd de hiervoor beschreven IRI lijst gebruikt om empathie te meten. Voor het meten van belevingsgerichte vaardigheden van professionele zorgverleners werd de Zelfbeoordelingsvragenlijst Belevingsgerichte vaardigheden in de Omgang met Dementerende ouderen gebruikt (BOD-lijst). Deze lijst meet de vaardigheden van professionele zorgverleners op drie
schalen: ‘Deskundigheid’ (α = 0.90), ‘Kennis’ (α = 0.82), en ‘Werken met een zorgplan’ (α = 0.90). Attitudes ten aanzien van dementie zijn gemeten met de Nederlandse vertaling van Approaches to Dementia Questionnaire (ADQ), die aan de hand van 19 vragen de attitudes ten aanzien van (de zorg voor mensen met) dementie meet\textsuperscript{22}; α = 0.83; vertaald door Trimbos Instituut, 2010). De ADQ heeft twee subschalen: de ‘Hope’ subschaal (Hoop; α = 0.76), en ‘Personcentered care’ (Persoonsgerichte zorg; α = 0.85). Arbeidstevredenheid werd gemeten met de Maastrichtse Arbeidstevredenheidsschaal voor de gezondheidszorg\textsuperscript{24}; MAS-GZ (α = 0.87). Deze lijst heeft tien vragen over de werktevredenheid van professionele zorgverleners in de zorg.

Procedure
De ontwikkeling van Into D’mentia begon in juli 2011 en in oktober 2012 werd het eerste prototype gepresenteerd. Het evaluatieonderzoek naar Into D’mentia vond plaats van oktober 2012 tot februari 2013. Via een aan het project deelnemende zorgorganisatie, een grote organisatie met 20 locaties in de regio Tilburg, werden in de regio Tilburg mantelzorgers en professionele zorgverleners uitgenodigd voor deelname aan het onderzoek. In de regio Amsterdam werden deelnemers geworven via ontmoetingscentra voor mensen met dementie en mantelzorgers. Voorafgaand aan deelname vulden deelnemers een informed consent formulier in. Deelnemers werden drie keer ondervraagd: 1) In de week voorafgaand aan de interventie werd schriftelijk een vragenlijst ingevuld om de achtergrondkenmerken en de secundaire uitkomstmaten te inventariseren. 2) Direct na de groepstraining werden (telefonisch) semigestructureerde interviews over gebruiksvriendelijkheid en bruikbaarheid van de Into D’mentia afgenomen en werd een kortere vragenlijst ingevuld met daarin alleen de IRI en (bij professionele zorgverleners) de ADQ. Er was gekozen voor een korte vragenlijst om de deelnemers niet teveel te belasten. 3) Twee maanden na de simulatie werden nogmaals schriftelijk vragenlijsten ingevuld om de impact van Into D’mentia na te gaan (de secundaire uitkomstmaten) en om het eindoordeel over de bruikbaarheid van Into D’mentia uit te vragen.

Analyse
Er werd beschrijvende statistiek verricht op de achtergrondgegevens van de deelnemers, en er zijn non-parametrische toetsen uitgevoerd om verschillen tussen voor- en nametingen en verschillen tussen de subgroepen (mantelzorgers vs professionele zorgverleners) te toetsen op significante (p < 0.05). Voor binnengroepsvergelijkingen is gebruik gemaakt van de non-parametrische Wilcoxon signed-rank test, die met name geschikt is voor analyses bij kleine groepen. Om verschillen tussen de groepen te testen, is gebruik gemaakt van Chi-kwadraat-toetsen, en t-toetsen. De semi-gestructureerde interviews werden met beschrijvende statistiek geanalyseerd en de antwoorden op de open vragen werden geanalyseerd en samengevat in thema’s.

Resultaten
Deelnemers aan het evaluatieonderzoek
In totaal werden tien mantelzorgers en 23 professionele zorgverleners gerecruteerd voor het evaluatieonderzoek. Tijdens het onderzoek stopte één mantelzorger vanwege overbelasting, en reageerden drie mantelzorgers ondanks herinneringen niet meer op de laatste vragenlijst. Van de professionele zorgverleners deden er drie alleen mee aan de interviews en niet aan de vragenlijsten. Daarnaast reageerden acht andere professionele zorgverleners niet meer op de vragenlijsten bij de derde meting. Mantelzorgers waren gemiddeld 58 jaar oud en overwegend vrouw (91%). De meeste mantelzorgers
en professionele zorgverleners waren gehuwd of samenwonend. De professionele zorgverleners waren gemiddeld 42 jaar oud, overwegend vrouw, en iets minder dan de helft was 5 jaar of langer werkzaam in de zorg. De groep professionele zorgverleners was significant jonger dan de groep mantelzorgers.

**Tabel 5.1. Achtergrondkenmerken deelnemers onderzoek**

<table>
<thead>
<tr>
<th>Kenmerken</th>
<th>Mantelzorgers (n=10)</th>
<th>Professionele zorgverleners (n=23)</th>
<th>Toetsings-grootte*</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Geslacht:</strong></td>
<td>man</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Vrouw</td>
<td>9</td>
<td>21</td>
</tr>
<tr>
<td><strong>Leeftijd:</strong></td>
<td>min</td>
<td>46</td>
<td>23</td>
</tr>
<tr>
<td></td>
<td>max</td>
<td>76</td>
<td>59</td>
</tr>
<tr>
<td></td>
<td>gemiddeld</td>
<td>58 (sd 9.6)</td>
<td>42 (sd 12.7)</td>
</tr>
<tr>
<td><strong>Burg. staat:</strong></td>
<td>ongehuwd</td>
<td>-</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>gehuwd/samenwonend</td>
<td>8</td>
<td>18</td>
</tr>
<tr>
<td></td>
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<td>1</td>
</tr>
<tr>
<td></td>
<td>gescheiden</td>
<td>1</td>
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</tr>
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<td><strong>Relatie tot verzorgde</strong></td>
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<td>4</td>
<td></td>
</tr>
<tr>
<td></td>
<td>kind</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td></td>
<td>anders</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>onbekend</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td><strong>Zorgstijl:</strong></td>
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<td>-</td>
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<td>-</td>
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<td></td>
<td>MBO</td>
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<td>12</td>
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<tr>
<td></td>
<td>Universiteit</td>
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</tr>
<tr>
<td></td>
<td>niet bekend</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td><strong>Huidige functie</strong></td>
<td>verzorgende verpleegkundige</td>
<td>6</td>
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<tr>
<td></td>
<td>ergotherapeut</td>
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<td></td>
<td>gastvrouw</td>
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<tr>
<td></td>
<td>zorgcoördinator</td>
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<tr>
<td></td>
<td>anders</td>
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<td></td>
</tr>
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<td></td>
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<tr>
<td><strong>Aantal jaren zorg voor familielid</strong></td>
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<td></td>
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<tr>
<td></td>
<td>2 jaar</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>3 jaar</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td></td>
<td>n.v.t. of onbekend</td>
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</tr>
<tr>
<td><strong>Werkervaring ouderenzorg</strong></td>
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<td></td>
</tr>
<tr>
<td></td>
<td>1 tot 5 jaar</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td></td>
<td>5 jaar of meer</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Onbekend</td>
<td>4</td>
<td></td>
</tr>
</tbody>
</table>

* vetgedrukte uitkomst is significant
Primaire uitkomsten

Bruikbaarheid: De vragen van de USE-vragenlijst worden gepresenteerd in tabel 5.2. De resultaten uit de semi-gestructureerde interviews worden hieronder besproken.

Algemene bruikbaarheid: Bezoekers waren unaniem positief over of Into D’mentia waardevol was voor andere mantelzorgers of professionele zorgverleners. Zo geeft één professionele zorgverlener aan dat “sommige collega’s nog weinig begrip [hebben], voor hen zou het goed zijn”. Op één professionele zorgverlener na zou dan ook iedereen Into D’mentia aanraden, omdat het helpt “betere zorg [te bieden] door te ervaren, kennis weegt niet op tegen ervaring”.

Herkenbaarheid van de situaties: Deelnemers waren unaniem positief over hoe goed ID een beeld geeft van het dagelijks leven van iemand met dementie. Op één mantelzorger na vond ook iedereen dat zij meer inzicht op hadden gedaan dankzij de simulator. Twee mantelzorgers vonden dat de simulatie niet zo’n goed beeld gaf van mantelzorgers: volgens hen was ‘de realiteit niet zo extreem”; anderen vonden de situatie van de mantelzorger juist ‘herkenbaar’. Alle mantelzorgers vonden dat ID goed inzicht gaf in de situatie van mantelzorgers. Zowel mantelzorgers als professionele zorgverleners gaven allen aan dat zij geen ‘minst herkenbare’ situatie konden noemen, zij vonden ‘alles herkenbaar’. Onder professionele zorgverleners gaf slechts één deelnemer aan dat de opgedane kennis niet te gebruiken was in het dagelijks werk, omdat hij/zij “niet dagelijks met de doelgroep werkt”.

Effect op empathie: Deelnemers gaven overwegend aan dat zij zich goed konden inleven in de hoofdpersoon en de mantelzorger uit de simulatie. Één mantelzorger kon zich niet goed inleven, omdat hij/zij naar eigen zeggen “niet goed in rollenspellen is”. Ook één professional antwoordde ontkennend, maar gaf aan dat dit “aan zichzelf lag”. Professionele zorgverleners konden zich minder inleven in de mantelzorger, sommigen hadden “met haar te doen” en “snappen het wel”, anderen vonden haar “verveelend” en vonden dat voor deze mantelzorger “haar moeder [de hoofdpersoon] maar een ongemak was”. Over hoe stressvol de ervaring was, was men verdeeld: een mantelzorger kwam “doodmoe thuis”, en een professional voelde zich “onmachtig, alsof de wereld om je heen doordraait en jezelf stil blijft staan”. Op één professional na meenden alle deelnemers dat ID invloed had gehad op hun vermogen zorg te bieden.

Nut van combinatie met training: Mantelzorgers waren positief over de training, allen vonden dit nuttig en vonden het “goed om met een gemengd gezelschap over de situatie te praten”. Drie professionele zorgverleners vonden dat volstaan kon worden met de simulatie, en hadden “liever een langer nagesprek”.
### Tabel 5.2. Bruikbaarheid-items uit de USE-vragenlijst

<table>
<thead>
<tr>
<th>Stelling: Into D’mentia ...</th>
<th>Antwoord</th>
<th>Mantelzorgers (n=8)</th>
<th>Professionele zorgverleners (n=16)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Help effectiever te zijn</td>
<td>Helemaal mee eens</td>
<td></td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Enigszins mee eens</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Mee eens/mee oneens</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Helemaal mee oneens</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help productiever te zijn</td>
<td>Helemaal mee eens</td>
<td></td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Enigszins mee eens</td>
<td></td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Mee eens/mee oneens</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Enigszins mee oneens</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Helemaal mee oneens</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Is nuttig</td>
<td>Helemaal mee eens</td>
<td></td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Enigszins mee eens</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Mee eens/mee oneens</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Enigszins mee oneens</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Helemaal mee oneens</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Geeft meer controle</td>
<td>Helemaal mee eens</td>
<td></td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Enigszins mee eens</td>
<td></td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Mee eens/mee oneens</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Enigszins mee oneens</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Helemaal mee oneens</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help dingen voor elkaar te krijgen</td>
<td>Helemaal mee eens</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Enigszins mee eens</td>
<td></td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Mee eens/mee oneens</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Enigszins mee oneens</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Helemaal mee oneens</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Was zoals verwacht</td>
<td>Helemaal mee eens</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Enigszins mee eens</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Mee eens/mee oneens</td>
<td></td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Enigszins mee oneens</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Helemaal mee oneens</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Maakt mij zekerder van mijn kwaliteiten</td>
<td>Helemaal mee eens</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Enigszins mee eens</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Mee eens/mee oneens</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Enigszins mee oneens</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Helemaal mee oneens</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>NVT/niet beantwoord</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Gebruiksvriendelijkheid: De vragen uit de USE-vragenlijst over gebruiksvriendelijkheid worden gepresenteerd in tabel 5.3. De resultaten van de semi-gestructureerde interviews worden hieronder besproken.

Gebruiksvriendelijkheid van de simulatie: Over de gebruiksvriendelijkheid was men bijna unaniem positief. Op één professional na, die het “verwarrend [vond], maar dat is juist goed!”, was het iedereen duidelijk wat te doen. De instructies tijdens de simulatie vonden alle gebruikers duidelijk, van zowel de “innerlijke stem” in de simulatie, als van de takenlijst en de (gesimuleerde) mantelzorger. Over de acteur (mantelzorger) en de ruimte (zowel de inrichting als de technische uitwerking van de simulatie, zoals sensoren en projectie) was tevens iedereen tevreden. Kritiek wat betreft gebruiksvriendelijkheid was er over de duur van de simulatie, volgens vijf professionele zorgverleners en één mantelzorger had het “langer mogen duren, [je bent je] tijdsbesefkwijt!”
### Tabel 5.3. Gebruiksvriendelijkheiditems uit de USE vragenlijst

<table>
<thead>
<tr>
<th>Stelling: Into D’mentia ...</th>
<th>Antwoord</th>
<th>Mantelzorgers (n=8)</th>
<th>Professionele zorgverleners (n=16)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Was makkelijk te doen</strong></td>
<td>Helmeeal mee eens</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Enigszins mee eens</td>
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<td>6</td>
</tr>
<tr>
<td></td>
<td>Mee eens/mee oneens</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Enigszins mee oneens</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Helmeeal mee oneens</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td><strong>Was eenvoudig</strong></td>
<td>Helmeeal mee eens</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td></td>
<td>Enigszins mee eens</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Mee eens/mee oneens</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Enigszins mee oneens</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Helmeeal mee oneens</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Niet ingevuld</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td><strong>Was gebruiksvriendelijk</strong></td>
<td>Helmeeal mee eens</td>
<td>4</td>
<td>11</td>
</tr>
<tr>
<td></td>
<td>Enigszins mee eens</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Mee eens/mee oneens</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Enigszins mee oneens</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Helmeeal mee oneens</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td><strong>Was begrijpelijk</strong></td>
<td>Helmeeal mee eens</td>
<td>5</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>Enigszins mee eens</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Mee eens/mee oneens</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Enigszins mee oneens</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Helmeeal mee oneens</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td><strong>Was moeilijk te doen</strong></td>
<td>Helmeeal mee eens</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td></td>
<td>Enigszins mee eens</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Mee eens/mee oneens</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Enigszins mee oneens</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Helmeeal mee oneens</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td><strong>Ik ben er tevreden over</strong></td>
<td>Helmeeal mee eens</td>
<td>5</td>
<td>12</td>
</tr>
<tr>
<td></td>
<td>Enigszins mee eens</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Mee eens/mee oneens</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Enigszins mee oneens</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Helmeeal mee oneens</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td><strong>Zou ik aanbevelen</strong></td>
<td>Helmeeal mee eens</td>
<td>7</td>
<td>13</td>
</tr>
<tr>
<td></td>
<td>Enigszins mee eens</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Mee eens/mee oneens</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Enigszins mee oneens</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Helmeeal mee oneens</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td><strong>Was leuk om te doen</strong></td>
<td>Helmeeal mee eens</td>
<td>1</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Enigszins mee eens</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>Mee eens/mee oneens</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Enigszins mee oneens</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Helmeeal mee oneens</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

**Secundaire uitkomstmaten**
Resultaten impact: In tabel 5.4 worden de resultaten weergegeven op de empathievragenlijst voor alle deelnemers (mantelzorgers en professionele zorgverleners) op de drie meetmomenten. De resultaten op de andere uitkomstmaten – de SSCQ, COPE en vragen over de kwaliteit van de relatie bij mantelzorgers, en de BOD en MAS-GZ bij professionele zorgverleners - (alleen pre- en posttest na 2 mnd) staan voor mantelzorgers in tabel 5.5, en voor de professionele zorgverleners in tabel 5.6.
**Tabel 5.4. Resultaten op de Empathievragenlijst (IRI) op de drie meetmomenten voor de totale groep (mantelzorgers en professionele zorgverleners); en beide groepen apart**

<table>
<thead>
<tr>
<th>Groep</th>
<th>Meting 1</th>
<th>Meting 2</th>
<th>Meting 3</th>
<th>Toetsingsgrootheid en significantie (p)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n=29</td>
<td>n=25</td>
<td>n=20</td>
<td></td>
</tr>
<tr>
<td>Totaal</td>
<td>m(sd)</td>
<td>range</td>
<td>m(sd)</td>
<td>range</td>
</tr>
<tr>
<td>Mantelzorgers</td>
<td>11,1 (4,7)</td>
<td>1-20</td>
<td>10,2 (4,6)</td>
<td>1-17</td>
</tr>
<tr>
<td>Professional</td>
<td>11,4 (4,8)</td>
<td>4-20</td>
<td>11,3 (3,4)</td>
<td>8-17</td>
</tr>
<tr>
<td>Professionele zorgverleners</td>
<td>11,0 (3,7)</td>
<td>1-17</td>
<td>9,7 (5,2)</td>
<td>1-17</td>
</tr>
</tbody>
</table>

**Evaluation**

*IRI* = Interpersonal Reactivity Index (Davis, 1980)

*De onderstreepte waarde is de meest gunstige uitkomst*

**Tabel 5.5. Resultaten op secundaire uitkomstmaten op verschillende meetmomenten bij mantelzorgers**

<table>
<thead>
<tr>
<th></th>
<th>Meting 1 m(sd)</th>
<th>range</th>
<th>Meting 3 m(sd)</th>
<th>range</th>
<th>Toetsingsgrootheid en significantie (p)</th>
</tr>
</thead>
<tbody>
<tr>
<td>SSCQ</td>
<td>n=9</td>
<td></td>
<td>n=6</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Totaal (0-7)*</td>
<td>3,7 (2,2)</td>
<td>0-6</td>
<td>2,3 (2,4)</td>
<td>0-6</td>
<td>Z=1,33</td>
</tr>
<tr>
<td>COPE</td>
<td>n=9</td>
<td></td>
<td>n=7</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emotion focus (10-40)</td>
<td>20,7 (2,8)</td>
<td>15-25</td>
<td>21,9 (2,7)</td>
<td>19-27</td>
<td>Z=0,00</td>
</tr>
<tr>
<td>Problem focus (6-24)</td>
<td>15,8 (3,1)</td>
<td>10-18</td>
<td>17,3 (2,4)</td>
<td>13-20</td>
<td>Z=-0,74</td>
</tr>
</tbody>
</table>
## Tabel 5.6. Resultaten op secundaire uitkomstmaten op verschillende meetmomenten bij professionele zorgverleners

<table>
<thead>
<tr>
<th></th>
<th>Meting 1 m(sd)</th>
<th>range</th>
<th>Meting 3 m(sd)</th>
<th>range</th>
<th>Toetsingsgrootheid en significantie (p)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kwaliteit van relatie</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>n=9</td>
<td>n=6</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hechtheid relatie</td>
<td>3,4 (0,7)</td>
<td>2-4</td>
<td>3,0 (0,6)</td>
<td>2-4</td>
<td>Z=-1,41 p=0,16</td>
</tr>
<tr>
<td>(1-4)*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Communicatie</td>
<td>2,4 (0,7)</td>
<td>1-3</td>
<td>2,5 (0,8)</td>
<td>1-3</td>
<td>Z=0,00 p=1,00</td>
</tr>
<tr>
<td>(1-4)*</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Goed kunnen</td>
<td>3,0 (0,5)</td>
<td>2-4</td>
<td>2,7 (0,8)</td>
<td>2-4</td>
<td>Z=-1,41 p=0,16</td>
</tr>
<tr>
<td>opschieten</td>
<td>(1-4)*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hoe goed begrijpt</td>
<td>2,7 (0,5)</td>
<td>1-3</td>
<td>2,7 (0,5)</td>
<td>2-3</td>
<td>Z=0,58 p=0,57</td>
</tr>
<tr>
<td>mz pmd</td>
<td>(1-4)*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

SSCQ= Short Sense of Competence Scale
COPE= Coping strategieënlijst
mz=matelzorger; pmd=persoon met dementie
* De onderstreepte waarde is de meest gunstige uitkomst (NB de COPE vragenlijst heeft geen gunstige/ongunstige antwoordcategorieën)

BOD= Zelfbeoordelingsvragenlijst Belevingsgerichte vaardigheden in de Omgang met Dementerende ouderen
MAS-GZ= Maastrichtse Arbeidstevredenheidsschaal voor de gezondheidszorg

¹ vetgedrukte uitkomst is significant
* De onderstreepte waarde is de meest gunstige uitkomst
Onder professionele zorgverleners is na deelname aan Into D’mentia een significant verschil gevonden in de mate waarin zij aangeven kennis van de persoon te hebben, en de mate waarin zij dat toepassen: zij hebben bij de posttest meer kennis en passen deze vaker toe dan bij de pretest (Z=1,97, p=0,05). Op de overige secundaire uitkomstmaten werden geen verschillen gevonden.

Op geen van de empathieschalen wordt een significant verschil gevonden tussen de verschillende meetmomenten, noch wanneer mantelzorgers en professionele zorgverleners als één groep worden beschouwd in de analyse, noch wanneer de groepen professionele zorgverleners en mantelzorgers afzonderlijk worden geanalyseerd. In het gevoel van competentie van de mantelzorgers, hun copingstijlen en kwaliteit van de relatie tussen mantelzorgers en persoon met dementie zijn evenmin verschillen gevonden tussen de metingen.

Conclusie en discussie

In een exploratief onderzoek werd onder mantelzorgers en professionele zorgverleners de bruikbaarheid en gebruiksvriendelijkheid van de Into D’mentia ervaring (simulator, nagesprek en groepstraining) geëvalueerd, en werd de mogelijke impact ervan onderzocht op mantelzorgers en professionele zorgverleners.


Wat betreft de mogelijke impact van Into D’mentia op de secundaire uitkomstmaten werd in deze exploratieve studie een significant positief effect gevonden onder professionele zorgverleners op de mate waarin zij kennis over de persoon met dementie toepassen in de zorg. Het zelf beleven van dementie lijkt er voor te zorgen dat professionele zorgverleners beter nadenken over de achtergrond en levensgeschiedenis van de persoon en dit beter toepassen in de zorg. In de simulatie wordt meerdere keren verwezen naar het verleden van de hoofdpersoon (onder andere vroegere vakanties, vrienden en huisdieren), mogelijk doet dit professionele zorgverleners nadenken over de individuele geschiedenis van de mensen voor wie zij zorgen. Wat betreft overige impact-uitkomstmaten voor mantelzorgers en professionele zorgverleners werden geen significante verschillen gevonden na de Into D’mentia ervaring. Ondanks dat, gaven deelnemers zelf wel spontaan aan dat Into D’mentia effect heeft gehad op onder andere hun empathie, begrip en gevoelens ten opzichte van (mensen met) dementie.

Dat er geen significante verschillen zijn gevonden, kan te maken hebben met de kleine groep mantelzorgers en professionele zorgverleners die voor dit onderzoek werd gerekruiteerd: met de aantallen
Deelnemers die uiteindelijk aan het onderzoek deelnamen (n=33; een aanzienlijk kleinere groep dan de beoogde 80) werd slechts een power van 0,50 bereikt om middelgrote effecten (d=0.05) statistisch significant aan te tonen bij een alpha van 0,05). Een van de redenen dat minder deelnemers werden gerekruuteerd dan beoogd was vertraging in het ontwikkelproces van Into D’mentia, waardoor de evaluatieperiode met enige maanden werd bekort – verwacht werd dat de eerste deelnemers al voor de lancering in oktober 2012 deel zouden nemen en dat het onderzoek rond de lancering afgerond zou zijn. Het projectbudget stond het niet toe om de evaluatieperiode te verlengen. Het bleek vooral moeilijk om mantelzorgers te werven buiten de bij het onderzoek betrokken zorginstelling. Mogelijk heeft dit te maken gehad met het feit dat het de simulator tijdens de hele onderzoekersperiode in Tilburg opgesteld stond, waardoor er uit de regio Amsterdam uiteindelijk geen deelnemers meededen. Een andere beperking in dit exploratieve effectonderzoek was het ééngroeps-design zonder controlegroep. Het is daardoor niet geheel met zekerheid te zeggen of het gevonden effect op professionele zorgverleners met betrekking tot kennis over de persoon met dementie en de toepassing hiervan in de zorg verklaard wordt door de Into D’mentia interventie of door andere factoren waarvoor in dit design niet werd gecontroleerd. Daarnaast waren alle betrokken deelnemers gerekruuteerd via één zorgorganisatie in Tilburg, en is het onbekend in hoeverre de cultuur binnen deze organisatie mogelijk mede bepalend is geweest voor de gevonden resultaten. Tenslotte is een beperking van het huidige onderzoek dat het voornamelijk vrouwelijke deelnemers bevatte, wat invloed gehad kan hebben op (het niet toenemen van) de ervaren empathie: zo blijkt uit onderzoek dat vrouwen over het algemeen sowieso al meer empathie ervaren dan mannen.\(^{25}\) Ten slotte kunnen de resultaten zijn beïnvloed doordat deelnemers sociaal wenselijk hebben geantwoord, waardoor een (positief) vertekend beeld is verkregen van de bruikbaarheid en gebruiksvriendelijkheid van de Into D’mentia. Er is echter zoveel mogelijk getracht dit te voorkomen door vragen neutraal te stellen, door bij de deelnemers te benadrukken dat de gegevens anoniem werden verwerkt en door de gegevensverzameling door onafhankelijke onderzoekers uit te laten voeren.

De resultaten van deze studie bevestigen de resultaten die gevonden werden in een eerder onderzoek waar dementie werd gesimuleerd. Beville (2002) onderzocht met de Virtual Dementia Tour\(^{12}\) of professionele zorgverleners die deelnamen aan een simulatie waarin de beperkingen van dementie en veroudering nagebootst werden, anders dachten na zo’n ervaring. Dit bleek inderdaad het geval te zijn: deelnemersgaben na afloop van de Virtual Dementia Tour aan dat zij ouderen met dementie beter begrepen, zagen mogelijkheden tot verandering van hun eigen gedrag en waren zich bewuster van hun eigen gedrag. In deze studie naar Into D’mentia gaven professionele zorgverleners ook aan dat zij meer begrip hadden, hun eigen zorg konden verbeteren en zich bewuster waren van hun eigen gedrag.

Andere vergelijkbare ontwikkelingen werden eveneens goed beoordeeld door gebruikers: Het videoproject “Alzheimer Experience”, dat deelnemers in video’s door de ogen van mensen met dementie laten kijken, bereikte dat deelnemers angaven meer begrip voor dementie te hebben.\(^{26}\) Deelnemers aan een andere simulatie, de Nederlandse “Paved with Fear” truck die het hebben van een psychose simuleert, gaven aan dat na ervaring met deze simulatie het begrip voor mensen met een psychose flink groeide (Volkskrant, 2010). Simulatie lijkt dus een doeltreffende mogelijkheid om in korte tijd deelnemers extra inzicht en begrip te geven. Vergelijkbare resultaten werden ook gevonden onder deelnemers aan online psycho-educatieprogramma’s. Zo gaven deelnemers aan de online cursussen dementieonline.nl en STAR (www.startraining.eu) respectievelijk aan dat zij ‘minder verdrietig’ waren na de cursus, en ‘de ziekte beter begrepen’ (ervaringen op www.dementieonline.nl), en dat zij meer empathie hadden voor mensen met dementie.\(^{27}\)
De resultaten van deze pilot suggereren dat Into D’mentia een bijdrage kan leveren aan verbetering van de zorg voor mensen met dementie. Deelnemers geven aan dat zij door de 'Into D’mentia ervaring' beter het gedrag van mensen met dementie begrijpen en hun eigen gedrag daarop willen aanpassen. Ook menen zij dat zij in de dagelijkse praktijk beter kunnen zorgen voor een persoon met dementie. Omdat mantelzorgers van mensen met dementie door hun zorgtak meer stress ervaren en veel mantelzorgers zich overbelast voelen is het belangrijk om effectieve methoden in te zetten om hen te steunen bij hun zorgtak. Deze steun kan mogelijk geboden worden door Into D’mentia aan te bieden aan mantelzorgers. Met de verdubbeling van het aantal mensen met dementie en de verwachte relatieve afname van professionele zorgverleners in de komende decennia zal een groot deel van de zorg op de schouders komen van mantelzorgers en vrijwilligers. Het is van groot belang dat zij adequate training ontvangen. Into D’mentia kan persoonsgerichte zorg mogelijk bevorderen doordat ze helpt het gedrag van mensen met dementie beter te begrijpen. Ook professionele zorgverleners kunnen hier mogelijk baat bij hebben. Persoonsgerichte zorg wordt gerelateerd aan hoger welbevinden van de persoon met dementie en is daarom belangrijk om te bevorderen.

Verder onderzoek (bij voorkeur met een gerandomiseerd gecontroleerd design) is wenselijk om na te gaan wat het effect van Into D’mentia is op het gevoel van competentie van mantelzorgers en het belevingsgericht werken en de arbeidssatisfactie van professionele zorgverleners. Ook onderzoek naar het effect van Into D’mentia op de empathie van mantelzorgers en professionele zorgverleners is aan te bevelen. Empathie werd in eerder onderzoek gevonden als een belangrijke component voor het leveren van goede zorg en lijkt gerelateerd te zijn aan minder stressgevoelens en burn-out bij professionele zorgverleners.

**Conclusie**

De resultaten uit dit pilot-onderzoek wijzen erop dat Into D’mentia een bruikbare methode kan zijn om mantelzorgers op een gebruikersvriendelijke manier meer inzicht te geven in de beleving van hun naaste met dementie en hen te helpen meer begrip te hebben voor zijn/haar gedrag. Ook voor professionele zorgverleners lijkt Into D’mentia een nuttige methode te zijn om meer inzicht in de beleving van dementie te krijgen en handvatten in de omgang met en zorg voor mensen met dementie.
Referenties


CHAPTER 6

STAR: Developing and evaluating online e-learning for caregivers

This is an adapted version* of the publication: Hattink, B.¹, Meiland, F.¹, Roest, H. van der¹, Kevern, P.², Abiuso, F.³, Bengtsson, J.⁴, Giuliano A.⁵, Duca, A.⁵, Sanders, J.², Basnett, F.², Nugent, C.⁶, Kingston, P.⁷, Dröes, R.M.¹ (2015). Web-based STAR E-learning course increases empathy and understanding in dementia caregivers: results from a randomized controlled trial in the Netherlands and the United Kingdom. Journal of medical Internet research, 17(10).

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*In this rectified version*, the scoring and interpretation of the Short Sense of Competence (SSCQ) Questionnaire were corrected. In the original version, one question was miscalculated, and the scoring of the questionnaire was misinterpreted. Please see below for a full list of changes resulting from this.

(Change of outcome in bold font)

*Page 115: (Abstract)* “Additionally, a significant *increase* in sense of competence was found among informal caregivers in the experimental group.”

*Page 122: (Measurement Instruments)* “The total score for the SSCQ was calculated by dichotomizing answers to 7 questions (e.g., “I feel strained in my interactions with my...”) on a 5 point scale, counting a score of 1, 2, and 3 as zero and 4 and 5 as 1. **The higher the score the higher the sense of competence.**

*Page 128: (Outcome table 6.5)* In outcome table 6.5, the scores on the SSCQ were recalculated. Additionally, the footnote for this table no longer reads that for SSCQ, a lower score is more favorable: “For all scores except distress, burden and attitude, the higher score is the more favorable.”

*Page 129: (Description of Impact on Outcome Measures)* “Additionally, we found a moderate to large positive effect on sense of competence of informal caregivers, which *improved* in the experimental group compared to the control group, implying that **participants in the course felt more competent to fulfill their care task after following the course** compared to the control group.”

*Page 129/130: (Discussion)* “The sense of competence *improved* (with a moderate to large effect) in the informal caregivers who followed the STAR course. **This improvement is in line with the finding** that a large number of the participants who followed the STAR training indicated that they felt more secure about their qualities as caregivers.”

*Page 131: (Discussion)* “based on the promising results of our study, especially the **positive effects** of the STAR training portal on empathy for both laypeople (informal caregivers and volunteers) and professionals, and **on feelings of competence of informal caregivers**, it is recommended to repeat the RCT on a larger scale and in more countries.”

*Page 131: (Discussion)* “The **positive effects of STAR** on attitudes, empathy and **feelings of competence of caregivers** may contribute to appropriate and high-quality dementia care in the community now and in the future.”
ABSTRACT

Background: The doubling of the number of people with dementia in the coming decades coupled with the rapid decline in the working population in our graying society is expected to result in a large decrease in the number of professionals available to provide care to people with dementia. As a result, care will be supplied increasingly by untrained informal caregivers and volunteers. To promote effective care and avoid overburdening of untrained and trained caregivers, they must become properly skilled. To this end, the European Skills Training and Reskilling (STAR) project, which comprised experts from the domains of education, technology, and dementia care from 6 countries (the Netherlands, Sweden, Italy, Malta, Romania, and the United Kingdom), worked together to create and evaluate a multilingual e-learning tool. The STAR training portal provides dementia care training both for informal and formal caregivers.

Objective: The objective of the current study was to evaluate the user friendliness, usefulness, and impact of STAR with informal caregivers, volunteers, and professional caregivers.

Methods: For 2 to 4 months, the experimental group had access to the STAR training portal, a Web-based portal consisting of 8 modules, 2 of which had a basic level and 6 additional modules at intermediate and advanced levels. The experimental group also had access to online peer and expert communities for support and information exchange. The control group received free access to STAR after the research had ended. The STAR training portal was evaluated in a randomized controlled trial among informal caregivers and volunteers in addition to professional caregivers (N=142) in the Netherlands and the United Kingdom. Assessments were performed with self-assessed, online, standardized questionnaires at baseline and after 2 to 4 months. Primary outcome measures were user friendliness, usefulness, and impact of STAR on knowledge, attitudes, and approaches of caregivers regarding dementia. Secondary outcome measures were empathy, quality of life, burden, and caregivers’ sense of competence.

Results: STAR was rated positively by all user groups on both usefulness and user friendliness. Significant effects were found on a person-centered care approach and on the total score on positive attitudes to dementia; both the experimental and the control group increased in score. Regarding empathy, significant improvements were found in the STAR training group on distress, empathic concern, and taking the perspective of the person with dementia. Additionally, a significant increase in sense of competence was found among informal caregivers in the experimental group.

Conclusions: The STAR training portal is a useful and user-friendly e-learning method, which has demonstrated its ability to provide significant positive effects on caregiver attitudes, empathy and sense of competence.
Introduction

The European Union (EU) is set to face major demographic challenges in the coming decades. Two main drivers for this are the (expected) doubling of the number of people with dementia and a rapid relative decline in the working population. In the Netherlands, for example, this is expected to change from a ratio of 1:42 for people with dementia to working people in 2010 to 1:16 in 2050 [1]. As a result, the task of caring for people with dementia will be provided increasingly by relatives or friends, the so-called informal caregivers, who provide this care unpaid and generally with minimal or no professional assistance. Additionally, many EU countries draft their health care policies toward an increased use of volunteers in the provision of care in addition to prolonging community-based dementia care. Therefore, to sustain and promote effective care for people with dementia, to avoid overburdening of informal and professional caregivers, and to prevent premature admission of people with dementia to long-term care settings, caregivers need to become properly skilled and feel competent in their care provision.

In an attempt to address this, e-learning interventions could prove to be a useful tool to assist informal caregivers, untrained volunteers, and professionals by offering them relevant education, training, and support [2,3] at a significantly lower cost than through face-to-face training or print distribution [4]. Interventions offered through the Internet are likely to have a lower threshold for participation given that participants can use these interventions at any time they wish, from their own homes, and with little effort. This will also help to offer access to people who would otherwise be put off by long travel times, avoid costs for visiting regular teaching sessions (eg, people living in remote areas [5]), or to people who cannot leave their home due to their caregiving role. Finally, the possibilities of the Internet allow for effective use of multimedia delivery of information (eg, graphics, animations, and interactive course material), which has been reported to enhance learning and make the material more attractive during the process of engagement [6]. Recent research has found beneficial effects from Internet-based interventions. A Cochrane review in 2005 found that “interactive health communication applications” were effective for increasing knowledge and may improve outcomes in patients and caregivers [7]. A typical means for distributing interactive health communication apps is the Internet. In another review, it was found that personalized (tailored to the individual) Internet-based interventions led to improved health in users [8].

Pilot studies offering an Internet-based program of learning for dementia caregivers found that the caregivers who evaluated it reported it as useful, educational, and convenient [9] and found positive results relating to knowledge, attitudes, self-efficacy, and empathy [10]. Among professional caregivers, e-learning was also found to be enjoyable and was reported to help acquire new skills for collaboration among professionals [11]. E-learning was also found to help staff in nursing homes to gain specific skills, such as delirium screening [12]. A review of the state-of-the-art of online course provision for providing care for people with dementia in 2011 for 4 European countries (Netherlands, the United Kingdom, Malta, and Romania) showed that 14% of the dementia courses were offered online in the Netherlands, 17% in the United Kingdom, and in both Malta and Romania there were no online courses relating to care provision for persons with dementia [13]. These findings formed the basis for the development and evaluation of a multilingual online learning platform for all types of dementia caregivers, within the EU Skills Training and Reskilling (STAR) project [14].
The European STAR project (2010-2014), funded by the European Commission in the Leonardo da Vinci Life Long Learning Programme, aimed to improve the knowledge about dementia for informal caregivers, volunteers, and professionals in dementia care by developing and evaluating an online training program in different languages and at different difficulty levels. The course content was developed from 3 theoretical perspectives: (1) the medical model of dementia, including information on types of dementia, symptoms, and diagnostics based on the Diagnostic and Statistical Manual of Mental Disorders (Fourth Edition, Text Revision) \[15\]; (2) the perspective of functional consequences in daily life based on the International Classification of Functioning, Disability and Health model from the World Health Organization \[16\] and how to compensate for disabilities; and (3) the perspective of dealing with the psychosocial consequences for the person with dementia and his family as described by the adaption-coping model of Dröes et al \[17\]. The content was composed by internationally recognized dementia experts. The platform aims to provide opportunities for collaboration, discussion, and sharing experiences between users across the EU. The main focus was to provide relevant content that was easy to find. Additionally, STAR aimed to promote accessibility to specialized knowledge by experts in the field and to offer an online community of caregivers and other stakeholders.

To this end, the STAR training portal was designed and developed (Figure 6.1) to offer the following functionalities:

- A collection of 8 modules on different topics in dementia care: 2 at a basic level and 6 at an intermediate and advanced level (Figures 6.2 and 6.3);
- A Learning Path Advisor through an online tool integrated in STAR that assesses baseline knowledge and confidence to help people decide at which point to start the course; and
- Facebook and LinkedIn communities to promote peer support and provide opportunities to contact other dementia care professionals.

The developed course is currently available for a nominal fee. It is fully available in English and Dutch with translation into Swedish, Italian, and Romanian underway at the time of writing this paper.

After development and testing of the training portal and e-learning course material during the first phase of the STAR project, the STAR training portal was evaluated in a randomized controlled trial (RCT) in the Netherlands and the United Kingdom from May 2013 to March 2014. The primary aim of this evaluation was to assess STAR’s usefulness, user friendliness, and impact on knowledge. Because the themes of the course, in addition to factual knowledge on the dementia syndrome, focus greatly on dealing with dementia and understanding dementia (eg, themes such as “adaptation and coping,” “positive and empathic communication,” and “emotional impact and looking after yourself as a caregiver”), the impact on empathy, attitudes, and sense of competence were studied as well. The aim of this paper is to describe the results of these different types of user evaluations.
**Figure 6.1. The main project page.**

**Figure 6.2. Overview of modules.**

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**Create your Star Training account**

STAR aims to improve the skills of carers for people with dementia by offering online training modules in dementia care across Europe. All modules are available at different skill levels (beginner, intermediate, advanced) and are accompanied by interactive materials such as exercises, videos, games, for a better user experience. Modules are currently available in English, Dutch, Romanian, Italian, and Swedish.

The STAR training is appropriate for all persons, from professionals to relatives, caring for a person with dementia at home. In order to make sure that our course is kept updated with the latest material, we are asking for a small fee of €23 per year.

This fee can be paid easily via PayPal after you register for your account.

- **M1** What is dementia?
- **M2** Living with dementia
- **M3** Getting a diagnosis and why it is important
- **M4** Practical difficulties in daily life and how to help by best practice
- **M5** The emotional impact of dementia: How adaptation and coping influences behaviour and mood
- **M6** Support strategies to help people cope with consequences of dementia
- **M7** Positive and empathic communication
- **M8** Emotional impact and looking after yourself
Methods

Design
An RCT design was used to assess the effectiveness of STAR among Dutch and English users. Participants were randomly assigned to either a group that could participate directly in the STAR training or to a group that had to wait for 4 months before they could register (free of charge) for the STAR training. Participants followed the course at their own pace; however, within a specified period of 4 months. Pretest data were gathered and follow-up data were collected after 2 to 4 months of finalizing the course in the experimental condition and after the same period in the waiting list group (control condition).

Setting and Participants
Participants were caring for someone with dementia as an informal caregiver, a volunteer in dementia care, or a professional caregiver, and were living in either the Netherlands or in the United Kingdom. Participants in the Netherlands were recruited through meeting centers for people with dementia and their caregivers, regional branches of the national Alzheimer’s organizations, case managers, care organizations, and via announcements through several informative websites targeted at informal caregivers, volunteers, and those with an interest in dementia. In the United Kingdom, participants were recruited through caregivers’ cafes, church groups, university service users and caregiver groups, and
local dementia care and welfare organizations. Because STAR was developed both for informal caregivers (family caregivers and volunteers) as well as professional caregivers, participants who fulfilled the following criteria were recruited for the evaluation study: (1) were sufficiently computer literate to utilize the STAR website and (2) were currently an informal caregiver for someone with dementia living in the community, or a volunteer working with people with dementia with direct contact with community-dwelling people with dementia, or a professional caregiver for people with dementia with direct contact with community-dwelling people with dementia.

The STAR Training Portal

The STAR platform was designed to be accessible through any Internet-enabled device so users could access the course at any time and place of their convenience. The STAR training portal consists of an online course with 8 modules relating to different topics. These topics were selected to cover a wide range of topics relating to dementia and dementia care. The modules consist of text, videos, interactive exercises, knowledge tests, and also include references to other websites, literature, and videos. The themes covered in the modules are as follows:

1. What is dementia?
2. Living with dementia
3. Getting a diagnosis and why it is important
4. Practical difficulties in daily life and how to help by best practice
5. The emotional impact of dementia: how adaptation and coping influences behavior and mood
6. Support strategies to help people cope with consequences of dementia
7. Positive and empathic communication
8. Emotional impact and looking after yourself

By answering questions from an interactive “learning advisor,” participants are provided with advice relating to which module and level to start with so they may follow what may be considered a personalized learning path through the modules. For example, professionals with earlier experience in dementia care could be directed to the advanced levels of the course (including modules such as “Practical difficulties in daily life and how to help by best practice”), whereas informal caregivers who have never had to deal with dementia will be suggested to start their course with the basic modules on “What is dementia?” and “Living with dementia.” Caregivers can then follow their own learning path, either gradually working their way up to the more advanced levels or they can choose not to progress beyond the basic modules/knowledge.

To ascertain what participants learn from the modules and to make the content more appealing, interactive exercises are included in the modules. These are used after each module at the basic and intermediate levels as quizzes to test level of knowledge. If an insufficient score is achieved in the quiz, participants are encouraged to reread the material and to try the quiz again following further learning.

Participants randomly allocated to the STAR training group could follow all STAR modules and were invited to take part in their national community (communities were created for all nationalities of users) on Facebook. They were explicitly asked to follow at least 4 modules, take part in the knowledge
tests offered at the end of the modules, to complete the interactive exercises during the modules, and to watch a selection of videos that were offered in the modules.

**Measurement Instruments**

All questionnaires were offered online and were self-assessed in the participants’ own language. Background characteristics were inventoried for all participants. These were age, sex, relation to the person with dementia (in case of informal caregivers), time involved in care for the person with dementia, and prior experience with courses on dementia. For assessing usefulness and user friendliness, a questionnaire was composed specifically for this study, based on the Usefulness, Satisfaction, and Ease of use (USE) questionnaire [18] and online course evaluations used by the site programmers (AcrossLimits, Malta). This questionnaire contained 29 questions with 2 open questions, 20 other questions that could be answered on a 5-point scale ranging from “strongly agree” to “strongly disagree” (eg, “I instantly knew where to click”), and 7 questions on usefulness in which participants rated the usefulness of specific parts of STAR on a 4-point scale from “very useful” to “useless.” Also, users were asked to indicate which modules they had followed and to grade each module on usefulness (1-10) to account for the fact that not all participants may have followed all modules of the course.

The primary outcome measures were knowledge on dementia and attitudes regarding dementia. Knowledge was measured with the Alzheimer’s Disease Knowledge Scale (ADKS) [19] (internal consistency α=.71, test-retest reliability=0.81). The ADKS consisted of 30 questions on different aspects of Alzheimer’s disease that could be answered with “true” or “false” (range 0-30; where a higher score refers to more knowledge of the disease), such as “People in their thirties can have Alzheimer’s disease.” Attitudes toward dementia were assessed with 2 questions from the Alzheimer’s disease survey (one question asking participants on a list of 7 diseases (diabetes, stroke, heart disease, dementia, cancer, depression, or influenza) to order which disease they are most afraid to develop; and another yes/no question if they would want family members to be examined by a doctor in case of memory complaints) [20] and approaches to dementia with the Approaches to Dementia Questionnaire (ADQ) [21] (α=.85 for person-centered care scale; α=.76 for hope scale; α=.83 total score). The latter questionnaire was also administered among informal caregivers with one question omitted (“It is important not to become too attached to people with dementia”) because it was deemed inappropriate. The ADQ consisted of 19 questions on attitudes toward dementia and could be answered on a 5-point scale ranging from “completely agree” to “completely disagree” (range 19-95), such as “People with dementia are like children.” For this questionnaire, higher scores are more favorable.

The secondary outcome measures were empathy, quality of life, burden, and sense of competence. The latter 3 were only administered among informal caregivers. Empathy was assessed with the Interpersonal Reactivity Index (IRI) [22]. This questionnaire consists of 28 items that were answered on a 5-point scale ranging from “does not describe me well” to “describes me very well” and with 4 subscales: (1) perspective taking (tendency to adopt the psychological point of view of others), (2) fantasy (tendency to imagine oneself into fictitious characters in books and movies), (3) empathic concern (“other-oriented” feelings of sympathy and concern for unfortunate others), and (4) personal distress (“self oriented” feelings of anxiety and unease in tense interpersonal settings). The range was 0 to 28 for each subscale, with a higher score being more favorable; except for 4) personal distress, where a lower score was more favorable.
Quality of life was assessed with 2 distinct questions (eg, “how would you rate your quality of life on a scale from 1 to 10?” with higher scores being more favorable) and burden was assessed with 1 question, with a score of 1 to 5 where lower is more favorable. Finally, for sense of competence, the Short Sense of Competence Questionnaire (SSCQ; α=0.7) was used. The total score for the SSCQ was calculated by dichotomizing answers to 7 questions (eg, “I feel strained in my interactions with my...”) on a 5-point scale, counting a score of 1, 2, and 3 as zero and 4 and 5 as 1. The higher the score the higher the sense of competence.

Procedure
Participants, including informal caregivers (72/142, 50.7%), volunteers (24/142, 16.9%), and professional caregivers (46/142, 32.4%), in the Netherlands and United Kingdom were recruited through different partners (refer to Setting and Participants), both in person and through email. When people were interested in participating, a researcher provided them with additional written and oral information and a consent form. When a signed informed consent form was returned, the participants received a link to the online baseline questionnaire by email.

After having filled in the questionnaires, participants in the Netherlands and the United Kingdom were randomized to either the experimental or the control group. Participants were randomized based on the following variables. In each country, strata for each participant group—informal caregiver, volunteer, and professional—and within these strata (1) for informal caregivers, spouse of a person with dementia or not and knowledge regarding dementia being low (ADKS score <19), average (ADKS 20-26), or high (ADKS >27), and (2) for volunteers, shorter or longer than half a year of work experience and, for professionals, education level high or low.

Randomization software was used to classify participants into either the experimental or control group. Participants in the experimental group received a link to the STAR registration webpage. People were free to choose the number of modules they followed with a baseline minimum of at least 4 to obtain a good impression of the course. People in the control group were informed that they were assigned to the group that could follow the course free of charge after post-test measurements 4 months later. At the end of the project, 2 to 4 months after the baseline measurement, all participants received a link to the questionnaires for post-test measurement. All personal data collected were anonymized. Participants were allocated a code number that was retained in a secured database under supervision of the project leaders at the evaluation sites.

Analyses
Descriptive analyses were performed to describe the baseline characteristics of the study population. Differences between the experimental group and the control group at baseline were analyzed with relevant difference tests (chi-square and t tests). The usefulness and user friendliness of the STAR training were analyzed with descriptive statistics. Impact on the outcome measures was assessed with univariate covariance analyses (ANCOVAs) on the post-test data of the participants at 4 months, whereas pretest data were included as covariates. The background variables with baseline values that differed significantly between the experimental and control group and appeared to be related to one or more of the outcome measures (ie, potential confounding variables) were also included in the analyses as covariates.
Results

Description of Participants

In total, 142 persons participated in the STAR evaluation study. In the Netherlands, 85 people took part in the research. Of these, 50 persons were informal caregivers, 7 were volunteers in dementia care, and 28 were professional caregivers. In the United Kingdom, 57 people participated; 22 were informal caregivers, 17 were volunteers in dementia care, and 18 were professional caregivers. We grouped the informal caregivers and volunteers together as laypeople because of the relatively small number of volunteers. The background characteristics of the participants that completed both pretest and post-test measurements are detailed in Table 6.1.

Table 6.1. Background characteristics of participants at baseline for laypeople (informal caregivers and volunteers) and professional caregivers that finished pretest and post-tests.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Experimental group</th>
<th>Control group</th>
<th>F (df1,df2)</th>
<th>χ² (df)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Laypeople</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Age (years), mean (SD)</td>
<td>52.93 (11.43)</td>
<td>54.69 (14.36)</td>
<td>2.02 (1,57)</td>
<td>.16</td>
<td></td>
</tr>
<tr>
<td>Sex, n (%)</td>
<td></td>
<td></td>
<td>0.2 (58)</td>
<td>.65</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>7 (26)</td>
<td>10 (31)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>20 (74)</td>
<td>22 (69)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relationship, n (%)</td>
<td></td>
<td></td>
<td>4.0 (58)</td>
<td>.41</td>
<td></td>
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<tr>
<td>Partner</td>
<td>9 (33)</td>
<td>9 (28)</td>
<td></td>
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</tr>
<tr>
<td>Child</td>
<td>8 (30)</td>
<td>5 (16)</td>
<td></td>
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</tr>
<tr>
<td>Sister/brother</td>
<td>0 (0)</td>
<td>1 (3)</td>
<td></td>
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<td></td>
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<tr>
<td>Other</td>
<td>4 (15)</td>
<td>10 (30)</td>
<td></td>
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</tr>
<tr>
<td>NA</td>
<td>6 (22)</td>
<td>7 (22)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Duration of care, n (%)</td>
<td></td>
<td></td>
<td>7.3 (58)</td>
<td>.17</td>
<td></td>
</tr>
<tr>
<td>&lt;3 months</td>
<td>2 (7)</td>
<td>6 (19)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3-12 months</td>
<td>2 (7)</td>
<td>1 (3)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-2 years</td>
<td>2 (7)</td>
<td>9 (28)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2-5 years</td>
<td>15 (58)</td>
<td>12 (38)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt;5 years</td>
<td>6 (21)</td>
<td>4 (12)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ADKS score, mean (SD)</td>
<td>24.67 (3.43)</td>
<td>24.13 (3.32)</td>
<td>0.01 (1,57)</td>
<td>.92</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Experimental group</th>
<th>Control group</th>
<th>F (df1,df2)</th>
<th>χ² (df)</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Professionals</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age (years), mean (SD)</td>
<td>46.90 (12.12)</td>
<td>48.07 (9.11)</td>
<td>1.04 (1,22)</td>
<td>.32</td>
<td></td>
</tr>
<tr>
<td>Sex, n (%)</td>
<td></td>
<td></td>
<td>3.1 (23)</td>
<td>.08</td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>2 (20)</td>
<td>0 (0)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>8 (80)</td>
<td>14 (100)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Duration of care, n (%)</td>
<td></td>
<td></td>
<td>3.5 (23)</td>
<td>.62</td>
<td></td>
</tr>
<tr>
<td>&lt;3 months</td>
<td>1 (10)</td>
<td>2 (14)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3-12 months</td>
<td>1 (10)</td>
<td>4 (29)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-2 years</td>
<td>1 (10)</td>
<td>2 (14)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2-5 years</td>
<td>3 (30)</td>
<td>1 (7)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt;5 years</td>
<td>4 (40)</td>
<td>5 (36)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ADKS score, mean (SD)</td>
<td>23.60 (3.40)</td>
<td>24.36 (3.52)</td>
<td>0.15 (1,22)</td>
<td>.70</td>
<td></td>
</tr>
</tbody>
</table>

aADKS: Alzheimer’s Disease Knowledge Scale.
During the pilot, 59 participants dropped out. The total response at post-test was 61%. Reasons for dropouts in the Netherlands (n=29) were no time (n=4) or unknown (n=25; no response to repeated emails of researchers to remind them of filling in the questionnaires). Reasons for dropouts in the United Kingdom (n=30) were no time (n=1), no computer at home (n=1), or unknown (n=28; no response to repeated requests by researchers to fill in the questionnaires). Due to a technical issue (the rule forcing participants to fill in all usefulness and user friendliness questions before continuing did not function), one Dutch participant did not fill in the questions on usefulness and user friendliness, although he filled in all impact questions. Analyses to test differences in background characteristics between completers and dropouts indicated that for both formal and informal caregivers and volunteers there were no significant differences in age, gender, relationship, and duration of care/work between these groups. Furthermore, at baseline there were no statistically significant differences in background characteristics and primary outcome measures, such as knowledge, empathy, and approaches between the experimental and control group.

Results of the Evaluation of Usefulness and User Friendliness of the STAR Training

At post-test, participants from the experimental group (following the STAR training) were asked to indicate if they followed a particular module and, if so, to rate its usefulness on a scale from 0 to 10 (the higher the score, the more useful/userfriendly). These ratings are presented in Table 6.2. Participants in the Netherlands and the United Kingdom were positive overall about the usefulness of the different modules. On average across the countries, the modules that were assessed as most useful were modules 4 (practical difficulties in daily life and how to help) and 6 (support strategies to help people cope with the consequences of dementia). The modules considered least useful were modules 1 (what is dementia?) and 3 (getting a diagnosis) and 5 (emotional impact of dementia).

Table 6.2. Rating of usefulness of modules by participants at post-test (mean score on scale 1-10).

<table>
<thead>
<tr>
<th>Module</th>
<th>Laypeople, mean (SD), n</th>
<th>Professionals, mean (SD), n</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Netherlands n=17</td>
<td>UK n=9</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Netherlands n=8</td>
</tr>
<tr>
<td></td>
<td></td>
<td>UK n=2</td>
</tr>
<tr>
<td>Baseline</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1. What is dementia?</td>
<td>8.07 (1.03), 15</td>
<td>8.22 (1.92), 9</td>
</tr>
<tr>
<td></td>
<td>8.40 (1.61), 7</td>
<td>6.00 (—), 1</td>
</tr>
<tr>
<td>2 Living with dementia</td>
<td>8.13 (1.13), 15</td>
<td>9.00 (0.76), 8</td>
</tr>
<tr>
<td></td>
<td>8.30 (1.80), 7</td>
<td>—</td>
</tr>
<tr>
<td>Intermediate</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Getting a diagnosis</td>
<td>7.76 (1.35), 17</td>
<td>8.88 (0.84), 8</td>
</tr>
<tr>
<td></td>
<td>7.75 (1.75), 8</td>
<td>—</td>
</tr>
<tr>
<td>4. Practical difficulties</td>
<td>7.76 (1.30), 17</td>
<td>9.14 (0.69), 7</td>
</tr>
<tr>
<td></td>
<td>7.55 (1.75), 7</td>
<td>—</td>
</tr>
<tr>
<td>5. Emotional impact of dementia</td>
<td>7.76 (1.56), 17</td>
<td>9.00 (0.82), 7</td>
</tr>
<tr>
<td></td>
<td>7.80 (1.67), 6</td>
<td>7.00 (—), 1</td>
</tr>
<tr>
<td>6. Support strategies</td>
<td>7.71 (1.45), 17</td>
<td>8.57 (0.98), 7</td>
</tr>
<tr>
<td></td>
<td>8.40 (1.51), 5</td>
<td>9.00 (—), 1</td>
</tr>
<tr>
<td>7. Empathic communication</td>
<td>7.53 (1.40), 15</td>
<td>9.00 (1.00), 5</td>
</tr>
<tr>
<td></td>
<td>8.00 (1.41), 4</td>
<td>10.00 (—), 1</td>
</tr>
<tr>
<td>8. Emotional impact for caregiver</td>
<td>7.86 (1.41), 14</td>
<td>9.00 (1.00), 5</td>
</tr>
<tr>
<td></td>
<td>8.00 (1.41), 4</td>
<td>10.00 (—), 1</td>
</tr>
<tr>
<td>Advanced</td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Getting a diagnosis</td>
<td>7.71 (0.76), 7</td>
<td>6.40 (3.64), 5</td>
</tr>
<tr>
<td></td>
<td>6.83 (1.17), 6</td>
<td>—</td>
</tr>
<tr>
<td>4. Practical difficulties</td>
<td>7.63 (1.19), 8</td>
<td>8.00 (1.00), 3</td>
</tr>
<tr>
<td></td>
<td>6.00 (1.00), 3</td>
<td>—</td>
</tr>
<tr>
<td>5. Emotional impact of dementia</td>
<td>7.75 (1.04), 8</td>
<td>7.67 (0.58), 3</td>
</tr>
<tr>
<td></td>
<td>8.33 (1.53), 3</td>
<td>10.00 (—), 1</td>
</tr>
<tr>
<td>6. Support strategies</td>
<td>7.29 (0.76), 7</td>
<td>8.00 (1.00), 3</td>
</tr>
<tr>
<td></td>
<td>7.50 (0.71), 2</td>
<td>—</td>
</tr>
<tr>
<td>7. Empathic communication</td>
<td>7.50 (0.84), 6</td>
<td>7.50 (0.71), 2</td>
</tr>
<tr>
<td></td>
<td>7.50 (0.71), 2</td>
<td>—</td>
</tr>
<tr>
<td>8. Emotional impact for caregiver</td>
<td>7.88 (0.84), 8</td>
<td>7.50 (0.71), 2</td>
</tr>
<tr>
<td></td>
<td>7.67, 3</td>
<td>—</td>
</tr>
<tr>
<td>Mean overall rating</td>
<td>7.74 (0.87)</td>
<td>8.27 (0.41)</td>
</tr>
<tr>
<td></td>
<td>7.16 (0.66)</td>
<td>8.67 (—)</td>
</tr>
</tbody>
</table>

*A higher score means participants considered it to be more useful.*
The results on the opinions about usefulness of the different elements, (eg, text or videos) of the STAR training are shown in Table 6.3. Opinions on user friendliness are shown in Table 6.4.

### Table 6.3. Ratings on usefulness of specific elements of the STAR training (range 1-4).

<table>
<thead>
<tr>
<th>Element</th>
<th>Laypeople, median (interquartile range)</th>
<th>Professionals, median (interquartile range)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Netherlands n=17</td>
<td>UK n=9</td>
</tr>
<tr>
<td>The text of the modules</td>
<td>3.0 (0.0)</td>
<td>4.0 (1.0)</td>
</tr>
<tr>
<td>The interactive exercises</td>
<td>3.0 (1.0)</td>
<td>4.0 (1.0)</td>
</tr>
<tr>
<td>The knowledge questions</td>
<td>3.0 (1.0)</td>
<td>4.0 (1.0)</td>
</tr>
<tr>
<td>The online community³</td>
<td>3.0 (1.0)</td>
<td>4.0 (1.0)</td>
</tr>
<tr>
<td>The comments from the expert community³</td>
<td>3.0 (1.0)</td>
<td>5.0 (2.0)</td>
</tr>
</tbody>
</table>

a Scoring: 1=useless; 2=a little useful; 3=useful; 4=very useful; NA=not applicable.

³ N/A in NL: n=8; N/A in UK: n=7.

### Table 6.4. Opinions on user friendliness (range 1-5).

<table>
<thead>
<tr>
<th>Userfriendliness aspects</th>
<th>Laypeople, median (interquartile range)</th>
<th>Professionals, median (interquartile range)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Netherlands n=17</td>
<td>UK n=9</td>
</tr>
<tr>
<td>Logging in was easy</td>
<td>1.0 (0.0)</td>
<td>1.0 (0.0)</td>
</tr>
<tr>
<td>I immediately noticed where I have to click</td>
<td>1.0 (1.0)</td>
<td>1.0 (0.0)</td>
</tr>
<tr>
<td>The overall layout is simple to follow</td>
<td>1.0 (1.0)</td>
<td>1.0 (0.0)</td>
</tr>
<tr>
<td>The STAR training was easy to do</td>
<td>1.0 (1.0)</td>
<td>1.0 (1.0)</td>
</tr>
<tr>
<td>The material has been well thought out</td>
<td>1.0 (1.0)</td>
<td>1.0 (1.0)</td>
</tr>
<tr>
<td>The length of the modules and exercises was just right</td>
<td>1.0 (1.0)</td>
<td>1.0 (1.0)</td>
</tr>
<tr>
<td>The course was nice to do</td>
<td>1.0 (0.0)</td>
<td>1.0 (1.0)</td>
</tr>
<tr>
<td>I knew what I had to do in the STAR training (navigating, exercises, etc)</td>
<td>1.0 (0.0)</td>
<td>1.0 (1.0)</td>
</tr>
</tbody>
</table>

a Scoring: 1=completely agree; 2=agree a little; 3=agree/disagree; 4=disagree a little; 5=completely disagree.

³ In the UK cases where there’s only 2 participants, the interquartile range could not be computed.

### Use of the Learning Path Advisor

Analysis of logging files of the STAR training indicated that most of the STAR participants in the experimental group used the Learning Path Advisor. In the Netherlands, 73% of informal caregivers and 91% of professional caregivers used the Learning Path Advisor to obtain a personalized suggestion where to start in the course. In the United Kingdom, 9% of informal caregivers and 17% of professionals used the Learning Path Advisor.
Table 6.5. Impact of STAR training on outcome measures for laypeople and professionals (Netherlands and United Kingdom together).

<table>
<thead>
<tr>
<th>Outcomes</th>
<th>Pretest, mean (SD)</th>
<th>Posttest, mean (SD)</th>
<th>Adjusted Means, (std. error)</th>
<th>F (df1,df2)</th>
<th>p</th>
<th>η²</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Experimental</td>
<td>Control</td>
<td>Experimental</td>
<td>Control</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Primary outcomes</strong></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>ADQ:</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Laypeople</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total (score 18-90)</td>
<td>69.15 (6.74)</td>
<td>60.13 (10.4)</td>
<td>71.59 (6.48)</td>
<td>64.66 (4.90)</td>
<td>71.07 (1.16)</td>
<td>65.10 (1.06)</td>
</tr>
<tr>
<td>Hope scale (score 8-40)</td>
<td>20.48 (4.26)</td>
<td>18.25 (3.89)</td>
<td>22.33 (5.33)</td>
<td>19.13 (3.68)</td>
<td>21.71 (0.79)</td>
<td>16.65 (0.72)</td>
</tr>
<tr>
<td>Person scale (score 10-50)</td>
<td>48.67 (4.45)</td>
<td>41.87 (9.50)</td>
<td>49.26 (3.49)</td>
<td>45.53 (3.56)</td>
<td>48.65 (0.67)</td>
<td>46.04 (0.61)</td>
</tr>
<tr>
<td>Professionals</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total (score 19-95)</td>
<td>76.30 (5.42)</td>
<td>56.78 (19.6)</td>
<td>77.21 (8.12)</td>
<td>80.23 (2.26)</td>
<td>75.41 (1.86)</td>
<td>72.54 (1.72)</td>
</tr>
<tr>
<td>Hope scale (score 8-40)</td>
<td>27.50 (3.89)</td>
<td>21.21 (5.74)</td>
<td>27.80 (3.68)</td>
<td>27.86 (4.59)</td>
<td>28.51 (1.49)</td>
<td>27.35 (1.22)</td>
</tr>
<tr>
<td>Person scale (score 11-55)</td>
<td>48.80 (2.78)</td>
<td>35.57 (14.4)</td>
<td>49.90 (3.03)</td>
<td>49.36 (4.41)</td>
<td>50.77 (1.32)</td>
<td>48.74 (1.09)</td>
</tr>
<tr>
<td>ADKS: (score 1-30)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Laypeople</td>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>24.67 (3.43)</td>
<td>24.13 (3.32)</td>
<td>24.44 (3.11)</td>
<td>24.26 (3.12)</td>
<td>24.85 (0.52)</td>
<td>24.40 (0.48)</td>
</tr>
<tr>
<td>Professionals</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>24.60 (3.41)</td>
<td>24.36 (3.52)</td>
<td>24.20 (2.57)</td>
<td>24.64 (2.40)</td>
<td>24.44 (0.51)</td>
<td>24.47 (0.43)</td>
</tr>
<tr>
<td>Attitudes (score 1-7)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Laypeople</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>2.91 (1.78)</td>
<td>2.59 (1.82)</td>
<td>2.75 (1.85)</td>
<td>2.10 (1.67)</td>
<td>2.68 (0.31)</td>
<td>2.14 (0.27)</td>
</tr>
<tr>
<td>Professionals</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>3.33 (1.32)</td>
<td>2.67 (1.61)</td>
<td>3.22 (1.39)</td>
<td>2.92 (1.68)</td>
<td>3.02 (0.47)</td>
<td>3.07 (0.40)</td>
</tr>
</tbody>
</table>

For all scores except distress and burden, the higher score is the more favorable.

Effect size (η²) is considered small at 0.01, medium at 0.06, and large at 0.14.

ADQ: Approaches to Dementia Questionnaire

ADKS: Alzheimer’s Disease Knowledge Scale

For professional caregivers, score is 11-55 because they had one additional question compared to informal caregivers.

ADKS: Alzheimer’s Disease Knowledge Scale

Here, the mean ranking (scale 1-7) of fear for contracting dementia is displayed.
<table>
<thead>
<tr>
<th>Outcomes&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Pretest, mean (SD)</th>
<th>Post-test, mean (SD)</th>
<th>Adjusted Means, (std. error)</th>
<th>F (df1,df2)</th>
<th>p</th>
<th>η²&lt;sup&gt;b&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Experimental</td>
<td>Control</td>
<td>Experimental</td>
<td>Control</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Secondary outcomes</td>
<td></td>
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</tr>
<tr>
<td>Interpersonal Reactivity (IR; score 0-28)</td>
<td></td>
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<tr>
<td>Laypeople</td>
<td></td>
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<td></td>
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<tr>
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<td>(n=32)</td>
<td>(n=27)</td>
<td>(n=32)</td>
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<td></td>
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<tr>
<td>Distress</td>
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<td>14.25 (5.85)</td>
<td>9.74 (5.33)</td>
<td>13.59 (5.63)</td>
<td>9.72 (0.91)</td>
<td>13.61 (0.84)</td>
</tr>
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<td>Empathy</td>
<td>12.56 (6.45)</td>
<td>12.81 (6.60)</td>
<td>20.40 (4.06)</td>
<td>13.03 (5.63)</td>
<td>20.47 (0.80)</td>
<td>12.98 (0.73)</td>
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<tr>
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<td>13.75 (4.24)</td>
<td>14.30 (5.24)</td>
<td>12.84 (4.43)</td>
<td>14.30 (0.91)</td>
<td>12.84 (0.83)</td>
</tr>
<tr>
<td>Perspective</td>
<td>13.11 (5.66)</td>
<td>13.06 (5.79)</td>
<td>18.81 (3.45)</td>
<td>13.75 (4.45)</td>
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<td>(n=14)</td>
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<td>(n=14)</td>
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<tr>
<td>Distress</td>
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<td>13.86 (7.68)</td>
<td>7.50 (2.80)</td>
<td>14.57 (7.00)</td>
<td>7.68 (1.22)</td>
<td>14.44 (1.03)</td>
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<td>14.15 (8.12)</td>
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</tr>
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<td>13.57 (4.18)</td>
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<td>14.64 (5.37)</td>
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<tr>
<td>Perspective</td>
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<td>19.10 (3.21)</td>
<td>13.93 (7.43)</td>
<td>18.95 (1.46)</td>
<td>14.03 (1.24)</td>
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<td>(n=21)</td>
<td>(n=25)</td>
<td></td>
<td></td>
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<td>(n=21)</td>
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<td>(n=21)</td>
<td>(n=25)</td>
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<td></td>
<td></td>
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<tr>
<td>Quality of life (grade 1-10)</td>
<td>7.24 (1.58)</td>
<td>6.23 (1.75)</td>
<td>7.05 (1.77)</td>
<td>6.48 (1.58)</td>
<td>6.75 (0.31)</td>
<td>6.73 (0.29)</td>
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<tr>
<td>Informal caregivers</td>
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<td>(n=24)</td>
<td>(n=21)</td>
<td>(n=24)</td>
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<tr>
<td>(n=21)</td>
<td>(n=24)</td>
<td>(n=21)</td>
<td>(n=24)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Burden&lt;sup&gt;c&lt;/sup&gt;</td>
<td>2.67 (1.11)</td>
<td>3.08 (1.13)</td>
<td>2.43 (0.98)</td>
<td>2.80 (0.96)</td>
<td>2.52 (0.18)</td>
<td>2.72 (0.17)</td>
</tr>
<tr>
<td>Informal caregivers</td>
<td>(n=21)</td>
<td>(n=24)</td>
<td>(n=21)</td>
<td>(n=24)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>(n=21)</td>
<td>(n=24)</td>
<td>(n=21)</td>
<td>(n=24)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sense of competence (SSCQ)&lt;sup&gt;d,h&lt;/sup&gt;</td>
<td>4.67 (1.59)</td>
<td>4.41 (1.86)</td>
<td>4.86 (1.46)</td>
<td>3.88 (1.62)</td>
<td>4.78 (0.26)</td>
<td>3.94 (0.25)</td>
</tr>
</tbody>
</table>

<sup>a</sup>These were questionnaires specifically relevant to informal caregivers; they were not applied in volunteers.

<sup>b</sup>SSCQ: Short Sense of Competence Questionnaire
Impact on Outcome Measures

In Table 6.5 are the results of the ANCOVA analysis to assess the impact of STAR training compared to a waiting list condition on the primary and secondary outcome measures of participants in the Netherlands and the United Kingdom.

For the primary outcome measures, we found a statistically significant effect on approaches toward dementia (ADQ total score) with a large effect size ($\eta^2$) and on its subscale, person-centered care among laypeople (informal caregivers and volunteers), with a large effect size. For both cases, both the experimental group and the control group increased in score. Differences in baseline scores were accounted for by adding these as a covariate in the analyses. We did not find outliers at baseline that could explain this result. For the remaining primary outcomes (knowledge about dementia (ADKS) and attitudes toward dementia – where participants were asked which disease they were most afraid to develop), we did not find statistically significant differences in the experimental or control group among laypeople and professionals. There were 2 separate questions relating to attitudes toward dementia. The first question related to which disease people were most afraid of contracting. There was no significant difference in the order of fear of contracting dementia (compared to six other diseases) between the experimental and control group. At pretest, 31% of laypeople in the experimental group were most afraid of developing dementia; for professionals in the experimental group, this was 13%. At post-test, in the experimental group 46% of laypeople and 8% of professionals were most afraid of developing dementia. In the control group, among laymen 38% were most afraid of dementia at pretest; and 63% at posttest. Among professionals, 25% was most afraid at pretest, and 14% at posttest. This suggests that, in both groups after completing the course, laypersons were more afraid of developing dementia, whereas this fear decreased in professionals, however these differences were not significant between experimental and control group. The second question on attitudes toward dementia was “if you had a family member who was exhibiting confusion and memory loss, would you want the person to see a doctor to determine if the cause of the symptoms was Alzheimer’s disease or not?”. This was answered with ‘yes’ by all who completed the research, both at pretest and at post-test; and as such was not analyzed further.

For the secondary outcome measures, we found statistically significant differences between the experimental and control group in the expected direction on several subscales of empathy: the distress subscale, empathy subscale, and perspective subscale. Although the scores on these scales remained largely the same in the control group at pretest and post-test, we witnessed a significant improvement in the experimental group, indicating that they felt less distressed in tense situations, had more empathy and concern for the well-being of other people, and were better able to understand situations and the actions of other people. Additionally, we found a moderate to large positive effect on sense of competence of informal caregivers, which improved in the experimental group compared to the control group, implying that participants in the course felt more competent to fulfill their care task after following the course compared to the control group.

Discussion

The STAR training, an online e-learning course developed to skill/reskill informal caregivers, volunteers, and professional caregivers of persons with dementia, was evaluated in the Netherlands and the United Kingdom on its usefulness, user friendliness, and effectiveness. This evaluation was undertaken in an RCT, comparing participants who followed the STAR training to a waiting list control group. The evaluation results indicated that, in general, the 8 modules of the STAR training were positively/very...
positively valued with regard to usefulness and user friendliness. The course was considered easy to undertake and the material was considered well thought out. Participants indicated that the course made them feel more secure about their quality as a caregiver. Although all modules were assessed positively, some modules, such as modules 1 and 3, scored lower than others did. The content of these modules will need to be reviewed for future versions of STAR.

The results of the RCT in the Netherlands and the United Kingdom demonstrated a significant positive impact of the STAR training course on maintaining feelings of empathy among informal caregivers and volunteers. Also, an effect was found on a person-centered care approach; both the person-centered care approach and the total score on positive approaches toward dementia increased among laypeople in both the experimental and the control group. The sense of competence improved (with a moderate to large effect) in the informal caregivers who followed the STAR course. This improvement is in line with the finding that a large number of the participants who followed the STAR training indicated that they felt more secure about their qualities as caregivers.

For professional caregivers, empathy improved among those who followed the course. This is an indication that after following the course they became better able to view situations from another’s perspective (e.g., a person with dementia) and that they showed more sympathy and concern, which may help them to provide better care for people with dementia. No effects were found on knowledge about Alzheimer’s disease. This was likely because the selected instrument, the ADKS, mostly has factual questions on symptoms and prevalence, although the STAR course predominantly focused on informing caregivers how to deal and cope with the consequences of dementia. Therefore, positive outcomes related to dealing with dementia (e.g., empathy and attitudes), rather than an increase in knowledge, were in line with our expectations. On other outcome measures, such as quality of life and burden, no effects were found.

These results are in line with recent research, which has also found beneficial effects from Internet-based interventions [7], among others on attitudes and empathy [10]. One of the explanations for the effectiveness of STAR is the opportunity to choose “personalized learning paths,” which make it possible for each individual caregiver to tailor the content of the training to their own needs and skill level by recommending which modules are most relevant to them. According to earlier research by Lustria et al. [8], tailored computer-based health interventions lead to improved health in caregivers. Previous research also indicates that increasing empathy in caregivers is highly relevant because it increases the well-being of the person with dementia [25].

Review studies on the effectiveness of psychosocial and technology-driven interventions to support family caregivers show that interventions using a psychoeducational or psychotherapeutic approach appear to be among the most powerful psychosocial interventions to improve quality of life of persons with dementia and their caregivers, and delay patient institutionalization [26-28]. Nevertheless, many studies suffered from serious methodological problems, such as unclear randomization methods, inadequate power calculation, selectively reported outcomes, and no use of an intention-to-treat analysis [29-31]. In addition, interventions were difficult to compare because type and intensity varied [32]. STAR adds to this research by offering an RCT with clear randomization methods and adequate numbers for sufficient statistical power. Additionally, all outcomes of STAR are clearly reported.

A strength of this study is that the STAR training portal was tested in an RCT design in 2 countries. A limitation of the study was the high number of dropouts in the RCT (34% in the Netherlands, 53% in
the United Kingdom), especially in the experimental group; 43% (Netherlands) and 64% (United Kingdom) dropped out of the study. It seems likely that participants in the control group were more motivated to participate in the post-test because participating in the questionnaires would offer them free access to the course afterward. Furthermore, given that the STAR training portal was still in late development at the time of testing, some errors occurred when people followed the course. Another limitation was the fact that the online communities were not used often by participants, making them less informative and supportive than originally anticipated. The communities only contained a small number of participants because access was limited to only those in the experimental group of the research. However, they are expected to become more active and supportive in the future. This expectation is based on the fact that the STAR website has recently been updated to show links to the community websites more clearly. Additionally, when STAR gets more users, more users will potentially visit these communities, making them more lively and, therefore, more interesting to use for other visitors. We found little use for the Learning Path Advisor in the United Kingdom compared to use of it in the Netherlands. One explanation for this could be that the British group consisted of more volunteers with less experience in dementia care, who may have been more interested to follow the entire course, whereas the Dutch group consisted largely of informal caregivers and the majority (79%) had been caring for a person with dementia for 2 years or longer. It is likely that these experienced caregivers tended to use the Learning Path Advisor more frequently to find out which modules would provide them with new information, taking into account the knowledge they already had.

In conclusion, based on the promising results of our study, especially the positive effects of the STAR training portal on empathy for both laypeople (informal caregivers and volunteers) and professionals, and on feelings of competence of informal caregivers, it is recommended to repeat the RCT on a larger scale and in more countries. STAR is currently available in Dutch and English; the basic and intermediate modules are available in Italian and Romanian, and some are available in Swedish as well.

The positive effects of STAR on attitudes, empathy and sense of competence of caregivers may contribute to appropriate and high-quality dementia care in the community now and in the future. Therefore, an Internet-based intervention such as STAR can be a very useful alternative for face-to-face education and support for caregivers/informal caregivers and low-/unschooled professionals [2, 3] and at lower costs [9], thus providing a means to cope with the challenge of taking care of the growing number of people with dementia in our society.

Acknowledgments

We gratefully acknowledge all participants in the RCTs in both the Netherlands and United Kingdom who participated in the course and supplied us with their opinions. We also gratefully acknowledge the writers of the course material. The STAR project was funded by the Leonardo da Vinci Life Long Learning Programme of the European Union (no. 510364-2010) and the BAVO Foundation in the Netherlands.

Conflicts of Interest

None declared.
References


Abbreviations used

ADKS: Alzheimer's Disease Knowledge Scale
ADQ: Approaches to Dementia Questionnaire
EU: European Union
IRI: Interpersonal Reactivity Index
RCT: randomized controlled trial
SSCQ: Short Sense of Competence Questionnaire
STAR: Skills Training And Reskilling
USE: Usefulness, Satisfaction, and Ease of use
CHAPTER 7

Digital Alzheimer Center: Evaluating a webbased patient portal

Published as:

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ABSTRACT

**Background:** Dementia is a progressive and highly disabling neurodegenerative disease that will likely become highly prevalent in the future due to the globally aging population. To improve health care efficiency and quality for dementia care, eHealth could help with, for example, an online portal, such as the Digital Alzheimer Center (DAC) of the Vrije Universiteit Medical Center Amsterdam. It provides up-to-date disease information, peer-to-peer contact, and methods for contacting the hospital and health professionals.

**Objective:** We aimed to investigate the usability and usefulness of the DAC for patients with dementia and carers to get insight into the feasibility and value of this eHealth app in dementia care and to recommend potential improvements.

**Methods:** A descriptive study among patients, carers, and health care professionals was performed. Mixed methods were used, consisting of observations (n=10; 4 people with dementia, 6 carers), an online survey (n=287; 88 patients, 199 carers), and semistructured interviews (n=18; 6 patients, 6 carers, 6 health care professionals). During the observations, participants performed a set of five different prescribed tasks on the portal. Speed, number of errors, and navigation were noted. The online survey aimed to assess users’ opinions on the portal’s usability and usefulness. Semistructured interviews were conducted in a subsample of patients, carers, and health care professionals to gain more in-depth information.

**Results:** In the usability assessment, eight categories of errors were distinguished, of which three were of critical, two of medium, and three of low severity. In the survey, 45% (40/88) of the patients and 53% (105/199) of the carers indicated they used the portal. In all, 33% (12/36) of patients and 61% (62/102) of carers found it easy to learn to work with the portal. Most considered the DAC generally useful: 65% (17/26) of patients and 78% (67/86) of carers found the DAC useful, especially for understanding dementia (patients: 64%, 16/25; carers: 62%, 53/86). In the semistructured interviews, the site was generally rated positively on usability and usefulness and being well designed. People with dementia and carers indicated it helped them to understand and deal with dementia.

**Conclusions:** To our knowledge, this is the first study investigating the usability and usefulness of an Internet portal especially designed for people with dementia and their carers. An online patient portal could be a useful means to help to support patients and carers in dealing with dementia: the majority of users positively evaluated usability and usefulness of the portal, and appreciated the information on it. However, only a minority of patients found it easy to work with the portal. Good design and frequent usability testing is essential to offer a good online portal.
Introduction

Dementia

Neurodegenerative diseases leading to dementia are highly disabling; they are characterized by cognitive decline, gradual loss of daily functioning, and eventually lead to complete dependency on others. Because age is the major risk factor for dementia, the global aging of the population will increase the prevalence of dementia worldwide in the coming years. Additionally, this aging population will lead to a decrease in the available workforce, including professional dementia carers. This will pose a great burden on the care system and on carers. It will also have great economic consequences: in approximately 25 years, dementia is projected to become the disease with the largest economic burden. Worldwide, the economic cost of dementia is estimated to be more than US $600 billion and increasing every year [1]. Therefore, novel solutions to efficiently provide dementia care are urgently needed. In addition to reducing costs, these tools should also improve the quality of life of those with dementia and their carers. One promising tool to deliver efficient care in the future is eHealth: "health services and information delivered or enhanced through the Internet and related technologies" [2].

Limited research into eHealth solutions for people with dementia has been carried out, but initial findings suggest certain applications can help to reduce the limitations that are encountered in daily life [3,4]: it can deliver information and coaching [5,6], it can allow remote consultation [7-14], and its use increases work satisfaction of care staff and improves care relations [15,16]. Additionally, communication tools can promote social contact and GPS- or sensor-based tracking can help to enhance feelings of safety by means of tracking and tracing systems, for example, that can help people with dementia when lost outside of the home [3,17-20].

A promising and increasingly used eHealth solution [21] is an online patient portal: a secure website for patients that offers access to a variety of functions, including secure messaging and protected health information [22]. Portals can offer more personalized health information and social contact. In a 2014 review, Otte-Trojel et al [23] studied 32 papers evaluating patient portals and concluded that these portals can lead to improvements in clinical outcomes, patient behavior, and patient experiences.

Background

Patient portals are being used for several different (chronic) conditions to offer different services, usually as part of electronic health record (EHR) services. One example is the American MyHealth portal, which uses patient data to generate a personalized health record in which patients can view detailed information about their disease. However, these portals are usually limited in functionality (e.g., only offering contact with physicians or only offering access to the health record) and are aimed at the general population of the hospital. They are not optimized for specific patient groups, who may have different needs and wishes. Other portals exist separately from patient records and are often managed by external nonprofit (e.g., patient federations) or commercial companies. One example is the patient portal for Dutch cancer patients, kanker.nl, which has more than 15,000 monthly users and is offered by the Dutch Cancer Society. Additionally, there are portals that focus on one specific aspect of support, such as offering information or education (e.g., the Skills Training & Re-skilling [STAR] portal for informal and professional carers of people with dementia [24], which offers online e-learning modules), or offer only communication tools, such as the online patient portal nextmd.com offered by
Nextgen Healthcare, which only offers contact between patients and their physicians. These are generally offered at a cost, either paid for by health insurance or by the user.

A literature review identified 176 studies that mention portals for viewing EHR data remotely [25]. Although most of these studies were reported to be of low quality, the authors did conclude that users appreciate the added convenience (i.e., easy access to information) a patient portal offers. Another review identified 120 articles on patient portals [26]. They found highly variable outcomes: some studies indicated that patients felt that their physicians responded more promptly to their questions than through other means, yet other studies found that users felt an increased workload because of the online portal. However, none of these portals are intended or designed for people with dementia and focus mostly on other chronic diseases, such as diabetes or cancer.

We recently developed an online patient portal, the Digital Alzheimer Center (DAC): the first patient portal on dementia care in the Netherlands. The aim of this portal is to offer comprehensive information on dementia, to enhance social activities, support peer-to-peer contact, and to provide easy access to communicate with health care professionals. A reference group of patients and carers was continuously involved by giving feedback on design and content during periodic focus meetings and usability testing. The DAC was launched in 2012 and has issued more than 1000 accounts since then.

In this study, we aimed to investigate how patients with dementia and their carers value the DAC. We studied this by evaluating two important properties of eHealth and other care innovations that are important for them to succeed: usability and usefulness. Usability is defined by the International Standards Organization as “the effectiveness, efficiency, and satisfaction with which specified users can achieve goals in particular environments.” Usefulness determines to what extent users judge a website or application to fulfill specific needs.

By evaluating the usability and usefulness this study aimed to provide data on the feasibility and added value of a patient portal in dementia care which can contribute to the existing knowledge on the feasibility and added value of patient portals in dementia care.

Methods

Design
To evaluate the usability and usefulness of the DAC, a descriptive, exploratory study was carried out among patients, carers, and health care professionals in which mixed methods were used: observations of patients and carers while they perform prescribed tasks on the DAC; an online survey among patients and carers; and semistructured interviews with patients, carers, and health care professionals.

Ethics and Informed Consent
This study was approved by the medical ethical committee of the Vrije Universiteit (VU) Medical Center in Amsterdam. For both the observations and interviews, participants received verbal information (by phone) as well as written information (an information letter), after which they were invited to sign a consent form if they were willing to take part in the research. Participants who opened the online survey first were presented with a screen with information about the research after which they could choose to stop or continue with the survey. They could quit the survey at any time without providing a reason.
Setting and Participant Selection

All participants in the study were clients (patients and carers) and health care professionals of the Alzheimer Center of the VU University Medical Center. The Alzheimer Center is a memory clinic in an academic hospital with a main focus on diagnosing early-onset dementia (dementia with an onset age earlier than 65 years).

Inclusion criteria varied per method. For observations, participants (patients or carers) needed to have participated in at least one DAC workshop (informal workshops organized in the Alzheimer Center, during which participants learn to use the DAC) to ensure that the observed participants had at least some degree of experience with the DAC. This was decided because, for a first exploratory research into the usability of the website, a fully blind “hallway testing” (in which users have never used the site at all) was not warranted yet. Additionally, they had to be physically able to use a computer. Participants were randomly selected from a list of workshop participants of the past four workshops. For the interviews, patients and carers were randomly selected from the list of workshop participants; all professionals that worked with the DAC were approached. An invitation to participate in the survey was sent out to all users registered with an account.

To recruit patients and carers for the observations during prescribed tasks, 10 persons were randomly selected and contacted by a researcher (BH) and asked if they wanted to take part in a usability study on the DAC. For the semistructured interviews, six patients with dementia, six carers, and six professionals participated. Of all 287 users (patients and carers) that started the survey, 40 patients and 105 carers indicated they used the DAC. Of these, 25 patients (63%) and 85 carers (81%) completed the entire survey. Incomplete surveys were also part of the analysis. In Table 7.1, the characteristics of the study participants in each part of the study are presented.

Overview of the Digital Alzheimer Center

The DAC offers a comprehensive menu containing information on diseases, an overview of appointments and dossiers, community sections, and information on upcoming events and news. The information is written in an accessible fashion and illustrated with animations to clarify pathological processes. Patients and carers can find practical tips on living with the changes that are caused by the disease, financial and legal matters, how to avoid carer stress, and much more. In a specially secured section, patients can email their health care professionals at the Alzheimer Center and view their appointments and medical correspondence. A community hosts a forum for questions and exchanging experiences (e.g., a photo and video gallery) and information among patients, carers, and health care professionals. In this forum, users can submit messages on several different subjects (e.g., “how to tell family and friends” or “practical tips”) and they can reply to one another’s messages. With the “friends” functionality, users can find others in their area with the same diagnosis and can communicate by a private messaging service. The community section also posts upcoming events and other news from the Alzheimer Center and the national and international Alzheimer community are shared.

Detailed in images subsequently is a walkthrough of the DAC in screenshots. The first page, which all users visit after logging in, is a welcome page (Figure 7.1) where users are presented with an overview of the main functionalities of the DAC. Clicking on one of the options leads further into the website. For example, if they choose “community,” participants are presented with the different functionalities within this section (Figure 7.2). Within the community, participants can select “forum” (Figure 7.3) to display all content. Within the “forum” function, participants can select different themes to discuss with others (Figure 7.3). The DAC can be accessed from anywhere through its URL [27].
Table 7.1. Characteristics of study population in each part of the study.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Observations during prescribed tasks (n=10)</th>
<th>Online survey (n=287)</th>
<th>Semistructured interviews (n=18)</th>
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<td></td>
<td></td>
</tr>
<tr>
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<td>67 (44-82) (n=88)</td>
<td>71 (61-78) (n=6)</td>
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<td>Carer</td>
<td>72.0 (58-78) (n=6)</td>
<td>63 (36-82) (n=199)</td>
<td>70 (59-79) (n=6)</td>
</tr>
<tr>
<td>Professional</td>
<td>—</td>
<td>—</td>
<td>44 (29-58) (n=6)</td>
</tr>
<tr>
<td>Patient gender, n (%)</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>3 (75)</td>
<td>44^a (50.0)</td>
<td>5 (83)</td>
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<tr>
<td>Female</td>
<td>1 (25)</td>
<td>35^a (39.8)</td>
<td>1 (17)</td>
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<tr>
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<td>9^a (10.2)</td>
<td>—</td>
</tr>
<tr>
<td>Carer gender, n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>3 (50)</td>
<td>41^a (20.6)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Female</td>
<td>3 (50)</td>
<td>80^a (40.2)</td>
<td>6 (100)</td>
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<td>Diagnosis patients^bc, n (%)</td>
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</tr>
<tr>
<td>Alzheimer’s disease</td>
<td>2 (50)</td>
<td>109 (38.0)</td>
<td>3 (50)</td>
</tr>
<tr>
<td>FTD</td>
<td>1 (25)</td>
<td>18 (6.3)</td>
<td></td>
</tr>
<tr>
<td>DLB</td>
<td></td>
<td>17 (5.9)</td>
<td></td>
</tr>
<tr>
<td>MCI</td>
<td>1 (25)</td>
<td>5 (1.8)</td>
<td>1 (17)</td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td>52 (18.1)</td>
<td>2 (33)</td>
</tr>
<tr>
<td>Missing</td>
<td></td>
<td>86 (29.9)</td>
<td></td>
</tr>
<tr>
<td>Patient experience with using computers, n (%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>1 (25)</td>
<td>3 (3.4)</td>
<td>1 (17)</td>
</tr>
<tr>
<td>Little</td>
<td>2 (50)</td>
<td>11 (12.5)</td>
<td>3 (50)</td>
</tr>
<tr>
<td>Average</td>
<td>0</td>
<td>34 (38.6)</td>
<td>—</td>
</tr>
<tr>
<td>High</td>
<td>1 (25)</td>
<td>39 (44.4)</td>
<td>2 (33)</td>
</tr>
<tr>
<td>Very high</td>
<td>0</td>
<td>1 (1.1)</td>
<td>0</td>
</tr>
<tr>
<td>Characteristic</td>
<td>Observations during prescribed tasks (n=10)</td>
<td>Online survey (n=287)</td>
<td>Semistructured interviews (n=18)</td>
</tr>
<tr>
<td>----------------</td>
<td>--------------------------------------------</td>
<td>-----------------------</td>
<td>----------------------------------</td>
</tr>
<tr>
<td>None</td>
<td>1 (17)</td>
<td>3 (1.5)</td>
<td>1 (17)</td>
</tr>
<tr>
<td>Little</td>
<td>3 (50)</td>
<td>15 (7.5)</td>
<td>3 (50)</td>
</tr>
<tr>
<td>Average</td>
<td>2 (33)</td>
<td>82 (41.2)</td>
<td>2 (33)</td>
</tr>
<tr>
<td>High</td>
<td>0</td>
<td>78 (39.2)</td>
<td>0</td>
</tr>
<tr>
<td>Very high</td>
<td>0</td>
<td>21 (10.6)</td>
<td>0</td>
</tr>
</tbody>
</table>

*aDue to an error, gender was not inventoried in the first questionnaire; therefore, these data were collected with a short follow-up questionnaire. Unfortunately, not all participants replied to this questionnaire, which explains the high number of missing values.

*bDLB: dementia with Lewy bodies; FTD: frontotemporal dementia; MCI: mild cognitive impairment.

*cIn the survey, diagnosis was both asked of patients; and for informal carers (of the patient they cared for)"
Evaluation Methods

The DAC was evaluated using mixed methods (i.e., observations, an anonymous online survey, and semistructured interviews). This evaluation focused on two main outcomes: usability and usefulness.

Observations
To assess the usability of the DAC, participants (N=10) were observed while completing a number of predefined tasks on their own computers in their own homes. Several quantifiable measures were recorded during testing. These measures were derived from earlier reports on usability research [28-32]:

1. The type of errors participants made before reaching the end-goal, where “error” was defined by any interaction with the site that did not lead to reaching the goal;
2. The number of errors; and
3. Time on task, the time it took participants to accomplish each task.

The tasks participants were requested to complete involved tasks representative of all functionalities of the site: (1) log in to the DAC, (2) post a message on the forum, (3) find information on driving with dementia, (4) watch a video about Alzheimer’s disease, and (5) view correspondence with the hospital. The types of errors noted were errors related to issues with operating hardware, such as the mouse; with operating software, such as the Internet browser; related to navigation of the website; to general understanding of the computer; or other issues that came up. Errors were categorized as low, medium, or critical in severity. For determining severity, the Severity Rating for Usability Problems by Nielsen was used [28]. To determine severity, the number of times “yes” was answered to the following questions was counted and one point was added, making a score of 1 to 4 possible:
1. Does the problem occur frequently or in a critical task?
2. Is the problem difficult to overcome?
3. Is the problem persistent?

Critical errors (score 4) are errors that disrupt website usage enough to prevent actual site usage. Serious errors (score 3) disrupt use and can be frustrating enough to stop users using the site or force them to find workarounds for problems. Medium (score 2) and low (score 1) errors can be bothersome to most users, yet are not likely to directly influence site usage.

**Online Survey**

The online survey contained multiple-choice questions with 4- or 5-point answer scales, regarding background characteristics, such as actual use (e.g., “Does one use the DAC?”), and questions on usability and usefulness. Usability was divided into three sections: attractiveness (e.g., “How do you appreciate the layout of the DAC?”), ease of use (e.g., “How easy is it to find the information you need?”), and appreciation of the content (e.g., “How understandable are the texts?”). Questions on usefulness concerned the experienced “value” (e.g., “Does the DAC help in understanding dementia?”) and “added value” (e.g., “Does the DAC offer added value over usual care?”). This online survey was created in Qualtrics (Qualtrics, Provo, UT, USA). The survey was accessible online for 1 month and contained 82 questions. Several questions were branched and were not shown to all participants (e.g., only participants that indicated they did not like the font used on the site were shown the question “What do you dislike about the font?”).

**Semistructured Interviews**

The interviews contained both structured questions and open-ended questions on usability and usefulness of the DAC. The interviews were constructed specifically for this study, using a format of semistructured interviews based on standardized questionnaires, such as the System Usability Scale (SUS) and the User Satisfaction and Ease of use (USE) questionnaires previously developed for evaluation of other technical innovations [18, 33] focusing on usability and usefulness. Usability was assessed on two domains: ease of using the site (e.g., being able to use the site independently, finding it easy to find information) and attractiveness of the site (e.g., appreciation of the layout, colors, font, and images). Two main questions were used to assess the usefulness: added value and areas in which people feel the DAC specifically helps. These questions were either structured with room for comments (e.g., “Does the DAC save time?” with options “yes, it saves time; neutral; no, it costs more time”) or open-ended (e.g., “What could, in your opinion, be done to make the DAC look more attractive?”). On average, these interviews lasted 21 minutes.

**Procedure**

If potential participants consented after initial contact, a researcher (BH) visited them in their own homes, explained the research, and then invited the participants to conduct the prescribed tasks on their own computer, except for two patients who were approached during a workshop and participated directly on a university workstation. A link to the online survey, along with a short explanation of the survey, was included in the monthly DAC newsletter, inviting participants to participate. Patients and carers who participated in the semistructured interviews were recruited among visitors of DAC workshops; professionals were asked to participate via email. Patients and carers were visited in their
own homes for the interview by the researcher (BH); professionals were interviewed at their workplace by the researcher (BH).

Analyses
The demographics of the participants in the different study parts and survey data were analyzed with descriptive statistics. Time on task and number of errors made during performing observation tasks were noted. The differences between groups (patients and carers) were analyzed using Mann-Whitney U tests (p<.05). Errors that occurred were first clustered in themes and subsequently analyzed by assessing the severity of the error. Every newly occurring error was categorized as a new error theme. We kept track of how many other participants made the same error. Subsequently, errors were categorized in the four possible levels of severity: critical, serious, medium, and low (see Figure 7.4). The online survey data were analyzed per group with descriptive statistics. Differences between the groups were analyzed using the Mann-Whitney U test for independent samples (P<.05).

Results from the semistructured interviews were analyzed with thematic analysis [19, 34]. This was performed both quantitatively by noting the number and the percentage of participants who answered a certain response on structured questions and qualitatively by thematically analyzing answers to open questions or additional comments (e.g., by looking for recurring themes in the answers). Some explanatory quotes from participants, representative of the themes we found, were selected to explain the results of the survey.

Figure 7.4. Nielsen’s severity rating for errors.
Results

Usability: Prescribed Tasks (Observations)

Time on task of each prescribed task was measured from start to completion. In Table 7.2, the time on task and the number of errors are presented. A distinction was made between patients and carers. Table 7.3 shows the different themes of the errors that were made by patients and carers while performing the prescribed tasks and the results of the severity analysis.

Table 7.2. Time on task and number of errors for patients and carers and results of the Mann-Whitney U tests.

<table>
<thead>
<tr>
<th>Task</th>
<th>Time on task (mins), median (range)</th>
<th>Number of errors, median (range)</th>
<th>U</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients (n=4)</td>
<td>Carer (n=6)</td>
<td>Patients (n=4)</td>
<td>Carers (n=6)</td>
<td></td>
</tr>
<tr>
<td>1. Log in to the DAC</td>
<td>7.5 (0-11)</td>
<td>2.5 (3-10)</td>
<td>9.0</td>
<td>.61</td>
</tr>
<tr>
<td>2. Post on the forum</td>
<td>10.5 (2-18)</td>
<td>5.5 (2-18)</td>
<td>12.0</td>
<td>&gt;.99</td>
</tr>
<tr>
<td>3. Find information on driving</td>
<td>8.5 (2-18)</td>
<td>3.0 (0-17)</td>
<td>11.5</td>
<td>.91</td>
</tr>
<tr>
<td>4. Watch a video on Alzheimer’s disease</td>
<td>5.0 (1-10)</td>
<td>5.5 (1-9)</td>
<td>8.0</td>
<td>.48</td>
</tr>
<tr>
<td>5. View correspondence</td>
<td>4.0 (3-10)</td>
<td>3.0 (3-4)</td>
<td>1.5</td>
<td>.57</td>
</tr>
</tbody>
</table>

Table 7.3. Thematic overview and severity of errors made by patients with dementia (n=4) and carers (n=6), coded for severity.

<table>
<thead>
<tr>
<th>Theme of error</th>
<th>Severity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Unable to log in to DAC</td>
<td>High</td>
</tr>
<tr>
<td>Entering wrong URL / not finding right page</td>
<td>High</td>
</tr>
<tr>
<td>Visiting sites external of DAC</td>
<td>High</td>
</tr>
<tr>
<td>Reading the sidebar as part of the other text</td>
<td>Medium</td>
</tr>
<tr>
<td>Following wrong links (that do not lead to required data)</td>
<td>Medium</td>
</tr>
<tr>
<td>Unnecessary clicking</td>
<td>Low</td>
</tr>
<tr>
<td>Unnecessary use of the “back” button</td>
<td>Low</td>
</tr>
<tr>
<td>Clicking nonlinks</td>
<td>Low</td>
</tr>
</tbody>
</table>
The biggest difference in time to completion was found, both for patients and carers, within task 2 (post a message to the forum), for which there was a 16-minute difference between the slowest and fastest performance. However, this task had a low variance in errors, with a minimum of zero and a maximum of five errors. The greatest variance in number of errors as well as the greatest difference in performance between patients and carers was found in task 5 (view correspondence with the Alzheimer Center), where the best performing participant did not make errors at all and the participant who had the most difficulty with the task (a person with dementia) made 22 errors before arriving at the right solution.

Patients and carers differed in the number of errors made in three of the five tasks: post a message on the forum, finding information on driving, and watching a video on Alzheimer’s disease. The tasks appeared more difficult for patients because they made more errors and took longer to complete the tasks. However, from the Mann-Whitney U tests, these differences between patients and carers did not appear to be statistically significant.

Both patients and carers made the same categories of errors (refer to Table 7.3), except for not understanding the sidebar, which only occurred in patients with dementia. All problem themes observed were analyzed by using the severity framework of Nielsen (refer to Figure 7.4) [28].

**Usability: Survey and Semistructured Interviews**

- **Layout**

The results of the survey show that the design of the site was appreciated by a small majority: 19 of 36 (53%) patients and 60 of 98 (61%) carers indicated that the layout was clear. They appreciated that it “looks very calm, there’s no clutter [distracting elements] on the screen” (indicated by a carer). The font used in the design of the website was appreciated positively: only 2 of 98 (2%) carers did not like the font.

- **Content**

The content of the DAC was rated understandable and clearly written by both carers (79/96, 82%) and patients (27/35, 77%) in the survey. The information was regarded “very well and comprehensively written” by all interviewed participants.

- **Ease of Use**

Survey participants valued the site mostly positively with regard to ease of use (general use and navigation). In all, 50.0% of carers (52/104) found it easy to use, 36.5% (38/104) were neutral on this subject, and 13.5% (14/104) found the site difficult to use. For patients, 42% (15/36) rated the site as easy to use, 50% as neutral (18/36), and 8% (3/36) as hard to use. All but one patient of those interviewed thought that they would be able to learn to use the site.

**Usefulness**

- **Added Value**

Overall, 17 of 26 (65%) patients and 67 of 86 (78%) carers indicated in the survey that the DAC was “very useful” or “useful” and both indicated it had an added value over the regular care offered by the
center. Interviewed participants specified that it was “very helpful—it really helps me in staying at home by myself” and that it “should certainly be continued in the future.” One professional commented that it was “not yet useful enough,” although they later indicated that they expected this would change by “adding more personalization [options].” A majority of users, 17 of 26 (65%) patients and 57 of 86 (66%) carers, would recommend the DAC to others: “It is certainly something you need in this day and age.”

- **Understanding of and Dealing with Dementia**

Participants indicated that the DAC was especially useful to them for understanding dementia and for dealing with dementia. In all, 53 of 86 (62%) carers and 16 of 25 (64%) patients who responded to this question indicated it was helpful for understanding dementia: “you can find all the information you might need” and “you can easily show this information to others.” In addition, 40 of 86 (47%) carers and 11 of 25 (44%) patients found the DAC useful for dealing with dementia. The availability of the information was appreciated: “you can check this information anytime, even in the middle of the night.”

- **Usage**

In the survey, 145 of the total 282 (51.4%) participants indicated that they had used the DAC at least twice. Of these 145 users, 40 (27.6%) were patients and 105 (72.4%) were carers. Participants in the semistructured interviews also indicated they regularly used the DAC; all but two indicated they did not use it. One interviewed patient specifically stated that he used the DAC “several times a week.”

In Table 7.4, survey data are presented on the use of features of the DAC. It shows that both patients and carers make (more or less) use of all different parts of the site. Most used by patients are the information on the disease and the Alzheimer Center function. Most used by carers is information on the Alzheimer Center and information for carers.

<table>
<thead>
<tr>
<th>Function</th>
<th>Patients, n (%) (n=25)</th>
<th>Carers, n (%) (n=85)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Information</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disease</td>
<td>12 (48)</td>
<td>14 (16)</td>
</tr>
<tr>
<td>Informal carers</td>
<td>1 (4)</td>
<td>20 (24)</td>
</tr>
<tr>
<td>About center</td>
<td>10 (40)</td>
<td>44 (52)</td>
</tr>
<tr>
<td><strong>Community</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Forum</td>
<td>7 (28)</td>
<td>13 (15)</td>
</tr>
<tr>
<td>Friends</td>
<td>4 (16)</td>
<td>3 (3)</td>
</tr>
<tr>
<td>Chat</td>
<td>3 (12)</td>
<td>2 (2)</td>
</tr>
<tr>
<td><strong>Contact</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>E-consult</td>
<td>6 (24)</td>
<td>17 (20)</td>
</tr>
<tr>
<td>Correspondence</td>
<td>2 (8)</td>
<td>9 (11)</td>
</tr>
</tbody>
</table>
Non-users

When participants indicated in the survey that they did not use the DAC, they were asked why they did not use it. Their answers were grouped into themes. The main reasons they indicated for not using the DAC are presented in Table 7.5.

Table 7.5. Reasons for not using the DAC.

<table>
<thead>
<tr>
<th>Reason</th>
<th>Patients</th>
<th>Carer</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Miscellaneous (e.g., &quot;I don't want anything to do with it&quot;) (n=12)</td>
<td>No need (n=31)</td>
</tr>
<tr>
<td>2</td>
<td>No need (n=9)</td>
<td>Technical or computer issues (n=23)</td>
</tr>
<tr>
<td>3</td>
<td>Unfamiliar with DAC (n=8)</td>
<td>Miscellaneous (e.g., &quot;I don't like the Internet&quot;) (n=18)</td>
</tr>
<tr>
<td>4</td>
<td>Too hard to use (n=7)</td>
<td>No time (n=13)</td>
</tr>
<tr>
<td>5</td>
<td>No time (n=4)</td>
<td>Unfamiliar with DAC (n=8)</td>
</tr>
<tr>
<td>6</td>
<td>Technical or computer issues (n=4)</td>
<td>—</td>
</tr>
</tbody>
</table>

Discussion

We found that, in general, patients with dementia, carers, and health care professionals who use the patient portal rate it positively with regard to usability, and consider it to be a useful addition to existing care that helps them to deal with dementia, among other things. Results for this study show that an Internet portal is a feasible means of offering support to people with dementia and carers. Both patients and carers indicate they appreciate such a portal positively. Although some had trouble in using the site or in learning to operate it, only a small percentage of users responded negatively to the patient portal as a means of offering support. The information sections especially appear to be well used and are indicated to be experienced as supportive. Nonetheless, we did also find some usability issues. The most notable issues are those functionalities for which severe errors were found during usability testing: the log-in screen, the process of finding the right URL, and the confusion of leaving the DAC for a different linked site. A positive note is that these are all areas related to reaching and accessing the site, and have nothing to do with the actual (functioning of the) site itself. We did find that patients with dementia and carers largely make the same kinds of mistakes, which means this is likely to be related to familiarity with using computers and websites.

Findings from this study are in line with previous research in this area [4,17,35-41]. We found that older users and users with dementia are able and willing to utilize Internet-based resources and that at least some of them are capable of using the technology involved. Research by Ellis and Kurniawan [35] showed that older users consider the Internet a useful tool for finding information and that they were able to access websites on computers with relatively few problems. Research into website usability among people with dementia found that they prefer websites that have little cognitive load (i.e., “the amount of mental processing power needed to use the site” [36]) and that minimize the amount
of clutter [35] and other distractions on the screen, such as on-screen animations and advertisements [37]. Besides making sites harder to use, earlier research states that cognitive load and clutter may cause “knock-off effects,” causing people to require so much cognitive effort for processing site usage that they cannot effectively process or engage with the material on the site [4,38]. The current research confirms these findings. In the observations, we found that users occasionally had trouble finding the correct links and, in the interviews, users mentioned that they appreciated how few distracting elements there were. Additionally, decreased motor skills and slower movements that occur in older age could affect the use of scroll bars or links and buttons [38]. This was found in website use as well as in usability studies of other technology such as mobile phones [39]; when observing the difference in usability of mobile phones between older and younger users, it was found that older users could use mobile phones but had significantly more difficulty with more complex mobile phones [39].

Research by Chadwick-Dias et al. [40] tested several enhancements to a website to make it more usable and found that clearer wording of links, more consistent visual identification of links, and the use of simpler terminology significantly improved performance on a website. These findings concur with the findings of our research: our users had some trouble identifying links. The simple and understandable language used on the DAC was appreciated by the participants. When research participants were offered two different versions of a website with the same information but with different layouts (one complex with lots of information on screen, one simple version with little information displayed at once), participants made fewer errors on the website with less complex screens [36,41]. Participants also rated the less complex site as more attractive and better to use [36].

This study highlights the importance of iterative development, in which user needs are assessed at the start, and the target audience participates throughout the process [19]. Design choices such as clear font, calm backgrounds, and contrasting colors are important to ensure optimal usability. These design considerations were all applied in development of the DAC and the majority of users evaluated these aspects positively or very positively. This is in line with earlier research into typography for websites [42,43]: when learning to work with computers, a 12- to 14 point sans serif typeface is best appreciated by older users and improves their reading performance on the screen. They also found that it is important to use contrasting colors (preferably black text on a white background) to ensure readability. Based on findings from our study and on earlier research, we made several practical suggestions for good website design, which can be useful for others intending to design an online portal for people with dementia and their carers. It is recommended to resolve usability issues as soon as possible. For example, problems with finding the URL could be alleviated by adding redirects on more URLs (e.g., variations and typos of the current URL www.digitaalalzheimercentrum.nl). Problems with leaving the site for another site could be solved, for example, by a warning page that lets users know they are about to leave the DAC and will be presented with another site with a different layout than the DAC. The different layouts of other sites, which are generally not specifically designed for older users or users with dementia, make them very confusing. Another critically severe error found during the observations was that participants had trouble logging in to the DAC. Because this is a very critical step—it being the first contact with the portal—it is highly relevant to find ways to fix this (e.g., by allowing log-in information to be saved or by considering other means of logging in).

We did not find any indication of harmful effects of the website. Some participants indicated that they did not use the DAC because they did not want to be confronted with all the information about their prognosis (several of the nonusers presented in Table 7.5 mentioned this when they indicated “no
need” as reason for nonuse). However, because use of the DAC is voluntary and not required for any services at the Alzheimer Center, there is no need for them to be confronted with this.

Limitations of the Study

The survey was sent out to all patients registered with an account for the DAC. Even though the response rate was relatively high for online surveys (39%; research generally reports rates from 5% to 40% for online surveys), there is no telling if the group that responded was representative of the population. It is possible that those positive toward the DAC were overrepresented in the group that responded.

To ensure that participants were familiar with the DAC, those taking part in the observations were selected from people who had participated in a workshop in which they learned to use the website. A group of participants that uses the site for the first time without any explanation may encounter different problems. It should be noted, however, that the latter group is not the target group of the current portal: it was specifically intended and designed for people with dementia who were patients of the Alzheimer Center. They were all invited to join a workshop to learn to use the DAC.

To further elaborate on the outcomes of this study in the future, answers to both the survey and the interviews could be compared and verified using website statistics/flow tools. Because of software limitations in the current version of the DAC, it was not possible to install tools such as these for this study.

Conclusion

Overall, this study shows that usability and usefulness of the researched portal are well appreciated. The use of an online portal seems a feasible option for providing eHealth to patients with dementia and their carers. It shows that (beginning) dementia or older age do not have to be a hindrance to computer or Internet use, although cognitive abilities change with dementia and are likely to affect computer use (eg, working memory, perceptual speed). Good website design can help to deal with these dementia-related changes. Using the correct font, colors, writing style, and navigation layout can make websites easier for people with dementia and their (often-older) carers to access. Designing websites in close collaboration with the target group and usability and usefulness testing within this group warrants optimal design and use of patient portals. Based on findings from our study, and on earlier research, we made several practical suggestions for good website design, which can be useful for others intending to design an online portal for people with dementia and their carers. It is recommended to improve on usability issues as soon as possible. For example, problems with finding the URL could be alleviated by adding redirects on more URLs (eg, accessing websites easier for people with dementia and their [often-older] carers). Because this is a very critical step—it is the first contact with the portal—it is highly relevant to find ways to fix this, such as by allowing log-in information to be saved or by considering other means of logging in. For other practical tips on portal design, please refer to the Textbox 7.1.
Text box 7.1. Practical tips for portal design.

Clearly identify clickable targets. Participants clicked even when not necessary, making it necessary to ensure that they do not click anything by accident to avoid confusion.

Break information into short sections. Long texts were found to be confusing to some participants; they found it hard to “follow the text”.

Make use of the “recognize, rather than recall” principle. Users appreciated that they could quickly recognize that the site was part of the Alzheimer Center because it used the “theme” colors.

Minimize complex steps such as logging in. Both the main log-in and the log-in required for further personal file access were considered too complex for users.

Acknowledgments

Thanks go out to all participants in the observations, survey, and interviews, who participated voluntarily in our research. We would also like to thank the Alzheimer Center reference group, who participated in workshops that were used for the design and development of the DAC. Finally, we thank the DAC’s editorial committee, the “reDACTieraad” members.

Conflicts of Interest

None declared.
References


17. Nijhof N. E-Health for People with Dementia in Home-Based and Residential Care [PhD thesis]. Enschede: University of Twente; 2013.


Abbreviations used

DAC: Digital Alzheimer Center
EHR: Electronic Health Record
SUS: System Usability Scale
USE: User Satisfaction and Ease of use
CHAPTER 8

General Discussion
Introduction

In this thesis we developed and studied several assistive care technologies on different domains of support: 1. (ADL-) independence, prompts and reminders; 2. safety and security; 3. leisure and lifestyle; 4. communication and telehealth; 5. carer support; and 6. information support.

The main research question that was addressed during the course of this thesis was: ‘Are needs-based enabling/care technologies that aim to support people with dementia and/or their (in)formal caregivers experienced as user-friendly, useful and effective, and what could be recommended for their further improvement and development?’

To answer this research question, for each care technology intervention that we studied, we addressed the following questions:

1. How do users (people with dementia, informal carers, care professionals) experience the user-friendliness of the intervention?
2. Do users experience the intervention as useful? If so, in what sense?
3. Is the care intervention effective in achieving its aims?

This chapter first provides a summary of the study results and answers to the research questions stated above and relates these to the existing literature on assistive technology for people with dementia and their (in)formal caregivers. Subsequently, methodological considerations that were encountered during these studies are discussed, followed by a discussion of the scientific, clinical and societal relevance of the findings, and recommendations for future research & practice.

Main findings

Chapter 2: Participation of end users in the design of assistive technology for people with mild to severe cognitive problems; the European ROSETTA project

The AAL-funded European ROSETTA project offered a personalizable assistive technology to be installed in the home, aiming to support people with dementia and caregivers. It integrated three existing interventions into one multimodular system: the Unattended Autonomous Surveillance – Advanced Awareness and Prevention System (UAS-AAPS), which can detect emergency situations (such as falls) in the home; the Early Detection System (EDS) that monitors behavior to detect changes in functioning, and the Elderly Day Navigator, which has two touchscreen devices (one fixed screen in the home, and a mobile device) that offered communication tools, an agenda with reminder messages, a photobook, and GPS functionality outside the house (only on the mobile device). It aided informal carers by offering them a sense of security regarding their family member with dementia, and helped them manage the agenda of their family member. All of this was aimed to support them as a couple as well. Besides, it helped professional carers to keep in touch with people with dementia in their own homes, and helped them stay up-to-date on the status of the patients under their care.

The chapter reports on the user-participatory designing of the multimodular ROSETTA system, more specifically the EDS and EDN, through several workshops and meetings in three phases of the development process: initial development phase, development phase, and fine-tuning phase. This was done in the Netherlands and Germany; in Belgium only the UAS-AAPS was evaluated in this project.
Initial development phase: During the initial development phase, two workshops were organized in the Netherlands, one with 3 and one with 4 community-dwelling people with dementia living in different parts of the country, both together with a dementia care professional; an expert meeting was organized with 9 dementia care professionals in the Netherlands; individual interviews were organized in Germany with 3 people with cognitive impairment. Finally, a consultation meeting with dementia experts of the project group was organized with 7 care partners within the project.

Development phase: During this phase, two mock-up workshops were held in the Netherlands with 4 persons with dementia, and interviews on the mockups were held with 5 professional caregivers in Germany.

Fine-tuning phase: During this phase, a workshop was held in a demonstration house (a house in which the full system was installed) in the Netherlands with 4 persons with dementia; another workshop in the house was held with 5 informal caregivers; and the system was pilot-tested in the demonstration house with one volunteer.

Of the possible functionalities of the ROSETTA system, and more specifically the Elderly Day Navigator, that were discussed, people with dementia and informal carers appreciated the following functionalities most: help in cases of emergency, navigation support and the calendar function with reminders. Dementia experts identified various behaviors as suitable to be monitored with EDS, for the timely detection of changes in functioning, e.g. eating, drinking, going to the toilet, taking medicine adequately, performance of activities and sleep patterns. Users supplied feedback on different design mockups to decide which design worked best for them. This user-participatory designing process resulted in valuable input from persons with dementia, informal carers and professional carers/dementia experts, based on which a first prototype of the ROSETTA system was built.

Chapter 3: The electronic, personalizable ROSETTA system for dementia care: exploring user-friendliness, usefulness and impact

In an exploratory evaluation study, the ROSETTA system was tested on its user-friendliness, usefulness and impact on people with dementia, their informal carers and professional caregivers. The system was installed in participants’ homes in the Netherlands, Germany and Belgium. People in the control group received care as usual. In the controlled trial with pretest and posttest measures, participants (42 people with dementia; 32 informal carers) were interviewed regarding user-friendliness and usefulness of ROSETTA using semi-structured interviews. In addition they completed questionnaires for impact measurement on, among other things, Quality of Life, perceived autonomy, caregiver feeling of competence, and use of care services. Six professional home care workers who worked with the system (3 in the Netherlands, 1 in Germany and 2 in Belgium) were interviewed with semi-structured interviews on user-friendliness and usefulness.

Users appreciated the usefulness of the ROSETTA system, and considered it an essential development for the future of care: All participants stated that ROSETTA is a (very) useful intervention. The user-friendliness of the first prototype version of the system, especially the user interface for the caregivers, was not rated very highly, mainly because users considered it unintuitive and hard to learn. This was mainly due to the limited budget and time constraints during the development phase. No significant effects were found on any of the objective impact measures.
Chapter 4: Experiencing dementia from three perspectives: problems, adaptation and quality of life

This study describes the preparatory research performed for the development of Into D’mentia, a mixed-reality simulation that lets visitors experience a day in the life of a person living with dementia. For an accurate representation of the experience of people with dementia, this study aimed to inventory relevant domains of experiencing the consequences of the disease as reported by people with dementia themselves. This was accomplished by performing an international literature search (publication date range 2000 – 2012) for articles reporting on people with dementia’s experiences and containing quotes from people with dementia about their experience. Based on their content, all collected quotes were categorized into three perspectives, referring to a) problem areas as identified in the Dutch National Dementia Programme (NDP), b) adaptation-coping aspects, and c) Quality of Life areas. Most of the found quotes related to items of the adaptation-coping model. The recognizability and relevance of these quotes for people with dementia were discussed in two focus groups with people with dementia and two focus groups with informal carers, and in an online survey among professional caregivers. A total of ten articles with quotes from people with dementia were found in the international literature (English language). In the focus groups, especially quotes related to adaptation-coping aspects were recognized by people with dementia and informal and professional caregivers. The Quality of Life areas were also recognized by most participants. The problem areas of the NDP were recognized to a lesser extent, which was to be expected as these mainly reflect problem areas experienced by the carers.

Based on the generally recognized and suggested most relevant experiences inventoried in this study, experiences were prioritized for inclusion in a mobile dementia simulation, which was then further developed. The finding that one perspective in particular, i.e. the adaptation-coping perspective, was recognized most by people with dementia and their carers underlines the general relevance of this perspective in the development of a simulation of the experience of dementia. It also warrants further research into the application of this perspective in dementia care research and practice.

Chapter 5: Experiencing dementia: evaluation of Into D’mentia

The Into D’mentia simulator offers informal carers and professional caregivers the chance to experience first-hand how dementia impacts a ‘day in the life’ of a person living with dementia. The aim is to improve their understanding of, and empathy for, the person(s) with dementia they care for. During this ‘day’, techniques such as sensors and projections, simulate the limitations and social and emotional consequences of having dementia. The simulation starts after an intake, and ends with a short interview.

The evaluation study showed that the simulation made informal and professional caregivers think about how they would cope and deal with the consequences of dementia. It confronted them, for example, with forgetfulness, disorientation, and the social stigma one experiences as well as the emotions these provoked. Nine informal carers and 23 care professionals took part in the pilot evaluation study and underwent the Into D’mentia simulation. Before and after their visit they filled in several questionnaires to measure its possible impact, such as the Interpersonal Reactivity scale, the Sense of competence scale for informal carers, and for professional caregivers the Work satisfaction scale. After the visit, they also filled in a questionnaire on their opinion on the user-friendliness and usefulness of this experience. Both informal carers and professional carers indicated they felt Into D’mentia was a user-friendly and highly useful innovation that provided them a way to learn about dementia in an
immersive way. They indicated that the simulation helped them to offer better care. Participants mentioned that they often thought back to their experiences in the simulation in their daily practice, to help them better understand the behavior of people with dementia. No significant effects were found on impact, probably due to the small sample. The positive evaluation of Into D’mentia in this pilot by informal and professional caregivers indicates that further, large-scale controlled research into the effectiveness of the Dementia simulation is warranted.

Chapter 6: Web-based STAR E-learning course increases empathy and understanding in dementia caregivers: Results from a Randomized Controlled Trial in the Netherlands and the United Kingdom

The STAR E-learning course intends to support informal carers, volunteers, and professional carers in understanding and dealing with dementia. The course consists of 8 modules with specific themes and 3 difficulty levels (basic, intermediate and advanced). In a Randomized Controlled Trial, with pretest and posttest measurements and a waiting list control group, the impact of using STAR on, among other things, attitude towards dementia, empathy, Interpersonal Reactivity, sense of competence and knowledge about Alzheimer’s Disease was investigated across two countries (the Netherlands and the UK). In addition, the user friendliness and usefulness of STAR were evaluated among informal caregivers (n=60) and professional caregivers (n=24) after 2-4 months of STAR training. Significant positive effects were found on several impact measures: the (in)formal caregivers’ person-centered care approach as well as the total score on positive attitudes towards dementia improved in both the experimental and the control group; although both groups increased at posttest, the score in the experimental group was higher at posttest. Compared to the control group, in which empathy scores remained the same at posttest, significant improvements with large effect sizes were found in the STAR training group on empathic distress, empathic concern, and on the ability to take the perspective of the person with dementia. Additionally, there was a significant increase in self-reported sense of competence in the group of caregivers who followed the STAR course compared to the control group. No improvement in knowledge on dementia specifically was found in caregivers who followed the STAR course compared to caregivers in the control group.

The different users appreciated the STAR course positively: most users indicated the course was helpful, user-friendly and useful. They rated the content of the modules positively with an average score of 8.0.

Chapter 7: Evaluation of the Digital Alzheimer Center: Testing usability and usefulness of an online portal for patients with dementia and their carers

The Digital Alzheimer Center (DAC) aims to help people with dementia and their carers by offering information, communication and peer contact tools through an online portal. The usability and usefulness of DAC was studied in a descriptive study among patients, carers, and health care professionals. Mixed methods were used, consisting of observations (n=10 participants, 4 people with dementia and 6 informal carers); an online survey (n=287 participants; 88 people with dementia and 199 caregivers) and semi-structured interviews (n=18; 6 people with dementia, 6 informal caregivers, 6 professional caregivers).

A majority (17/26; 65% of people with dementia; 67/86; 78% of informal carers) considered the DAC useful, most notably for understanding dementia (which 16/25; 64% of people with dementia and 53/86; 62% of informal carers indicated). A minority, 42% (15/36) of people with dementia and 61%
(62/102) of informal caregivers indicated that they found the site easy to work with. However, in qualitative, semi-structured interviews (with people with dementia, informal caregivers and professionals) the site was generally rated positively on usability and usefulness and design of the website/interface. As the majority of users positively evaluated the usefulness of the portal, and appreciated the information on it, it was concluded that an online patient portal could be a useful means to support patients and carers in collecting the information they need to deal with dementia. However, as only a minority of patients found it easy to work with the portal, it was also concluded that for patients, good, participative designing and repeated usability testing is needed to further improve and develop the portal into a user-friendly online portal for people with dementia.

Analysis and discussion of the findings

In this thesis we investigated the development process, and analyzed the user-friendliness, usefulness, and impact of several assistive technology interventions that aim to support people with dementia and/or their caregivers. Below we will discuss the findings.

1. User-participatory development process

For two of the interventions described in this thesis, we researched the development process in creating the first prototypes. These were the ROSETTA system, and the Into D’mentia simulator. Both of these interventions were developed in a user-participatory iterative design process, in which future users (i.e. people with dementia, informal carers, and care professionals) were closely involved.

The ROSETTA system was developed in collaboration with all stakeholders (people with dementia, carers, professionals, dementia experts and technology experts), for example by organizing design meetings in which users suggested potential design-mockups on paper (known as ‘paper prototyping’, a widely-used method for user interface design; see for example Snyder, 2003 and Sefelin et al., 2003).

Into D’mentia was aimed specifically at informal and professional caregivers, and was designed in collaboration with them: before developing the full version of Into D’menia, pilot user experience tests were organized with informal caregivers and care professionals, and the pilot was discussed with representatives of the Dutch Alzheimer’s Association, care professionals and dementia experts.

For both interventions, user participation appeared feasible across the target groups: people with dementia, informal carers, as well as care professionals took part in design workshops, and were able to indicate their wishes. Other research confirms that collaborative design can be used for developing solutions with informal caregivers (Hwang et al., 2015) and people with dementia (Smeenk et al., 2017). The information provided by participants during these design meetings proved very valuable for the development of both ROSETTA and Into D’mentia: for example, during ROSETTA development informal carers indicated that the most important functionality was support in emergencies; they also indicated, for example, having little interest in support during specific daily activities. For Into D’mentia, people with dementia mentioned, for example, how especially ‘being talked about as if no one is there’ was bothersome to them: they suggested adding this to the simulator. This is in line with a 2013 review of Span et al., who studied 26 publications on technological development, and highlighted the importance of involving people with dementia and carers frequently and throughout the iterative design process. They emphasized that research shows that people with dementia can express their preferences consistently, even in the more advanced stages of dementia (see also Whitlatch and Menne,
In their review they pointed out that most research nevertheless only involved people with dementia in the first phases of developing tools and services: 13/26 publications involved them in the explorative phase to identify user needs; 11/26 publications involved them in the technical development phase by having people use the devices or services. Only three publications involved people with dementia in the ‘adaptation’ phase when adapting the innovation based on the user feedback (Astell et al., 2007; Hanson et al., 2007; Riley et al., 2009).

Organizing these user-participatory design meetings requires time, which is important to factor into research projects: much research is only funded for a fixed period of time, and as such time reserved for design sessions, before creating, piloting and evaluating the prototype, is often limited. Extending the time for collaborative design at the start of the project is, however, expected to result in prototypes that better match the needs of users. Regarding usability testing experts advise repeated testing with small groups (often as small as 5 users), since such a small group of users is usually very able to identify the majority of usability issues with a technology (Nielsen, 2000). This iterative process is necessary to constantly keep the design and intervention in line with the wishes and demands of the future users.

The fact that despite this co-design process some interventions we studied were still experienced as non-user friendly by part of the users, highlights the complexity of the design process of assistive technology interventions, especially for people with dementia. Besides the necessity of repeated usability testing during the design and development process, other specific factors should be taken into account as well, such as: the severity of dementia; how well people with dementia are able to use novel services and devices; the presence of an informal carer; time and budget constraints; and use of other services besides the technology.

2. User-friendliness

The user-friendliness of the interventions described in this thesis proved far more variable than their perceived usefulness:

The ROSETTA system, still in development during the study, suffered from several usability issues, which made people rate the system as not very user-friendly. Especially people with dementia (5/10; 50%) mentioned that they found it hard to learn how to operate parts of the system: for example, the handheld device of the Elderly Day Navigator (EDN) was considered ‘unintuitive’ and slow. Due to its early development, and therefore sometimes false alarms and other unexpected errors, the overall ROSETTA system (with its three subsystems) was also rated low on user-friendliness.

The Digital Alzheimer Center (DAC) suffered from several usability issues as well, both general computer-related issues (i.e. the problem was not related to the programming or functionality of the DAC, but to normal computer and internet browser functionality) and specific site-related issues (i.e. some design issues prevented people from fully using the site).

The Into D’mentia was rated much more positively on user-friendliness: caregivers considered it very easy to take part in the simulated dementia experience. STAR was also rated highly on user-friendliness by informal and professional caregivers. STAR was based on a combination of literature study into the needs for information of caregivers, an inventory of existing (digital) dementia courses in Europe, and several user feedback workshops with dementia experts and care professionals.
Regardless of the collaborative design, however, ROSETTA was experienced as lacking user-friendliness by informal carers involved in the care. This was partly due to time and financial restrictions, leading to some solutions being set up inefficiently (e.g. uploading of photos into the photo album, logging into the agenda). The same applied to the DAC, which was developed during co-design sessions with people with dementia and caregivers, yet still had some usability issues, both for patients with dementia and for informal caregivers.

The differing opinions on user-friendliness highlight how important it is, especially when developing assistive technology for people with dementia, to strongly focus on design and the user experience (also mentioned by, for example, Wherton & Monk, 2008). At the same time, however, our study shows that utilizing user participatory design does not automatically lead to a higher user-friendliness experience in all users, as will be discussed below.

Our finding that even interventions that are developed in cooperation with people with dementia and carers are partly rated low on user-friendliness underlines the importance of keeping the intended users as closely involved as possible. Apparently more developmental iterations (in the lab and in the user homes or intervention site, where other contextual factors may play an important role) are required to get the necessary feedback from users, which is needed to adapt the technology and make it personalizable in a way that it is usable for individuals of this user group. Additionally, it is important to make sure that potential users get sufficient information on how to use interventions through, for example, manuals, instructions, and/or workshops.

Finally, it is important to consider the variability within this user group of people with dementia, which can be related to different stages of dementia and contextual aspects such as the presence of one or more informal caregivers and the availability of services and professional caregivers. Purposive sampling is therefore important to represent this variability in the user group in studies focused at the user-participatory development of assistive technology.

Need for matching user ability

Among the users of the different studied interventions, we found a great variability in the degree of dementia (different degrees of dementia result in differences in (in)ability to utilize complex technological interventions or websites), as well as in general computer skills. For example: in the user testing of the Digital Alzheimer Center, the person with dementia that performed best on the usability test hardly made any mistakes when completing tasks on the website; whereas the person performing worst on the usability test made 20+ errors in almost every task. The DAC was also made for caregivers, who differed greatly in age and prior experience with computers and using the Internet. This large variance requires strong personalization options where the system can be adapted to the competence and wishes of the user. In the ROSETTA study, for example, we attempted to deal with this by providing different system options (modular system) requiring different degrees of interaction. Patients in the milder stages of dementia and carers who were comfortable and able using the touchscreen device (EDN) were offered it, but patients in the more advanced stages of dementia were offered only the monitoring systems (monitoring of behavior patterns by EDS and fall detection by UAS), which functioned automatically and thus required no user interaction. Into D’mentia and STAR were both fully designed for informal and professional caregivers, and as such were not designed with cognitive impairment in mind.
3. Usefulness

All interventions that we developed and/or evaluated were considered (highly) useful by their users:

The ROSETTA system was considered useful to enhance feelings of safety (mainly of caregivers, who indicated they felt more at ease at home, knowing the system would ‘watch over’ their family member with dementia), and to enhance independence of people with dementia. Remarks such as these are in line with a recent study by Mulvenna et al. (2017) that shows that assistive technology as home surveillance can enhance feelings of safety, and help the self-sufficiency of people with dementia.

Into D’mentia was found useful to enhance feelings of understanding and empathy; the STAR course was found very useful for increasing knowledge on dealing and coping with dementia, and to enhance understanding and empathy; and the Digital Alzheimer center (DAC) was found especially useful for understanding dementia. Understanding, in turn, is found in many other studies to be very important for managing care well, both on the part of the caregiver (Lamm et al., 2007) who can manage the care better and longer when they have better understanding of the consequences of dementia, and on the part of the care receiver/person with dementia, who shows slower cognitive decline when cared for empathically (Norton et al., 2010).

Although research into care technology for people with dementia is still very limited, some other research confirms the experienced usefulness of this type of technology, reporting that such interventions are deemed useful by users (Hendrikk et al., 2013; Davoody & Hägglund, 2016) and match the needs that users would want fulfilled by technological interventions (van Hoof et al., 2010).

A common and recurring theme regarding the usefulness of the technology among users (carers, people with dementia, as well as professional caregivers) across the studied interventions in focusgroups, interviews and questionnaires, is that developments such as these ‘are indispensable for good care in the future’.

Considering the increasing number of people with dementia, the decreasing number of professional caregivers left to care for them in the coming decades, and ever increasing, healthcare costs, innovative interventions such as these indeed seem useful in terms of offering care to people with dementia and providing psychoeducation and support to their carers in more cost-effective ways.

4. Impact of the interventions on people with dementia, informal caregivers, and professional caregivers

Most of the interventions studied offered benefits to the users involved, which were measured for impact with standardized questionnaires in explorative pilot studies. The major benefit we found in almost all studies, was reduced caregiver stress. This was mentioned mainly in the interviews and focus groups. For ROSETTA, Into D’mentia, as well as DAC, caregivers indicated that it reduced their feelings of stress. Since caregiver stress/burden is one of the main factors leading to admission of the person with dementia in a long-term care facility, this is an important issue to be able to help on.

Both Into D’mentia and STAR resulted in statistically significant effects (with large effect sizes in STAR; and a small effect size in Into D’mentia) on standardized impact questionnaires administered among caregivers. For Into D’mentia we found that caregiver knowledge about the person with dementia (a
subscale of the “Emotion-oriented Skills in the Interaction with Elderly People with Dementia questionnaire) improved significantly at posttest for professional caregivers. STAR resulted in significant effects on Approaches towards Dementia for laypersons (informal caregivers and volunteers); on empathy, most notably on empathic concern, personal distress, and taking the perspective of the person with dementia, for both laypersons and professional caregivers, and on the informal caregivers’ sense of competence.

Cost-effectiveness

One important aspect of the impact of many of these interventions is how they allow care to be offered more cost-effectively. For example, the costs of installing ROSETTA (in the pilot phase around 10,000 euros per home; currently offered at 40 euros per month) and maintaining usual home care (depending on severity of dementia between 2,500 and 28,000 euros a year) is substantially lower than the long-term costs of admittance in a nursing home, which are around 60,000 euros per year (most recent published figures: NZa, 2007). If installation of the ROSETTA system allows people to live in their own homes for 2 months longer, it will already save costs.

The cost of participating in STAR (25 euros per person per year) is much lower than other (face-to-face) courses that are offered; even when compared to other online courses such as Dementie-Online (which costs 500 euros per person) or ‘Dichter bij Dementie’ (“Closer to Dementia”), it is still lower. STAR, being offered through the Internet, is also less expensive than regular face-to-face courses because there are no travel time and/or lecturer and logistics costs associated with STAR. Provision through the Internet also makes it easier to access. We did not conduct a systematic cost-effectiveness evaluation between STAR and face-to-face courses in our study and it is therefore unknown if STAR is indeed more cost-effective.

Into D’mentia could prove cost-effective, since the enhanced empathy and understanding for people with dementia might help informal caregivers to keep caring for their family members for a longer period, delaying costly nursing home admission. The same holds true for the Digital Alzheimer Center, which can be easily accessed from anywhere, at any time, something which several users indicated finding useful during interviews and in the questionnaire. These explorative studies however did not include an economic evaluation so no conclusions can be drawn on this yet. Other studies on the cost-effectiveness of assistive technology often found that assistive technology can prove cost-effective (Craig et al., 2013; Beazly et al., 2015) mainly by delaying nursing home admission.

Methodological considerations

Level of development of the intervention

An issue across the studied interventions was the level of development of some of the evaluated systems. All interventions studied were developed and subsequently evaluated within the same research projects which each took two to three years. This limited both the time for development of the systems and for testing their user-friendliness, usefulness and impact. As a consequence in some cases the system was not fully finalized when usability or impact testing started. This was especially true for ROSETTA, where the opinions and comments of users on the early prototype appeared to be strongly influenced by the many technological usability issues that were to be addressed in a later version of the product. To a somewhat lesser degree this also applied to STAR and the Digital Alzheimer Center:
for STAR the community/chat functionality was not yet fully developed; and because of the ongoing development at the time of testing, some system and software errors occurred when people followed the course (for example not being able to access videos; not being able to open certain links; display/compatibility issues, etc.). For the Digital Alzheimer Center the ‘community’ function was in its early phases and not very active at the time the evaluation took place. Additionally, because of government regulations certain parts of the site were only accessible through (complex) third-party security measures, which made it difficult for most people with dementia to access these parts without the help of another person.

Small user groups

Two of the four intervention studies, (ROSETTA and Into D’mentia) had a relatively small group of participants, and as such were underpowered for impact measurements. For ROSETTA, the small group size was deliberate because of the explorative pilot-nature of the research and the budget constraints (installing the system in a test home was quite expensive). Into D’mentia was also a pilot study in which a first small group of users visited the prototype version of the simulated dementia experience.

The user groups in the descriptive research on DAC and the effect evaluation of STAR were much larger. In the case of STAR numbers needed to conduct a fully powered randomized controlled trial were achieved without any problem.

Recruitment of potential users is often a concern in studies into the development and evaluation of assistive technology/ehealth studies in particular (Murray et al., 2009; Campbell et al., 2011), especially in the home-dwelling setting (where it is harder to reach patients). In addition, technology and/or online studies commonly encounter high rates of dropout (higher than compared to other forms of questioning or recruiting). Donkin et al. (2011) note that ‘Despite each user’s choice to engage with the site [on which the intervention is hosted], only a small proportion of users persist with the trial and associated follow-ups’. In the case of e-therapy interventions, it is theorized that this is caused by the participant’s discretion in using e-therapy (Advocat & Lindsey, 2010), rather than therapy that is prescribed, as in a drug trial. We tried to prevent people dropping out of the studies by offering a helpdesk during the intervention periods and/or by regular telephone contact or home visits by the researchers.

User selection bias

By advertising both online (e.g. Institute websites, twitter and facebook) and offline (e.g. flyers posted in hospitals, contact with care centers) we tried to recruit user groups as broad as possible, of people with dementia and caregivers, thus aiming to prevent a selection bias by recruiting predominantly people (already) using online tools.

However, in studies such as these, there still remains a risk of selection bias: persons that indicate their interest in participating in technology research are most likely those that are prone to be more positive towards technology and scientific research in the first place. For the Digital Alzheimer Center especially, a concern was that the patient population of this center generally consisted of younger and higher educated patients. Also considering the sometimes intrusive nature of technology research in some of the current pilot studies (e.g. the installation of a camera and sensors in the homes of participants in the ROSETTA study), it is likely there was some selection bias in the recruitment of participants, overrepresenting people who are willing to contribute to innovative research.
Scientific relevance

The research described in this thesis adds to the existing knowledge on the use of ehealth and assistive technology by people with dementia and their caregivers, on the domains of 1) (ADL-) independence, prompts and reminders; 2) safety and security; 3) leisure and lifestyle; 4) communication and telehealth; 5) carer support; and 6) information support. This area has only been gaining attention from the scientific community since the last decade. In all studies described in this thesis we found that (part of the) people with dementia and/or carers were very able and willing to use ehealth interventions or assistive technology, and appreciated the opportunities they offer.

The findings of the ROSETTA study add to the knowledge about security and surveillance systems, and provide information about how to integrate such systems in one multi-modular system with different functionalities that can be attuned to different stages of the disease. The interviews with users confirmed that people with dementia appreciated the system, as it would possibly allow them to live at home longer. Informal carers mainly appreciated the system because it relieved their feelings of stress and concern over the wellbeing of their family member living with dementia.

The Into D’mentia study adds to the body of research regarding simulation of the experience of dementia as a means to improve empathy in caregivers of people with dementia. To date very little research has been done into the simulation of living with dementia. Most studies focused merely on simulating sensory impairments (MIT AgeLab, 2012) or other psychiatric disease (e.g. psychosis; Formose et al., 2012). As far as we know from the literature, only one other simulation for living with dementia was developed and evaluated, the Virtual Dementia Tour (VDT; Beville, 2002), which (like Into D’mentia) also found good results on empathy and understanding in professional caregivers (VDT only studied nursing home staff). This shows that simulation can indeed support informal and professional caregivers in their caregiving role. However, the VDT was a mainly low-tech solution, which focused more on physical shortcomings (e.g. using tinted glasses to simulate reduced vision).

The STAR study adds to the knowledge about online learning for carers of people with dementia. E-learning is a popular research topic that in recent research has been found to be very useful for a variety of conditions and audiences, such as depression (Iakimova et al., 2016; Cuijpers et al., 2017); stress management (Heber et al., 2017); or psychosis (Barbeito et al., 2014), yet has shown relatively little attention for dementia and other neurodegenerative diseases (Lahti et al., 2014). So far only few courses are offered on dementia for caregivers, such as Dementie-Online (formerly ‘Dementie de Baas’; Pot et al., 2015) and the Dementielearning course of the Social Care Institute for Excellence (SCIE). Additionally, the Dutch Alzheimer’s Association has recently developed a being ‘dementia-friendly’ training course (Alzheimer Nederland, 2017). Most developments in the area of e-learning, however, focus on chronic disease management, such as diabetes (Nijland et al., 2011; Bond et al., 2007) or heart disease (DelSindaco et al., 2007), and psychiatric disorders, as mentioned.

Finally, the findings from the research into the Digital Alzheimer Center (DAC) add to the knowledge of the use of online portals by patients aimed at, among other things, improving communication with medical specialists, therapists and peers (Lin et al., 2005); improving self-management of patients (Stinson et al., 2010); and improving therapy adherence (Klein et al., 2014).

Online portals have already been studied in some detail, yet focus mainly on other illnesses such as diabetes and cancer (Ronda et al., 2014; McMahon et al., 2009). Little research has been carried out...
in the field of dementia (often only small, local initiatives, such as the Warwickshire ‘Living well with Dementia’ portal at https://dementia.warwickshire.gov.uk/ (Warwickshire County Council, 2017); or associated with electronic patient records offered as a standard at hospitals). Additionally, through the usability testing results the research into the DAC adds to the knowledge on designing and optimizing websites for people with dementia, a target audience that is often overlooked in website design.

**Clinical and Societal relevance**

As described in the introduction of this thesis, with the prevalence of dementia doubling in Europe in the coming three decades and the number of caregivers decreasing, technological interventions such as those evaluated in this thesis are essential to maintain good care for people with dementia in the future. The studied systems may help, among other things, enable people with dementia to live in their own homes for longer (ROSETTA; DAC) by supporting their cognitive abilities, offering meaningful activities and social contact and by enhancing their safety; they may help caregivers feel more secure about the safety of their family member with dementia (ROSETTA), and help to understand the consequences of living with dementia and the changed behavior of their family member, thus increasing their empathy (Into D’mentia, STAR, DAC). As such they may offer society alternative means of dementia care and innovative ways to deal with the pressure that dementia will produce in the coming decades.

The aim of -especially- ROSETTA to help people with dementia to live in their own home as long as possible closely matches governmenta policies in the Netherlands and other European countries. Among people with dementia, we identified this preference as well: almost all participants interviewed in the ROSETTA and DAC studies indicated that they very much wanted to stay in their own home, and that any assistance technology could give them was really valuable. Into D’mentia and STAR also aim to contribute to this, by improving carers’ understanding of the behavior of the person they are caring for.

A better understanding is shown to be associated with more empathy (Lamm et al., 2007a), and more empathy is associated with better care (Lamm et al., 2007b) and less stress for both caregivers and persons with dementia (Norton et al., 2010). This will benefit the person with dementia and will support the carer in fulfilling their care task, which will allow the person with dementia to stay in their own home for longer. Some informal carers using the DAC also indicated that, because of the information offered to them through the DAC they felt they could offer better care and experienced less stress. One person with dementia who lived alone and used the DAC frequently even indicated that it helped in living alone – this person indicated that without this system, he would probably not have been able to live independently. Although likely not representative for large groups of patients, this demonstrates the high value people with dementia may place on such a system.

**Recommendations for future research**

Future research into ehealth and assistive technology is advised to build on the findings of the research described in this thesis, based on which we make the following recommendations:

1. Make sure that systems are designed and developed together with the intended users (user participatory designing) throughout the whole development process, using several iterations, to optimally
match their wishes and preferences, needs and abilities, thus optimizing the experienced user-friendliness and perceived usefulness. Additionally, other stakeholders can be included when developing interventions, such as from a design perspective, or from other fields, such as gaming developers.

2. Make sure that the system is at or near its final phase of development when exploring or evaluating its effectiveness: unfinished systems, still under development, can cause frustration and dropout of participants, and may lead to findings that do not reflect the impact of the completed system. Make sure that users understand what they can expect from the system. This will prevent unrealistic expectations.

3. When testing the product aim to recruit participants both on- and offline (e.g. through websites and newsletters, but also through flyers at GP practices, memory clinics and meeting centers for people with dementia and caregivers) to ensure a diverse and representative group of users.

4. Focus on a diverse range of outcomes. Besides studying the intended or expected outcomes (e.g. empathy or knowledge), also focus on assessing the user-friendliness and usefulness of the intervention, to get input for continuous optimization of the system.

5. Finally, to enhance eventual implementation of assistive technology interventions, it is important to also evaluate the cost-effectiveness of the interventions: to convince users, care organizations and insurance companies to utilize or support the usage of interventions on a larger scale, proof of such benefits is needed. It also needs to be researched how interventions such as those researched perform in clinical practice, and how they can be implemented in daily dementia care.

**Recommendations for clinical practice**

Most of the investigated interventions in this thesis can be recommended for use in current practice, and several of them are already being used by people working in daily clinical practice:

The STAR course can be recommended for use by care staff (as well as being offered to informal caregivers and volunteers), as positive effects were found on caregivers’ understanding and empathy, both of which are indispensable for offering good care. The e-learning course is currently being offered by several care and mental health organizations throughout the Netherlands to train their staff and volunteers in dementia care.

Especially the fall-detection (UAS-AAPS) subsystem of ROSETTA, which was found to be useful for relieving caregiver stress and improving safety, can be recommended for use in clinical practice. A combination of UAS-AAPS and EDS has been brought on the market as a separate system in 2014, by Dutch Domotics (https://www.dutchdomotics.nl).

Into D’mentia is recommended for use by care professionals during their training in dementia care to allow them to quickly learn and experience the consequences of living with dementia. Into D’mentia is offered throughout the Netherlands, providing visits to the simulation specifically tailored towards professional caregivers or informal caregivers. Especially professional caregivers frequently make use of it (http://www.intodmentia.nl/agenda/). Visitors of the simulation indicated that the visit to Into D’mentia was really helpful for them, and an experience they frequently think about during their daily work. In addition to the Into D’mentia experience in 2015, an easy access Virtual Reality (VR) experience (the ‘Dementiebril’) was developed, using VR glasses to simulate the impairments of dementia.
Pilot research by the Trimbos Institute into this VR experience showed that users rate it highly on usefulness and ease of use (Royers, 2015).

The findings of the research into the Digital Alzheimer Center showed that using an online patient portal for people with dementia and informal carers is considered useful and feasible; continued offer of this service to patients is recommended. The research findings have been used to further develop the portal into a new version, now offered through the software provided with the Electronic Patient Record (EPR) currently used in the VU University medical center. The main focus of this new version is the ability to view patient records (which was indicated to be useful); the community functionality has been removed (it was found to have little use).

**Overall conclusion**

This thesis shows that assistive technology interventions, designed together with users, that aim at helping and supporting people with dementia and their carers according to their needs, overall are experienced positively by the users with regards to their usefulness. Users are less unanimous about the user-friendliness of technology, especially with regard to systems made to be used by people with dementia.

Regarding the impact of assistive technology interventions, this study showed that the evaluated assistive technologies were able to enhance feelings of safety and a sense of security of people with dementia and carers (ROSETTA); and to enhance caregivers’ understanding and empathy for people with dementia (ID, STAR). The assistive technologies were well accepted by all parties involved.

With regards to user-friendliness, we can conclude, based on the different experiences found among users, that the usability of assistive technologies is not matter-of-course for people with dementia and carers. Assistive technologies for this target group require a thoughtful designing process, in which especially people with dementia participate in all phases of the process, from needs specification, identification of functional, user and technical requirements, to the actual development and evaluation of the usability and impact of the assistive technology intervention. Throughout the process attention should be given to the possibility to personalize the use of, and interaction with, the technology.

Considering the great role assistive technology can play in offering people with dementia potentially efficient, effective and affordable care in the future, it is recommended to further improve and develop assistive technology and eHealth interventions for people with dementia and their informal and professional caregivers and to implement them in dementia care. Based on our research we have made several recommendations for further research into assistive technology for people with dementia and their caregivers and their implementation in clinical practice.
References


Samenvatting
(Summary in Dutch)
Vanwege de verouderende wereldbevolking, en het toenemend risico op dementie met een hogere leeftijd, zal het aantal mensen met dementie wereldwijd steeds verder toenemen. Dit betekent ook dat het aantal jongere mensen dat beschikbaar is om voor deze mensen met dementie te zorgen relatief beschouwd steeds verder af zal nemen. Daarom is het noodzakelijk om innovatieve en efficiënte oplossingen te vinden om goede zorg voor mensen met dementie in hun dagelijkse leven te kunnen waarborgen. In het onderzoek waarover in dit proefschrift wordt gerapporteerd ontwikkelden en onderzochten we een aantal technologische oplossingen, die zich richten op het helpen van mensen met dementie, mantelzorgers, en professionele zorgverleners bij het omgaan met de gevolgen van dementie. De eerste interventie die we ontwikkelden en onderzochten is het ROSETTA systeem, een geïntegreerd systeem dat de veiligheid in de woning monitort, gedragspatronen in huis kan beoordelen, dagstructuur, dagelijkse bezigheden en contact kan ondersteunen, en mensen buiten de deur onder andere veiligheid en contact kan bieden (hoofdstukken 2 en 3). De tweede interventie is Into D’mentia, een simulator die mantelzorgers en professionele zorgverleners helpt meer begrip en empathie te krijgen voor het leven met dementie door hen zelf een dag in het leven van iemand met dementie te laten ervaren (hoofdstukken 4 en 5). In het STAR project ontwikkelden en onderzochten we een online e-learning cursus over dementiezorg, die bedoeld is om mantelzorgers, vrijwilligers en professionele zorgverleners kennis op te laten doen over dementiezorg en hoe om te gaan met dementie (hoofdstuk 6). Als laatste bestudeerden we een online patiëntenportaal, het Digitaal Alzheimer Centrum (DAC), dat het mogelijk maakt voor patiënten van het Alzheimercentrum, en hun mantelzorgers, om vanuit huis informatie over dementie in te zien, contact te onderhouden met anderen, en makkelijk toegang te krijgen tot hun afspraken en contact met hun behandeldiend arts (hoofdstuk 7). Hieronder vatten we de hoofdstukken van het proefschrift samen.

Hoofdstuk 2: ROSETTA: Participatory designing domotica
Het ROSETTA project onderzocht een geïntegreerd en personaliseerbaar systeem, dat in de huizen van deelnemers geïnstalleerd werd. Het doel van het systeem was het ondersteunen van mensen met dementie en mantelzorgers, door middel van communicatie-tools, een digitaal fotoboek, een digitale agenda met herinneringen, een valdetectiesysteem, eengedragsmonitorings-systeem, en GPS-ondersteuning (met de mogelijkheid direct noodoproepen te doen) voor buiten. Het systeem beoogt de zorgbelasting van mantelzorgers te verlichten door hen een gevoel van veiligheid over het welzijn van hun familielid met dementie te bieden. In dit hoofdstuk rapporteren we over het ‘user-participatory’ ontwerpproces van het geïntegreerde systeem, gedurende de verschillende fases van het ontwerpproces: het initiële ontwerp, de ontwikkeling van de interventie, en de ‘fine-tuning’. Dit werd gedaan door middel van workshops met gebruikers georganiseerd in Nederland en Duitsland, en met interviews met mensen met dementie, mantelzorgers, en dementie-experts. Daarnaast namen zorgpartners binnen het project, en een vrijwilliger deel aan een workshop in een demonstratiehuis, waarin het volledige systeem geïnstalleerd was. Tijdens deze workshops werd onder andere gebruik gemaakt van ontwerp-schetsen, pilot-testen van het systeem, en systeemtesten in een demonstratiehuis waar het volledige systeem geïnstalleerd was. Van alle mogelijk functionaliteiten die besproken werden, vonden mensen met dementie en mantelzorgers de volgende functionaliteiten het meest nuttig: hulp in noodsituaties, navigatie-ondersteuning, en een kalender met herinneringen. Dementie-experts gaven aan welk gedrag zij relevant vonden om te monitoren, zodat naar hun oordeel tijdigveranderingen

Hoofdstuk 3: ROSETTA: Evaluating domotica


Hoofdstuk 4: Into D’mentia: Designing and developing a dementia simulator

Dit hoofdstuk beschrijft het voorbereidende werk voor het ontwikkelen van Into D’mentia, een ‘mixed-reality’ simulatie die het mogelijk maakt voor bezoekers om een dag in het leven van iemand met dementie mee te maken. Voor een natuurgetrouwe weergave van deze ervaring, werd in dit onderzoek gezocht naar de meest nauwkeurige weergave van dementie. Hiertoe werd een internationale literatuursearch uitgevoerd naar uitspraken van mensen met dementie over hun beleving van dementie. Deze werden gecategoriseerd naar drie domeinen: probleemgebieden, adaptatie-coping, en kwaliteit van leven. Deze uitspraken werden vervolgens besproken op herkenbaarheid en relevantie in focusgroepen met mensen met dementie, en in focusgroepen met mantelzorgers. Daarnaast werd er een online vragenlijst verstuurd naar zorgprofessionals over de herkenbaarheid en inschatting van de relevantie voor het dagelijks leven van deze domeinen. Vooral uitspraken met betrekking tot het adaptatie-coping model werden herkend door mensen met dementie en mantelzorgers. Domeinen met betrekking tot kwaliteit van leven werden ook veel herbonden, de probleemgebieden van het Nationaal Dementie Programma minder.

Hoofdstuk 5: Into D’mentia: Evaluating a dementia simulator

De Into D’mentia simulator biedt mantelzorgers en professionele zorgverleners een mogelijkheid om de effecten van dementie op het dagelijks leven te ervaren. Hiermee beoogt het het begrip van, en empathie voor, het gedrag van mensen met dementie te verhogen. Gedurende deze ‘dag’ worden door middel van technieken als sensoren en projecties de beperkingen van dementie, en de sociale en emotionele gevolgen daarvan, gesimuleerd. De simulatie zette mantelzorgers en professionals aan het denken over hoe zij met mensen met dementie omgingen en/of hoe zij daar zelf (beter) mee om zouden kunnen gaan. Het confronteerde hen bijvoorbeeld met vergeetachtigheid, desoriëntatie, en het sociale stigma dat mensen met dementie ervaren. Zowel mantelzorgers als professionals gaven aan dat Into D’mentia een zeer bruikbare en gebruiksvriendelijke innovatie was, die hen hielp om dementie beter te begrijpen en betere zorg te kunnen bieden. Deelnemers gaven aan dat zij tijdens hun
dagelijkse zorg vaak tergdachten aan hun ervaringen in de simulator, en daardoor beter het gedrag van mensen met dementie konden begrijpen.

Hoofdstuk 6: STAR; developing online e-learning for caregivers
De STAR e-learning cursus helpt mantelzorgers, vrijwilligers, en professionele zorgverleners in het begrijpen van, en omgaan met, dementie. De cursus bestaat uit 8 verschillende modules, met specifieke thema’s op drie moeilijkheidsniveaus (beginner, halfgevorderd en gevorderd). In een gerandomiseerde, gecontroleerde trial met pre- en posttest condities in Nederland en Engeland, werden de gebruiksvriendelijkheid en bruikbaarheid van STAR geëvalueerd onder leken (mantelzorgers en vrijwilligers) en professionele zorgverleners. De verschillende gebruikers waardeerden de STAR cursus positief: de meeste gebruikers gaven aan dat de cursus behulpzaam, bruikbaar en gebruiksvriendelijk was. Ze beoordeelden de inhoud van de modules met een gemiddelde score van een 8,0. Daarnaast werden significante effecten gevonden op enkele impact-vragenlijsten: mantelzorgers en vrijwilligers die de STAR cursus hadden gevolgd, hadden een positievere attitude tegenover mensen met dementie dan mantelzorgers en vrijwilligers die op de wachtlijst voor de cursus stonden (de controlegroep). Significante positieve effecten werden ook gevonden op empathische stress, empathische zorg, en het vermogen te denken vanuit het perspectief van mensen met dementie. Ook bij professionele hulpverleners werd een significant positief effect op empathie gevonden. Ook hadden mantelzorgers na afloop van de cursus een toegenomen gevoel van competentie, hetgeen wil zeggen dat zij zich beter in staat voelden de zorg voor de persoon met dementie op zich te nemen.

Hoofdstuk 7: DAC: Evaluating a webbased patient portal
Het Digitaal Alzheimer Centrum (DAC), een online patiëntenportaal, beoogt mensen met dementie en hun mantelzorgers te helpen door hen een persoonlijk portaal te bieden met informatie over dementie, communicatie-tools, en lotgenotencontact. Het DAC werd bestudeerd in een exploratieve studie onder patiënten, mantelzorgers, en zorgprofessionals. Er werden meerdere methoden gebruikt: observaties van gebruik van de site, een online vragenlijst en een semi-gestructureerd interview. Een meerderheid van de deelnemers (zowel patiënten met dementie, als mantelzorgers en professionele zorgverleners) vond het DAC nuttig, met name voor het begrijpen van dementie. Minder mensen ervoeren het DAC als gebruiksvriendelijk: slechts een klein deel gaf aan dat zij het DAC eenvoudig in gebruik vonden. In interviews werd de site door alle gebruikers positief beoordeeld op bruikbaarheid/nut en op het ontwerp van de site. Omdat men het portaal overwegend positief ervoer, en de inhoud waardeerde, werd geconcludeerd dat een online patiëntenportaal een nuttig hulpmiddel zou kunnen zijn om patiënten en mantelzorgers te helpen met dementie om te gaan. Echter, omdat slechts een klein deel van de gebruikers de site makkelijk te gebruiken vond, werd ook geadviseerd dat een goed, gezamenlijk ontwerproces zeer belangrijk is om een toegankelijk online portaal aan te kunnen bieden.

Hoofdstuk 8: Algemene discussie
Hoofdstuk 8 bevat een korte samenvatting van de verrichte studies en uitkomsten en bespreekt deze in relatie tot de wetenschappelijke literatuur. Daarnaast worden in dit hoofdstuk een aantal methodologische overwegingen, aanbevelingen voor onderzoek en praktijk en voor het verder ontwikkelen van ondersteunende technologie voor mensen met dementie en mantelzorgers besproken. De meeste van de onderzochte systemen beschreven in dit proefschrift werden ontworpen in een ‘userparticipatory design’ (co-creatie). Bij deze vorm van ontwerpen is het belangrijk om toekomstige
gebruikers (mensen met dementie, mantelzorgers, en professionele zorgverleners) van het systeem zo vroeg mogelijk in het proces betrekken, om er zeker van te zijn dat een systeem voldoet aan hun eisen en wensen. We concludeerden op basis van de verschillende studies dat het haalbaar is om de doelgroep mensen met dementie en mantelzorgers te betrekken in zo’n ontwerpproces. We vonden echter ook dat, ondanks een co-creatie proces, sommige interventies nog steeds door een deel van de gebruikers als niet-gebruiksvriendelijk werden ervaren. Dit bevestigt de complexiteit van het ontwerpen van ondersteunende technologie en het belang van personalisatiemogelijkheden.

Ingegaan wordt ook op hoe gebruikers de verschillende bestudeerde systemen hebben ervaren. Deze werden geëvalueerd op gebruiksvriendelijkheid, bruikbaarheid/nut, en effectiviteit (in het behalen van de beoogde doelen). De ervaren gebruiksvriendelijkheid bleek variabel: hoe dit ervaren werd ging onder meer af van het niveau van ontwikkeling van het systeem. Daarnaast was het belangrijk om op voorhand goed te communiceren met gebruikers wat zij konden verwachten van het systeem, om zo irreële verwachtingen te voorkomen. We vonden dat alle interventies als zeer nuttig werden ervaren, onder meer voor het vergroten van gevoelens van veiligheid, voor het versterken van empathie, begrip en gevoel van competentie, en voor informatievoorziening. Bijna alle gebruikers meenden dat ontwikkelingen zoals deze ‘essentieel zijn voor goede zorg in de toekomst’. Met betrekking tot de effectiviteit van de systemen moest geconcludeerd worden dat met een prototype op kleine schaal geen effecten konden worden gemeten (ROSETTA), terwijl bij de meer uitontwikkelde systemen zoals bijvoorbeeld Into D’mentia en de STAR e-learning course (die ook op grotere schaal werd onderzocht) met name effecten werden gevonden op (verminderde) belasting en hoger competentiegevoel van de mantelzorger, en op empathie en begrip voor mensen met dementie. De belangrijkste methodologische beperkingen en overwegingen in de verrichte studies waren: het niveau van ontwikkeling van de interventie; de invloed hiervan op de tevredenheid met en ervaring van de gebruiksvriendelijkheid; de kleine gebruikersgroepen in een deel van de studies, waardoor er in deze studies een te geringe statistische power was om significante effecten waar te nemen; en de mogelijke selectiebias doordat de kans groot is dat vooral deelnemers met een affiniteit voor technologie bereid waren deel te nemen aan de studies. Dit kan de uitkomsten van de studies hebben beïnvloed.

Wetenschappelijk draagt dit proefschrift bij aan de groeiende hoeveelheid kennis op het gebied van ehealth en ondersteunende technologie, en levert het nieuwe inzichten op ten aanzien van monitoringstechologie, hoe dementie wordt ervaren, online e-learning voor mantelzorgers, en online patiëntportalen (voor zowel mensen met dementie als hun mantelzorgers). Vanuit maatschappelijke oogpunt is dit proefschrift relevant omdat het meerdere technologische oplossingen beschrijft om de steeds groeiende aantallen mensen met dementie en hun mantelzorgers te ondersteunen. Tenslotte worden in dit hoofdstuk aanbevelingen gedaan voor toekomstig onderzoek naar ondersteunende technologie voor mensen met dementie en de toepassing ervan in de klinische praktijk.
Summary
Summary

Due to the aging population worldwide, the number of people with dementia is expected to increase dramatically in the next decades. This also means that the number of people that are available to care for these people with dementia, will decrease. As such, innovative and efficient solutions are needed to help people with dementia in their daily lives. In this thesis, we developed and researched several innovative care technology solutions that aim to help people with dementia, their informal caregivers, and professional carers. The first intervention we developed and studied is the ROSETTA system, an integrated system that assesses safety in the home, monitors behavior, and helps participants outside their homes (Chapters 2 and 3). The second intervention, Into D’mentia, aimed at helping informal and professional caregivers gain insight into the behavior of people with dementia, by having them experience a day in the life of someone with dementia (Chapters 4 and 5). In the STAR study, we developed and researched an online eHealth course on dementia care, which helped informal and professional caregivers to understand and deal with dementia (Chapter 6). Finally, we studied an online patient portal that allowed people with dementia and informal caregivers to find information on dementia; to contact other people; and to view their appointments and contact their physician directly (Chapter 7). Below, we summarize the results of these studies.

Chapter 2: ROSETTA: Participatory designing of domotica

The ROSETTA project offered an integrated, personalizable assistive technology solution that could be installed in participants’ homes, and aimed to support people with dementia and caregivers by providing communication tools, a photo book and an on-screen agenda with reminders, a fall detection system, a behavior monitoring system, and GPS tracking for outside. It helped informal carers by offering a sense of security regarding their family member with dementia, and helped them manage the agenda of their family member. The chapter reports on the user-participatory designing of the ROSETTA system through several workshops and meetings in three phases of the development of the system: initial development, development, and fine-tuning. This was done in the Netherlands and Germany; in Belgium only the UAS-AAPS was evaluated in this project. The workshops included design mockups, system pilot tests, and system tests in a demonstration home. Of the possible functionalities that were discussed, people with dementia and informal carers considered the following functionalities most helpful and relevant: help in cases of emergencies, navigation support and the calendar function with reminders. Dementia experts rated various behaviors as being relevant be monitored for the timely detection of changes in functioning, e.g. eating, drinking, toilet usage, taking medicine adequately and appropriately, performance of daily activities and sleep patterns. The user-participatory design process resulted in valuable input from persons with dementia, informal carers and professional carers/dementia experts, based on which a first prototype of the ROSETTA system was built.

Chapter 3: ROSETTA: Evaluating domotica

This chapter describes an exploratory evaluation study in which the usefulness, user-friendliness and impact of the ROSETTA system developed in the previous chapter was tested among people with dementia, their informal carers and professional caregivers involved in the care. The ROSETTA system was installed in participants’ homes in the Netherlands, Germany and Belgium. In a controlled trial with pre-test and post-test measures, participants took part in semi-structured interviews regarding usefulness and user-friendliness of ROSETTA, and completed impact measurement questionnaires on, among other things, Quality of Life, perceived autonomy, caregiver feeling of competence, and use of
care services. All participants stated that ROSETTA is a (very) useful development. Since the current system was a first prototype version it was not rated highly on user-friendliness, especially the user interface for the caregivers. This was mainly caused by budget- and time constraints during the development. We found no significant effects on any of the impact measurements.

Chapter 4: Into D’mentia: Designing and developing a dementia simulator

This study describes the preliminary study performed for the development of Into D’mentia, a mixed-reality simulation that lets visitors experience a day in the life of someone with dementia. For an accurate representation of their experience, this study aimed to find the most important domains of experience for people with dementia. This was achieved by performing an international literature search for articles containing quotes by people with dementia about their experience. These were categorized according to three domains: problem areas, adaptation-coping, and Quality of Life. The quotes were discussed regarding their recognizability and relevance for people with dementia during two focus groups with people with dementia and two with informal carers and by an online survey with professional carers. In the focus groups, especially quotes in the adaptation-coping domains were recognized by people with dementia and all caregivers. The domains regarding Quality of Life were also recognized by most participants. The problem areas of the National Dementia Programme were recognized to a lesser extent.

Chapter 5: Into D’mentia: Evaluating a dementia simulator

The Into D’mentia simulator offers informal carers and professional caregivers the chance to experience first-hand the effects dementia has on a ‘day in the life’ of someone with dementia, with the aim to improve their understanding of, and empathy for, the person(s) with dementia they care for. During this ‘day’, techniques such as sensors and projections simulate the limitations and social and emotional consequences of having dementia. The simulation made informal and professional caregivers think about how they would cope and deal with the effects this disease has. It confronted them, for example, with forgetfulness, disorientation, and the social stigma one experiences as well as the emotions these provoked. Both informal carers and professional carers indicated they felt Into D’mentia was a highly useful and user-friendly innovation that offered them an immersive means to learn about the effects of dementia. They indicated the simulation helped them to offer better care. Participants mentioned that they often thought back to their experiences in the simulation in their daily practice, to better understand the behavior of people with dementia. No significant effects were found on impact measurements.

Chapter 6: STAR: developing online e-learning for caregivers

The STAR E-learning course helped informal carers, volunteers, and professional carers in their understanding of, and dealing with, dementia. The course consisted of 8 different modules with specific themes and 3 difficulty levels (basic, intermediate and advanced). In a Randomized Controlled Trial with pre-test and posttest conditions across two countries, the user-friendliness and usefulness of STAR were evaluated among laypersons (informal caregivers and volunteers), and professional caregivers. The different users appreciated the STAR course positively: most users indicated the course was helpful, useful, and user-friendly. They scored the contents of the modules with an average score of 8.0. Additionally, significant positive effects were found on several impact measurements: the (in)formal caregivers’ person-centered care approach as well as the total score on positive attitude towards
dementia improved in both the experimental and the control group increased in score. Significant improvements were found in the STAR training group on empathic distress, empathic concern, and on the ability to take the perspective of the person with dementia. Professional caregivers improved on empathy. In addition, after the course carers also had an increased sense of competence, meaning that they felt better able to take care for the person with dementia.

Chapter 7: DAC: Evaluating a web-based patient portal

The Digital Alzheimer center (DAC), an online patient portal, helped people with dementia and their carers by offering information, communication and peer contact tools through an online portal. The DAC was studied in a descriptive study among patients, carers, and health care professionals. Mixed methods were used, consisting of observations; an online survey and semi-structured interviews. A majority considered the DAC useful; most notably for understanding dementia. Fewer people found the DAC user-friendly: only a minority indicated that they found the site easy to work with. In semi-structured interviews the site was generally rated positively on usability and usefulness and design of the website/interface. As the majority of users evaluated the usability and usefulness of the portal positively, and appreciated the information it provided, it was concluded that an online patient portal could be a useful means to help to support patients and carers in dealing with dementia. However, as only a minority of patients found it easy to work with the portal it was also concluded that good, cooperative design and frequent usability testing is essential to offer a good online portal.

Chapter 8 General discussion

Chapter 8 contains a short summary of the research and studies performed, and describes these in relation to other scientific literature. Additionally, it describes methodological considerations, recommendations for future research and daily care practice, as well as recommendations for developing care technology and supportive technology.

It first describes how most of the systems were designed in a user-participatory design process. In this design process, it is important to involve future users (people with dementia, informal carers, and/or professional carers) of a system as early as possible, to ensure a system that matches their needs and wishes. We concluded, based on the different studies performed, that it is feasible to involve our intended target groups. However, we did find that despite a user-participatory design process, some interventions were still considered to be non-user friendly. This highlights the complexity of designing (assistive) technology solutions. Second, it described how users evaluate the systems that were studied in this thesis; these were analyzed on user-friendliness, usefulness, and effectiveness (in achieving the intended aims).

The experienced user-friendliness of the interventions was variable; it depended greatly on the level of development of the system how this was experienced. Besides, it was important to communicate with users, to manage expectations of the system. On usefulness, all solutions were found to be considered very useful. The studied interventions were considered useful to enhance feelings of safety, to enhance understanding, empathy and sense of competence in family caregivers, and to provide information. Nearly all users agreed that developments such as the interventions studied were ‘indispensable for good care in the future’. With regards to the effectiveness of the systems, it was concluded that it was not possible to find effects with small-scale prototype studies (such as ROSETTA), whereas larger-scale, more developed systems (such as Into D’mentia and the STAR e-learning) found effects
on (reduced) caregiver stress, higher sense of competence, and on empathy and understanding towards people with dementia.

The main methodological issues that we encountered were: the level of development of the intervention; the influence this had on user satisfaction and experience of user-friendliness; the small user groups in some of the studies, which influenced the statistical power to find significant effects; and the possible user selection bias, which may have influenced the results by only including those with a positive attitude towards technology.

Scientifically, this thesis add to the growing body of knowledge on e-health and assistive technology, offering new insight into research in surveillance systems, dementia experience, online e-learning, and online patient portals (specifically for people with dementia and their informal carers). With regards to societal relevance, this thesis describes several possible solutions to support people to deal with the increasing burden of dementia. Finally, recommendations are made for future research into assistive care technology for people with dementia, and the application of such technologies in clinical practice.
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About the author
Bart Hattink was born on the 26th of December, 1983. Up to an age later than he’d dare to admit, he believed that Christmas trees were placed everywhere in celebration of his birthday.

He completed a Nature & Technology profile at high school in Castricum, after which he went to study psychology at the VU University in Amsterdam. Upon learning of his maternal grandfathers’ diagnosis of Alzheimer’s Disease, his interest in this peculiar disease was piqued. Both his bachelor’s and master’s theses of the Clinical Neuropsychology specialisation were into psychosocial research into dementia. He remained interested in both technology and dementia, and started as a junior researcher at the department of Psychiatry of VU University medical center in May 2011. There he worked on several different European and national projects aimed at developing and evaluating assistive technology for people with dementia and their informal caregivers.

From May 2015 to March 2018 he worked as a grant coordinator at KWF Kankerbestrijding, the Dutch Cancer Society. He recently started working as a Data Protection Officer for several elderly care organizations in Amsterdam. He is married to Renate. They live together in Weesp and are expecting their first child in May.
Publication List


Dissertation series

Department of Psychiatry, VU University Medical Center


If I had been Terry Pratchett the farmer, or Terry Pratchett the dentist, nobody would have paid any attention if I had announced I had Alzheimer’s. But there is something fascinating about an author losing the power over words.

-Sir Terry Pratchett