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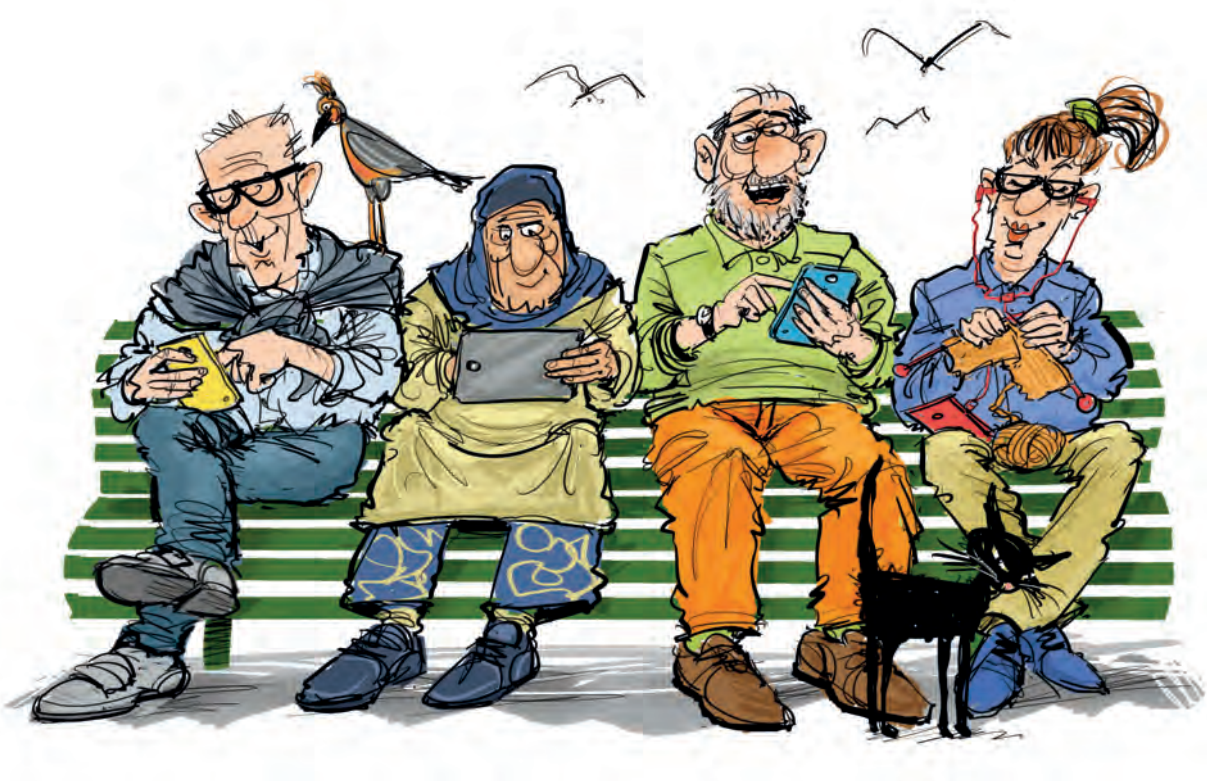

Yvonne Kerkhof

Digital support for people with mild dementia

This thesis reports on the research that was conducted to develop and pilot test a person-centred touchscreen-based program that supports people with mild dementia and their informal carers in how to use a tablet and apps for self-management and meaningful activities. The program consists of a training for informal carers in supporting people with mild dementia in using a tablet and a web-based selection tool designed to help people with mild dementia find apps for self-management and meaningful activities that fit their needs, wishes and abilities. The program was developed following the Medical Research Council (MRC) Framework for the design and evaluation of complex interventions and in co-creation with end users. The chapters of this thesis describe the first three phases of this framework.

Digitale ondersteuning voor mensen met beginnende dementie

Dit proefschrift beschrijft een onderzoek dat is uitgevoerd om een persoonsgericht tablet-programma te ontwikkelen en te testen.

Dit programma ondersteunt mensen met beginnende dementie en hun mantelzorgers bij het gebruik van de tablet en apps voor zelf-management en betekenisvolle activiteiten.

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We are like dwarfs sitting on the shoulders of giants.
We see more, and things that are more distant, than they did,
not because our sight is superior or because we are taller than they,
but because they raise us up, and by their great stature add to ours.

John of Salisbury (1120-1180)

The studies presented in this thesis were conducted at the Amsterdam University Medical Centres, location VUmc, Department of Psychiatry and within the Amsterdam Public Health Research Institute, Amsterdam, The Netherlands.
This study was funded by an educational grant from the Dutch Ministry of Education, Culture and Science and the School of Health of Saxion University of Applied Sciences. The development and design of the FindMyApps selection tool was funded by a grant from the Foundation of Support VCVGZ.

Nederlandse titel
Digitale ondersteuning voor zelfmanagement en betekenisvolle activiteiten voor mensen met beginnende dementie. De ontwikkeling, implementatie en haalbaarheid van een persoonsgericht tablet programma.

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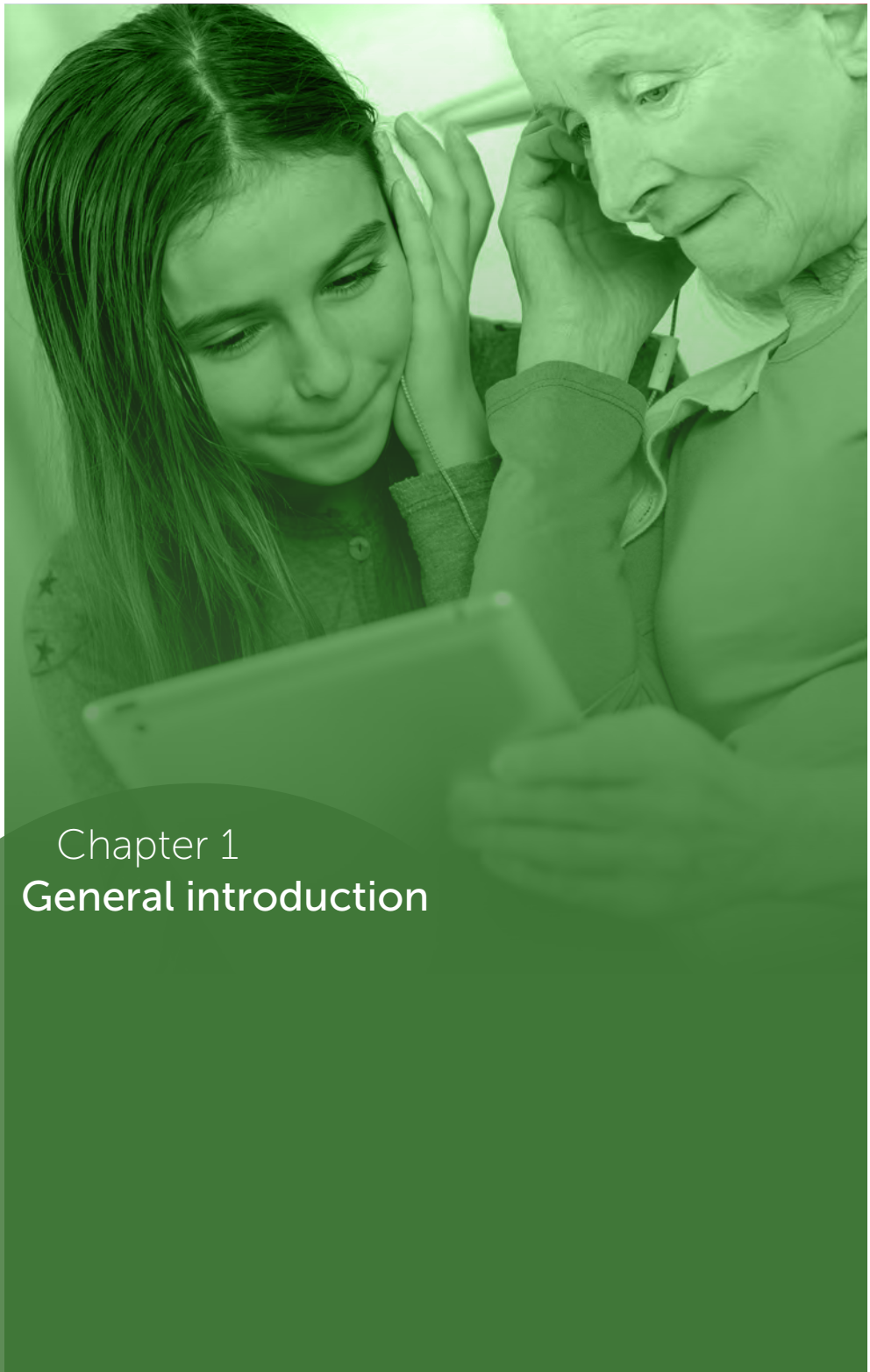

Chapter 1
General introduction

Dementia: definition and prevalence

Dementia is a chronic and progressive syndrome in which there is deterioration in cognitive functioning. It affects memory, thinking, orientation, comprehension, calculation, learning, language, and judgement.[1] In the 5th edition of the Diagnostic Manual Disorders (DSM), dementia is defined as a 'major neurocognitive disorder' (NCD), based on four diagnostic criteria:[2]

1. Evidence of significant cognitive decline from a previous level of performance in one or more cognitive domains (complex attention, executive function, learning and memory, language, perceptual–motor, or social cognition) based on: concern of the individual and substantial impairment in cognitive performance;
2. The cognitive deficits interfere with independence in everyday activities;
3. The cognitive deficits do not occur exclusively in the context of a delirium;
4. The cognitive deficits are not better explained by another mental disorder (e.g. depression or schizophrenia).

Alzheimer's disease is the most common type of dementia/NCD and is present in 60-70% of cases.[1,3] Other types of dementia/NCD are, for example, vascular NCD, NCD with Lewy-Body Dementia, NCD due to Parkinson's disease and frontotemporal NCD.[2] In this thesis we will still use the term dementia as this is still most commonly used in clinical practice and dementia care research.

Nowadays, 50 million people are living with dementia globally and this number will increase to 152 million by 2050.[4] In the Netherlands there are 280,000 people with dementia. This number will double in the coming decades to 690,000 in 2050.[3]

Approximately 75% of people with dementia are living in the community, often with the help of relatives.[3] The focus of this thesis is on people with mild dementia living in the community. Mild dementia is characterized by the following clinical characteristics:[5]

(a) decreased knowledge of current and recent events; (b) some deficit in memory of one's personal history; (c) concentration deficit elicited on serial subtractions;

(d) decreased ability to travel, handle finances or the inability to perform complex tasks (Stage 4 Global Deterioration Scale). At this stage there are frequently no deficits in the following areas: (a) orientation to time and place; (b) recognition of familiar persons and faces; and (c) ability to travel to familiar locations. Denial is a dominant defence mechanism.[5]

Unmet needs of people with dementia and informal carers

Dementia has major implications for people living with this neurocognitive disorder and for their informal carers. As mentioned, approximately 75% of the people with dementia live at home receiving care from informal carers.[3] In the early stages of dementia people often experience insufficient support from professionals and healthcare services to stimulate self-management abilities.[6,7] Interventions to help people cope with the consequences of their dementia in daily life after confirmation of the diagnosis are rare. From a medical

perspective the focus remains on diagnosis and treatment rather than adopting a holistic view of the person with dementia and their needs.[7,8] The most frequently experienced unmet needs of community-dwelling people with dementia and their informal carers is support in the domains of memory, daytime activities, company and psychological distress/safety.[9-12] 51% of informal carers stated that the offered daytime activities by day care services are not sufficiently tailored to the personal needs of people with dementia, 38% of informal carers experienced having less contact with family and friends and feeling twice as lonely compared to the general Dutch population.[13] 52% of informal carers feel rather heavily burdened and 1 in 8 (13%) feel very heavily burdened or overburdened [13] which is often the reason for institutionalisation of the person with dementia.[14]

Due to the increasing number of people with dementia, labour shortages and limited care finances [3], effective low-cost interventions are needed for people with dementia and their informal carers in order to maintain a good quality of care that will improve their quality of life and health as well as reducing the burden on caregivers. Tailored eHealth interventions that support the self-management and engagement in meaningful activities of people with dementia, would be such a low-cost intervention. However, little is known about whether such eHealth interventions can actually improve the self-management and engagement in meaningful activities of people with dementia and whether these are cost-effective.

Social health and Dementia

In 2011, partly in view of the aging society and its increasing number of older people with chronic diseases, Huber and several other international specialists in elderly care medicine, suggested replacing the WHO definition of Health from 1948 ("a state of complete physical, mental and social well-being and not merely the state of absence of disease or infirmity") with a new conceptual framework of health involving the ability to adapt and self-manage in the physical, mental and social domains.[15] This definition of health provides another perspective on care for people with chronic diseases, focusing on empowerment of their personal strengths and abilities rather than focusing on deficits. Huber *et al.* defined three dimensions of social health: the capacity to fulfil one's potential and societal obligations; the ability to manage one's own life with a certain degree of independence; and participation in meaningful daily and social activities.[15] Dröes *et al.* specified three dimensions of social health for people living with dementia and made an inventory based on literature and practice, of factors influencing the functioning of people with dementia in these dimensions.[16] Although it is evident that dementia has a major impact on someone's life and their capacity to adapt and self-manage, their social health also depends on many other factors [8,9,16,17] for example: personal factors such as personality, competencies and coping skills; disease related factors, such as specific disabilities and comorbidities; social factors, such as social support, competence of (in) formal carers, recognition of care needs, living situation (e.g. living alone or cohabiting);

and, environmental factors, such as living in a dementia-friendly environment. Also the availability of assistive technologies that can support people in an empowering, inclusive and non-stigmatizing manner may promote social health.[18, 19] Optimizing the factors which can be influenced, like supporting self-management and engagement in meaningful activities, is expected to be supportive to people with dementia and their informal carers in adjusting to living with dementia and improving their social health, quality of live and ability to live independently in their own home for longer.[16,20]

Supporting self-management and meaningful activities

To maintain social health it is essential for people with dementia that they are enabled to manage their life and engage in meaningful activities with the support of their informal carers and possible adaptions in their social and physical environment. Self-management can be defined as: "an individual's ability to manage the symptoms, treatment, physical and psychological consequences, and lifestyle changes inherent to living with a chronic condition".[21] In the context of dementia self-management refers to the ability of a person to preserve autonomy and solve problems in daily life, as well as adapting to and coping with the practical and emotional consequences of dementia.[16,22,23]

Areas of self-management are:[24]

1. Maintaining relationships with family, friends and carers;
2. Maintaining an active lifestyle;
3. Preserving psychological wellbeing;
4. Applying techniques to cope with memory change;
5. Staying informed on dementia.

Dealing with the loss of memory and other disabilities, requires adaptation and self-management skills that are also deteriorating gradually during the dementia process.[6] Therefore people with dementia will increasingly need more support to be able to manage their own lives during the dementia process.

The same counts for engaging in meaningful activities. Meaningful activities can be described as: "activities having a specific value for individuals and may be all types of daily activities in the areas of self-management, household and work or leisure activities".[20,25] In the context of dementia, meaningful activities refer to the act of being occupied or involved with activities, including social interactions and having social ties and relationships, which are meaningful to the person with dementia.[16] Meaningful activities are often still possible through stimulating the use of remaining capacities and compensating for deficits.[26-28] Through involvement in meaningful activities, persons with dementia can experience feelings of pleasure and enjoyment; feel a sense of connection and belonging; and retain a sense of autonomy and personal identity.[29]

A range of interventions can improve self-management in people with dementia [16], such as: cognitive rehabilitation therapies, cognitive stimulation group therapy, cognitive training, exercise and psychomotor therapy; case management based on the

empowerment model, other interventions aimed to enhance a person's strengths and capabilities, interventions aimed at recognizing care needs and providing meaningful activities creating stimulating, positive experiences.

Examples of effective interventions for meaningful activities include psychosocial programs, such as the combined Meeting Centres Support Program for people with dementia and their informal carers [30], community based occupational therapy for patients with dementia and their informal carers [31], support groups, intergenerational programs, people with dementia acting as volunteers, and activities such as singing in chorus, listening or making music, dance, theatre, creative artwork and museum visit programs, and dementia-friendly environments.[16,32-34]

Tailored, person-centred interventions

Tailored interventions, i.e. based on specific needs, wishes and abilities of people with dementia and their informal carers, are generally more beneficial than non-tailored interventions.[23,35,36] Their use and development are therefore recommended and should be further stimulated. The development of tailored interventions is in harmony with the principles of person-centred care.[37,38] According to the National Institute for Health and Care Excellence (NICE) in the UK these principles assert:

- "the human value of people living with dementia (regardless of age or cognitive impairment) and their families and carers;
- the individuality of people living with dementia, and how their personality and life experiences influence their response to dementia;
- the importance of the person's perspective;
- the importance of relationships and interactions with others to the person living with dementia, and their potential for promoting wellbeing.

Finally, the principles emphasize the importance of taking into account the needs of carers (whether these are family and friends or paid care-workers), and supporting and enhancing their input."[39]

Use of touchscreen technology and apps by people with dementia

Technology can potentially support people in their ability to manage their own life and engage in meaningful social activities. eHealth is defined as: 'the deployment of information and communication technologies (ICT), especially Internet technology (IT), to support or improve health and health care'.[40] eHealth interventions can support self-management and they are expected to reduce healthcare costs.[40] The development of eHealth in the last decade resulted in the availability of a large number of applications (apps) in the field of health and social care.[41] Apps are software applications specifically developed for use on smart phones or tablets. Touch screen devices, such as tablets, provide a good interface for eHealth purposes: they are user-friendly, and the development of apps for tablets is relatively simple. Based on first positive results with tablets in elderly care [42],

healthcare organizations and academic researchers are exploring whether specific target groups, such as people with dementia, could also benefit from apps on tablets and how to assist them in the effective use of the tablet. Due to their intuitive interface, tablets and apps are promising tools in supporting people with dementia's self-management and engagement in meaningful activities.[19,43,44] Research has shown a preference among elderly people for touchscreen devices rather than mouse and keyboard input devices.[45] Nowadays, the use of apps on hand-held touchscreen devices is becoming an integral part of everyday life, also among the older generation.[46] There is growing evidence that apps have potential to support people with mild dementia in their self-management and to engage them in meaningful activities.[47-51] Examples in the area of self-management are apps for timely medication intake (MedAlert), social contact (Nextdoor, Skype), daily structure (Visual schedule planner, Fello, MyInlife), navigation (Blokje Om), language and communication support (Dat ben ik, Dementie en herinneringen). Examples in the area of meaningful activities are apps for memory training, art, history, reminiscence, music, and games. However, as there are thousands of apps on the market which are too complex to be used by people with dementia, a careful selection is required when searching for particular apps.[19,47,49,52,53] A top ten of most suitable apps for people with mild dementia would not solve the problem since needs, wishes and abilities can vary considerably between individuals due to personal, social and environmental factors and specific disabilities.[16] This increases the need to develop an IT application that helps people with mild dementia find apps for self-management and meaningful activities that fit their needs, wishes and abilities and which can be used by them, regardless of physical or cognitive impairments.

Teaching people with dementia to use a tablet and apps

People with dementia need support in learning how to use touchscreen devices when they are unfamiliar with them.[19,47,49,50,52] Kessels & Joosten-Weyn Banningh (2008) describe how new skills can be taught to people with dementia using their implicit memory. This part of the long term memory is responsible for performing procedural tasks, such as cycling and washing hands, which are acquired through fixed routines and then are conducted automatically, in other words without conscious awareness.[54] One learning method that makes use of implicit memory is Errorless (EL) learning. EL refers to a method of learning involving the elimination of errors during the learning process as memory limitations prevent learning from mistakes.[55,56] The review by De Werd *et al.* found that an EL learning approach is more effective than an errorful (EF) learning approach in teaching people with dementia a variety of meaningful daily tasks or skills.[56] In EF approaches the idea is that skills can be learned by guessing the correct response and learning from any errors made.[57] Several studies showed that by means of EL people with mild dementia were able to learn how to use everyday technologies and new technologies, such as smartphones and tablets.[58,59] EL might be the best way

to introduce tablets to people with dementia, but due to the broad scope of the review by De Werd *et al.* it is inconclusive regarding the effectiveness of EL specifically for (re) learning skills for using technologies, including handheld touchscreen devices.[56] In order to offer people with dementia the best support in tablet use, it is important to know which training methods are most effective and how informal carers and professionals can support people with dementia during the training method. As apps for self-management and meaningful activities, which could also potentially support people with mild dementia, are becoming increasingly available, learning to operate touchscreen devices by means of a feasible training method, may help increase the autonomy of people with dementia and help reduce social exclusion. This is turn improves the quality of life of people with dementia and their informal carers.

Participatory design

In the past, designers often developed technology in an isolated way, neglecting the needs of specific end-user groups, such as people with dementia. However, the importance of involving people with dementia in technology development has been generally acknowledged in the last decade, so ensuring that their needs are addressed and promoting technology acceptance.[18,60] The principle of participatory design is giving a voice to end-users in the design, development, evaluation and implementation of the product by approaching them as experts with the aim of bringing their knowledge and their skills into the development process.[61]

Different participation roles in participatory design have been used to prevent users only having a passive role in technology development and to stimulate an active involvement and equivalent cooperation with users.[62] Different gradations of participation in research have been distinguished from a minimum role, as research object or respondent, to the highest degree of participation, as research partner or research principal.[62]

Focus of this thesis

The goal of the research presented in this thesis is to develop and pilot test a person-centred program that supports people with mild dementia and their informal carers in how to use the tablet for self-management and meaningful activities.

The research questions were:

1. How to develop a person-centred program that supports people with mild dementia and their informal carers in the use of hand-held touchscreen devices (study-protocol)?
2. What do people with dementia find important in their choice and use of apps and what requirements can be identified based on these perceptions (user needs studies)?
3. Which training interventions are effective for people with mild dementia in (re)learning how to use technology, including handheld touchscreen devices (literature review)?
4. How to develop a selection tool that helps people with dementia find suitable apps for self-management and meaningful activities that match their individual needs, wishes

and abilities (development selection tool)?

5. What is the feasibility of the person-centred tablet program and research design (exploratory trial)? This includes the themes context, implementation strategy, mechanism of impact, the potential impact on users (people with dementia and informal carers) and research methods to prepare for a definitive trial.

As a person-centred tablet program would involve people with dementia and informal carers and different components, such as a tablet, apps and training, it can be viewed as a complex intervention. We therefore followed the Medical Research Council (MRC) framework to first define the problem/needs the tablet program is directed at, to model the intervention, and to prepare and execute the definitive evaluation in an exploratory trial.[63,64] This thesis describes this process in the first three phases of the MRC framework i.e.: the preclinical or theoretical phase (0); the modelling phase (I) and the exploratory trial (feasibility) phase (II). Mixed methods, i.e. both qualitative and quantitative research methods, were used for designing and evaluating the program. Phase III, the execution of an RCT, and further implementation in case the intervention proves effective, are beyond the scope of this thesis.[63,64]

In this thesis existing person-centred care interventions [65] and programs [31,33,66] were studied and the procedural aspects of these interventions taken into account in the development of a person-centred touchscreen intervention. To guarantee a useful and user-friendly IT application, it was developed in closed cooperation with the end users i.e. people with dementia and their informal carers by means of a user-participatory design.[60] People with dementia were individually (in the absence of their carers) involved fulfilling the roles of research object, informants and advisors.[62]

During the preclinical or theoretical phase (0) we first explored the literature and performed user needs studies to identify user requirements for desired activities in the context of self-management and meaningful activities and to explore the needs, wishes and abilities related to the use of apps. Since people with dementia may need support to learn how to use touchscreen devices, we also developed a training to be included in the person-centred program. To this end we conducted a literature review to gain insight into effective training methods to support people with dementia in using the tablet. Next, in the modelling phase (I), by means of participatory design, we developed a concept and a first prototype of the web-based selection tool to find suitable apps in the area of self-management and meaningful activities that match individual preferences, needs and wishes of people with mild dementia. The developed person-centred program consists of two components: 1) a web-based selection tool to help people with dementia find apps that fit their needs, wishes and abilities; and 2) a training for informal carers to support people with dementia in using the tablet and tool. Finally, the person-centred program, i.e. the selection tool and training were tested in an exploratory trial (II) as preparation for a future definitive trial (see Figure 1.1).

We expect that this person-centred program will contribute to increased self-management

abilities, participation in daily and social activities, perceived self-efficacy and autonomy of people with dementia and also to an improved quality of life for people with dementia and their informal carers along with an increase in the sense of competence and positive care experiences for informal carers.

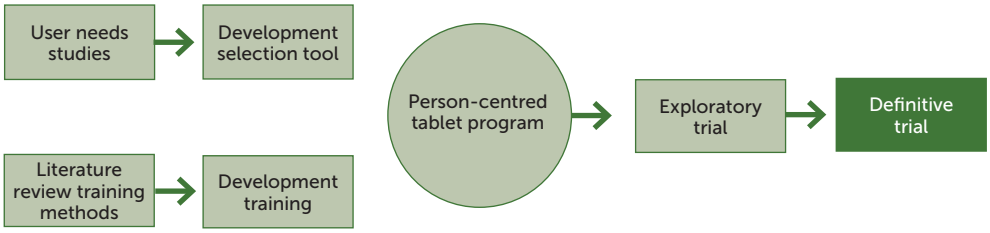

Figure 1.1 Development and testing person-centred tablet program

This thesis is structured as follows:

Chapter 2 describes the study protocol of how the person-centred tablet program was developed and tested according to the first three phases of the MRC framework. It is also explains how users were involved during all study phases of the research.

Chapter 3 reports on the results of the two user needs studies with regard to 1) the kind of self-management and meaningful activities that are important to people with dementia and 2) the needs, wishes and abilities of people with dementia regarding the use of apps. The user-requirements (filters) for the selection tool were formulated based on the results of these studies.

Chapter 4 presents the results of a literature review on training interventions that people with mild dementia can use as support in (re)learning the use of technologies, including handheld touchscreen devices.

Chapter 5 describes the development of the (web-based) selection tool in close collaboration with users and experts e.g. designers, developers and researchers. Our aim was to develop a selection tool that works as a filter so that apps are selected that, based on their specific features and content, match the individual preferences, needs, wishes and abilities of people with dementia. In three short iterative rounds – so called 'sprints' – potential users were invited to test whether the prototypes were in line with their needs, wishes and abilities.

Chapter 6 describes the exploratory feasibility trial. We explored the context, implementation strategy, mechanisms of impact and the potential impact of the person-centred tablet program on people with dementia and their informal carers as well as research methods in preparation for a definitive trial.

Finally, in *chapter seven*, 'general discussion', the main findings of this thesis are presented and discussed. Methodological issues are discussed along with the scientific and clinical relevance of the conducted study and its results, and recommendations for future research and implications for practice.

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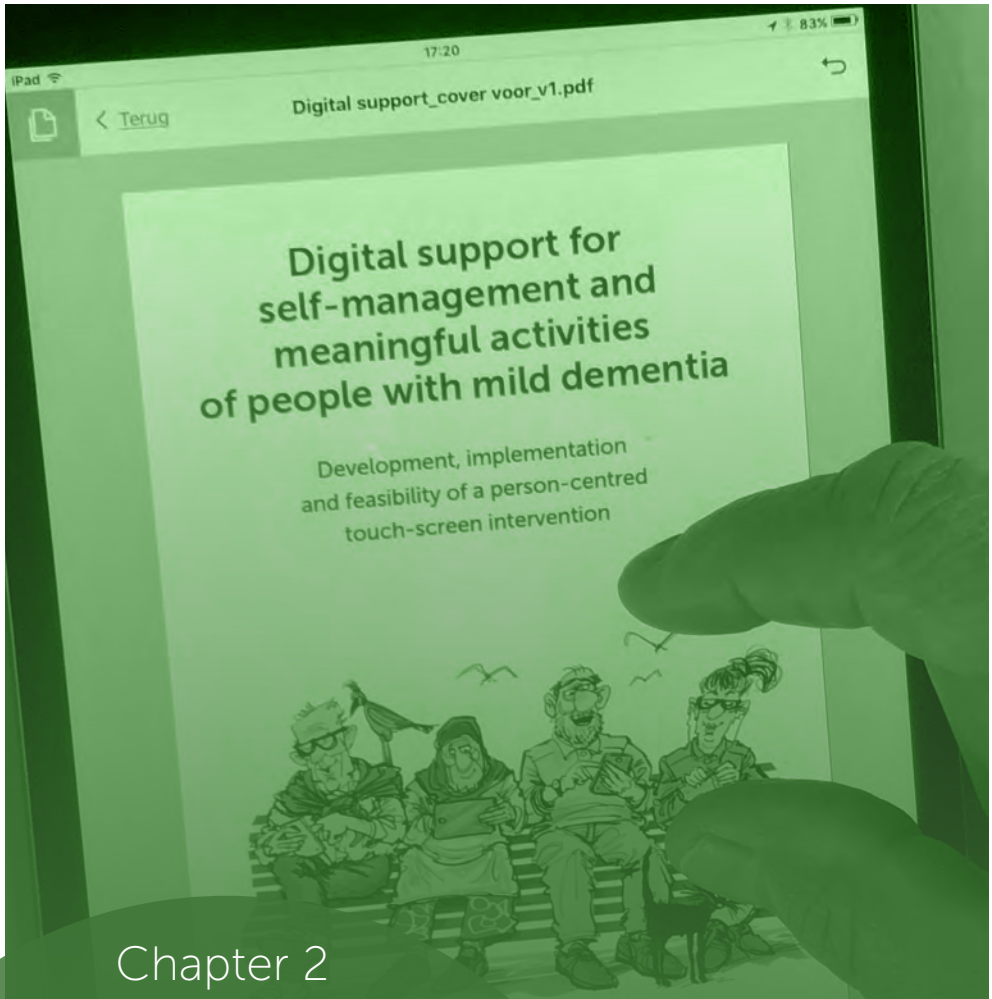

Chapter 2

Study protocol: development of a person-centred program to support people with mild dementia and their carers through use of hand-held touch screen device

Published as

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Abstract

Background

To offer good support to people with dementia and their carers in an aging and Internet society the deployment of hand-held touch screen devices, better known as tablets, and its applications (apps) can be viable and desirable. However, at the moment it is not clear which apps are usable for supporting people with dementia in daily life. Also, little is known about how people with dementia can be coached to learn to use a tablet and its apps.

Methods

A person-centred program, with tools and training, will be developed that aims to support people with mild dementia and their (in)formal carers in how to use the tablet for self-management and meaningful activities. The program will be developed in accordance with the Medical Research Council's (MRC) framework for developing and evaluating complex interventions and the study will cover the following phases: a preclinical or theoretical (0) phase; a modeling phase (I) and the exploratory trial phase (II). The users (people with dementia and their carers) will be involved intensively during all these phases, by means of individual interviews, workshops, focus groups and case studies.

Discussion and conclusion

The iterative process inherent to this framework makes it possible to develop a user-oriented intervention, in this case a person-centred program, for the use of tablets in dementia care. Preparatory work will be done to perform a methodologically sound randomized controlled trial (RCT) in the near future, which aims to investigate the contribution of this person-centred program for tablet use to the quality of life of people with dementia and their carers.

Introduction

In 2013, 44 million people worldwide lived with dementia and this number is expected to rise to 76 million in 2030 and 135 million in 2050.[1] In the early stages of the disease people may experience an 'informational and support gap'. Medical components of care such as diagnostic tests and prescribing medications are generally delivered adequately, but the counseling and educational aspects of living with dementia are often neglected [2,3] or seen as not feasible for people with dementia.[4] As a result meaningful life roles are lost and the quality of life deteriorates. Self-management can be defined as: 'an individual's ability to manage the symptoms, treatment, physical and psychological consequences and life style changes inherent to living with a chronic condition'.[5] Dealing with the loss of memory and other abilities requires self-management skills that deteriorate in people with dementia at the same time because of the disease itself.[2] People with dementia therefore need self-management support to be able to carry on living and potentially delay further progression of losses.[6] That the support received is not always satisfactory is demonstrated by the unmet needs people with dementia (and carers) experience regarding, for example, memory, psychological distress, social contact/company and meaningful activities.[7-10] Recently, it has been acknowledged that in case of elderly people living with a chronic condition, health care should focus more on empowering people in their personal strength and abilities rather than focusing on deficits.[4,11]

Technology potentially can support people in their ability to manage life despite chronic diseases.[11] It is generally expected that eHealth can stimulate self-management among users and cut health care costs.[12] eHealth is defined as: 'the deployment of information and communication technologies (ICT) to support or improve health and health care'.[13] The development of eHealth resulted in the availability of new applications (apps) in the field of health and social care.[14] In the case of the early stages of dementia, information and communication technology may compensate for some of the cognitive losses and offer functional support. A Pictoplanner for example, can help to structure the day and prompt behavior for people who are no longer able to get through the day independently.[15]

Touch screen devices, such as tablets, provide a good interface for eHealth purposes, they are user-friendly, and the development of apps for these tablets is relatively simple. Based on the first positive results with tablets in the elderly care,[16] health care organizations have become interested to extend the use of tablets to specific target groups, such as people with dementia. Because of its intuitive interface, the tablet and its apps may be useful in supporting self-management.[14,17] although people with dementia will need support to learn how to use the touch screen and its applications.[17-23]

Three case-studies involving nine participants with mild cognitive impairment (MCI) and mild dementia living at home, demonstrated that people with MCI and mild dementia were able to learn to use the tablet and its apps, and that it had a positive influence on their self-confidence and involvement in society.[24-26] Self-confidence or self-

efficacy is an important basis for self-management abilities.[6] Several, mainly qualitative, studies showed that people with dementia who used touch screen technology and its applications, evaluated it as user-friendly and experienced it as valuable.[17,19-23,27-30]
Existing apps, and apps specifically developed for people with dementia, could support the five targets of self-management identified by [31], i.e:

1. Relationship with family/friend/carer e.g. CIRCA (28) and apps to provide care at a distance e.g. the PAL4 dementia system [20];
2. Maintaining an active lifestyle e.g. the TalkMeHome Service [32];
3. Psychological wellbeing e.g. apps for leisure activities [33], such as, music [27], reminiscence [29,] art [30], gaming [22,34];
4. Techniques to cope with memory losses e.g. the COGKNOW Day Navigator [19] and the Pictoplanner [15] and
5. Information about dementia e.g. the PAL4-dementia system.[20]

Self-management in the context of dementia refers to dealing with, and adapting to, the changes dementia brings in the person's life, and preserving a good quality of life.[35,36] Apps to support self-management should therefore not be limited to compensation for deficits, but also promote meaningful positive experiences.[4] Engaging people with dementia in meaningful activities which are still possible by stimulating the use of remaining capacities and compensating for deficits will contribute to their quality of life.[37-39] Meaningful activities can be defined as: 'the spectrum of occupations a person performs in his or her everyday life and that are perceived as significant to the person'.[40] For people with dementia in particular, activities are expected to be meaningful when they result in: experiencing pleasure and enjoyment; feelings of connection and belonging; and retaining a sense of autonomy and personal identity.[40] Meaningful activities have a specific value for an individual person and can be all types of daily activities in the areas of self-management, household or leisure activities.[41] Thus, most apps mentioned above could also be of benefit to stimulate meaningful activities in people with dementia.
When introducing the tablet to people with dementia, it is important to take into account some specific preconditions, e.g. related to their cognitive decline and context. Careful consideration is required to select usable apps for the target group. Usable refers to the extent to which an app is useful, user-friendly, easy to learn, and satisfying.[42] The present study intends to develop a person-centred tablet program that will help individual people with dementia and their carers to select and use apps for self-management and meaningful activities that match their needs, wishes and functional abilities. An individual based approach is necessary because what activities are meaningful or supportive for self-management is different for each person. The person-centred tablet program will consist of:

- a requirements-based assessment tool to select usable apps that match the individual needs, wishes and functional abilities of people with dementia;

- a training for people with dementia to learn how to use the tablet; and
- a training for professionals and informal carers (including volunteers) to support/ coach people with dementia in using the tablet.

The expected results of this person-centred tablet program for self-management and meaningful activities is to improve their self-management ability of people with dementia and to promote their engagement in meaningful activities and participation in daily and social life. It is expected that the program will contribute to the quality of life of people with dementia and their careers.

Methods

Design

As the person-centred tablet program can be viewed as a complex intervention, we will use the Medical Research Council (MRC) framework for the development and evaluation of complex interventions to better define the problem/needs the program is directed at, how to model the intervention, and to prepare and execute the evaluation in an exploratory trial.[43,44] This paper describes the methods used in these first three phases of the MRC framework (Figure 2.1) i.e.: the preclinical or theoretical phase (0); the modeling phase (I) and the exploratory trial (II).

In the theoretical phase an explorative study will be done to develop, or adapt existing, tools and training for the person-centred tablet program. Next, in the modeling phase,

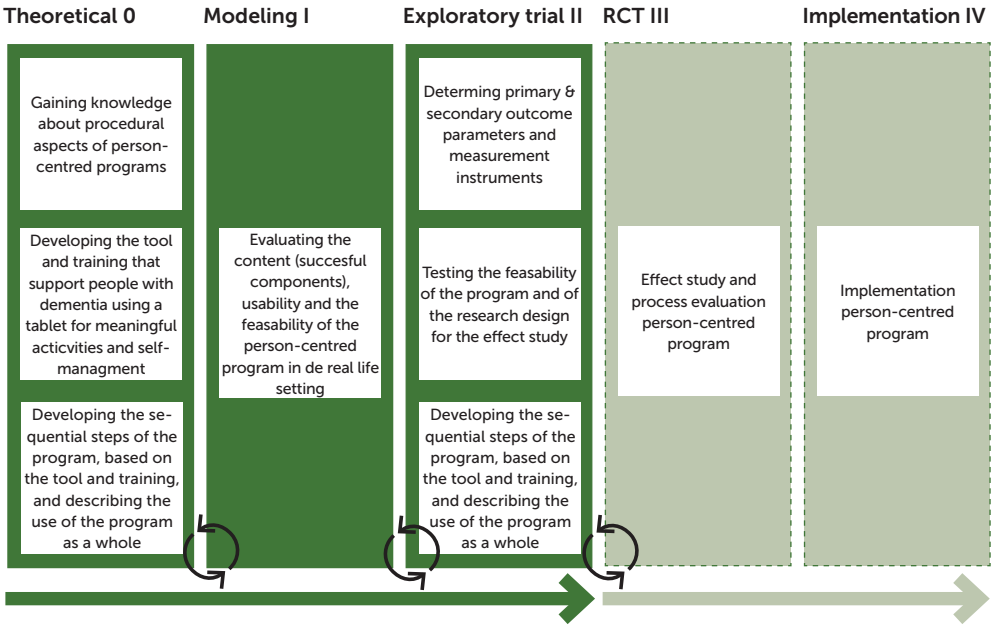

Figure 2.1 First phases of development and testing of a person-centred tablet program according to the MRC framework.

the successful components of the program, the usability and feasibility of the program will be explored and evaluated. In an exploratory trial, the intervention and the measurement instruments will then be pilot-tested on feasibility, and the intervening factors for measuring the effectiveness of the program will be evaluated. Mixed methods, i.e. both qualitative and quantitative research methods, will be used for designing and evaluating the program. After these three phases are concluded, the effect of the program can be evaluated in an RCT (phase III) and, when effective, the program can be further implemented (phase IV). The execution of the RCT and (possible) further implementation are beyond the scope of the present study.

Below, the aim, research questions, methods, analysis strategies and expected results are outlined for each phase. The rationale of the study will be described in the first phase. According to the MRC framework, the progression from one phase to another, especially in the first three phases, may not be linear but can be conducted in an iterative process [43-45], i.e. return to an earlier phase of the development e.g. from the modeling phase back to the theoretical phase, or from the exploratory trial back to the modeling phase, based on feedback or new information collected in a later phase. This provides the possibility to constantly optimize the person-centred tablet program, i.e. to adjust it to the needs of users and their context. Using 'participatory designs', user needs are inventoried and integrated in the person-centred tablet program.[46-48] In all phases of the development of the program we will involve users, i.e. clients and carers, by means of individual interviews, workshops, focus groups and case studies. In the end, the intervention will be offered to community dwelling people with mild dementia. The MMSE score [49] in combination with the Global Deterioration Scale [50] will be used to determine the sample and people with mild dementia with scores for cognitive functioning between 18 and 24 (MMSE) and level 4 (GDS) will be included in the modeling phase and exploratory trial. In addition to people with mild dementia, people with mild cognitive decline or MCI could be included in the theoretical phase (MMSE 24-27 and GDS levels 2 or 3) of the development of the tool for selecting usable apps as representatives for the future needs and wishes of people with mild dementia.[51] In this phase people will be individually (apart from carers) involved fulfilling the roles as informants and advisors.[52] In the modeling phase and exploratory trial they will be involved as dyads fulfilling the roles as informants and research subjects.[52] However, to gain a comprehensive insight into their needs, (group) interviews in these phases will be conducted with persons with dementia apart from informal carers as we know that the needs reported by persons with dementia can differ from those mentioned (about the person with dementia) by carers.[7,9,10] Because we only include community dwelling participants, the recruitment will take places via health and homecare organizations, day centers and meeting centers for people with dementia and their informal carers.

Ethical considerations

The Medical Ethics Committee of the VU University Medical Center in Amsterdam approved the study protocol. The ethical principles; respect for autonomy, beneficence, non-maleficence and justice [53] will be taken into account during recruitment, data collection, analysis and reporting. During all the phases special attention will be paid to the informed consent of people with dementia by performing an on-going consent procedure in order to ensure that participation is voluntarily.[54] Furthermore, strategies for the meaningful inclusion of people with dementia such as, creating a safe environment, spending time by getting to know them, emphasizing the importance of their participation and recognizing signs of discomfort, will be taken into consideration.[54]

Methods of Preclinical or theoretical phase (phase 0)

The aim of the theoretical phase is to explore relevant theory that will guide the best choice of intervention.[43] The following research questions will be addressed in this phase:

1. What are important procedural aspects (e.g. recruitment, inclusion, process and effect evaluation and implementation issues) of person-centred programs for people with dementia to take into account in the development of the person-centred tablet program?
2. What needs, wishes and abilities of people with dementia should be taken into account when selecting usable apps on the tablet with regard to self-management and meaningful activities?
3. How to design and develop a requirements based assessment tool for usable apps with regard to self-management and meaningful activities that matches with the individual needs, wishes and abilities of people with dementia?
4. What training or coaching intervention(s) on how to use the tablet and its applications is/are most appropriate and/or effective for people with dementia and informal and professional carers?

Rationale and methods related to procedural aspects of person-centred programs (question 1):

In recent decades psychosocial interventions are promoted to improve the quality of life of people with dementia.[55] Many of these interventions have been shown to be effective.[35,36,56,57] However, psychosocial interventions that are tailored to specific needs, wishes and abilities of people with dementia and their carers are more beneficial than non-tailored interventions, and their use and development should therefore be stimulated.[36,57,58] Moreover, in a review on psychological interventions in dementia it is found that personalized dyadic programs are effective (van't Leven *et al.*, 2013). This development of tailored interventions is in accordance with the principles of person-centred care.[59,60]. In this study existing person-centred psychosocial interventions [61] and programs that focuses on both the person with dementia and their informal carer [41,62-64]

will be explored, and an additional literature study will be performed to gain knowledge about the procedural aspects of these interventions.

Rationale and methods for assessing the individual needs, wishes and abilities of people with dementia (question 2):

Due to the wide variety of available and limited apps specifically developed for people with dementia [33] careful consideration is required to select usable apps for people with dementia. It is therefore essential to develop a requirements-based assessment tool that will help people select usable apps in the domains of self-management and meaningful activities. Although there are several studies done and underway that focus on identifying usable apps for people with dementia [17,22], there is no tool available specifically for people with dementia yet. The tool has to match individual needs, wishes and abilities of people with dementia to important features of apps so that tailored apps can be selected. To develop this tool it is important to get an understanding of the needs, wishes and abilities of people with dementia with regard to their choice and use of apps so that user requirements for the tool can be identified.

To ensure that the desired activities in the context of self-management and meaningful activities of people with dementia are adequately identified and supportive, the methodology of the OPHI-II-NL will be applied.[41,65] The OPHI-II-NL is a narrative interview that focuses on the identification of meaningful activities and the experiences of these activities in the past, the present and what this means for the future. To get a comprehensive understanding of individual needs, wishes and experiences as well as capabilities, despite existing impairments, two focus groups with people with mild dementia and two focus groups with informal carers will be conducted, based on the OPHI-II-NL interview.[41,62,65] This will help to gain insight into the target group relevant self-management activities and other meaningful activities, so that user requirements for the tool to select apps can be identified.

In addition, two focus groups sessions with people with cognitive decline, MCI and mild dementia and two focus groups sessions with informal carers, with a two weeks period in between, will take place to explore their needs, wishes and abilities in their current use of apps and new introduced apps. To avoid embarrassment among participants due to memory problems, participants will be asked to bring their tablet to capture experiences while using different kind of apps. As a result, additional user requirements with regard to the use of apps can be identified and user requirements with regard to choices of apps can be complemented.

An inductive content analysis, based on principles of grounded theory [66], will be performed on the verbatim transcriptions of the focus groups. The procedure of 'open coding', 'axial coding' and 'selective coding' will be performed to identify themes with regard to choices and use of apps of people with dementia. Based on these findings user requirements for the tool will be listed. These requirements are expected to contribute

to the selection of the best usable apps for people with dementia, attunable to their individual needs, wishes and abilities

Rationale and methods related to the design and development of a requirements-based assessment tool (question 3):

After the identification of user requirements, the tool will be designed and developed in close cooperation with the users and other important stakeholders such as formal carers and experts (designers, developers and researchers) to ensure its user-friendliness. Inspired by the work of [67,68,69] three iterations will take place whereby the users will be invited in several rounds to test whether the prototypes match with their expectations.

First, focus group sessions with people with cognitive decline, MCI and mild dementia and sessions with informal carers and sessions with formal carers will take place. Mock-ups will be created and discussed with the users and the first prototype will be refined.[67] Secondly, based on the feedback of the mock-ups, the first interactive prototype will be built and tested in a cognitive walkthrough session with experts (designers, developers and researchers).[67,69] The participants will test the tool and perform tasks in a think aloud session [70] to identify potential usability problems.[67,69] Third, based on the results of the cognitive walkthrough, we will test the usability with an adapted prototype aiming at a further refinement of the tool and to make the tool ready to use it in the next phase (modeling) of the study. The quality of the tool will be assessed with the help of Three-Step Test-Interviews (TSTI) first with people with cognitive decline and MCI and later on with people with mild dementia and interviews with informal and formal carers. The TSTI consists of three steps: respondent-driven, observation of response behavior including 'say aloud what you think'; interviewer-driven, retrieval of additional data by follow-up probing aimed at remedying gaps in observational data and validation by interviewer-driven debriefing aimed at eliciting experiences and opinions.[70]

During the three iterations a deductive content analysis, based on the framework analysis [71], will be performed on the verbatim transcriptions of the focus groups sessions, the cognitive walkthrough session and the interviews. Main themes will be identified with regard to three quality levels of the design: system quality (user-friendly and safe), content quality (understandable and meaningful) and service quality (adequately).[67]

Rationale and research methods related to the training and coaching interventions (question 4):

After the selection of usable apps, people with dementia will be taught to use the tablet and apps. Training or coaching interventions are defined as: any strategy or rehabilitation technique that stimulates the procedural (implicit) memory and that explicitly targets the use of the tablet and its applications by individuals with dementia. Progress has been made in the field of successful training or coaching interventions for people with dementia, for example: Errorless (EL) learning, Errorful (EF) learning, Space Retrieval Training (SRT)

and Method of Vanishing Cues (MVC).[72] However, the findings of previous reviews on cognitive interventions for people with dementia [73-75] provide insufficient information to determine what training or coaching intervention(s) is/are most effective for people with dementia to learn how to use the tablet and its applications. Most reviews concentrate on *cognitive stimulation* in general which aims to improve cognition, behavior and quality of life, and on *cognitive training* which aims to improve the performance on specific cognitive tasks.[72] However, from the perspective of developing a training or coaching intervention, we are particularly interested in how to teach people with dementia new skills rather than to improve their cognitive performance. Kessels & Joosten-Weyn Banningh (2008) describe that new skills can be taught to people with dementia via their implicit memory.[76] Our research question therefore better fits the scope of *cognitive rehabilitation*.[72] Within this concept, individually designed compensatory interventions are aimed at addressing specific practical difficulties with daily activities, identified by the person with dementia and/or the family carer, that are relevant to everyday life and are related in some way to cognitive impairment. The overall aim is to support aspects of everyday functioning and well-being by compensating for disabilities.[72] Teaching people with dementia to use the tablet and its applications by means of a person-centred program is in line with the rehabilitation concept.

It is necessary to investigate what training or coaching intervention(s) is/are most effective to support the procedural (implicit) memory in learning new skills. A systematic literature review will be conducted to explore the effectiveness of such training or coaching interventions. A systematic search of the literature will be performed in the electronic databases PubMed, PsycINFO, and Cinahl. An independent assessment of the methodological quality of the included articles based on appropriate guidelines [77] will be performed by two researchers. How to summarize the results depends on the variation of the included studies. A quantitative analysis (statistical pooling of results) is possible depending on the level of homogeneity. If there is too much variation a qualitative analysis can be conducted. In any case the most important characteristics of the studies will be described including: the authors of the study; the aim of the study; characteristics of the population; research method and the outcome (primary and secondary outcome parameters and follow-up time).

This phase will result in a theoretical framework for the person-centred tablet program and its sequential steps. The program as a whole will be described and this will result in a digital practical manual/ guide for person-centred use of the tablet and its apps. This forms the basis for the next phase.

Methods of modeling phase (phase I)

The aim of this phase is to evaluate the content, usability and feasibility of the person-centred tablet program in the 'real life setting'. The following research questions are addressed in this phase:

1. What are the experiences of people with dementia and their carers with the content of the person-centred tablet program (successful components)?
2. How do people with dementia and carers appreciate the usability of the person-centred tablet program?
3. Is the person-centred tablet program feasible in practice?

A pilot with case studies will be conducted in a 'real life setting' with the objective of comparing cases of participants with mild dementia *(n=5)* to gain insight into the experiences with the content of the program, and to identify, based on these experiences, the most important and successful components of the program; the usability of the program; and the feasibility of the program. With regard to the feasibility of the program it is important to explore the facilitating and impeding factors in the execution of the program: what works/does not work in practice (practical applicability). We furthermore want to gain knowledge about any important adaptations necessary to make the program fit for different contexts and to explore the mechanism of how the program brings change.[78]

For this study, primarily qualitative research methods will be used, as most of the research questions require an in-depth understanding. Various data sources: documents, interviews, (participant) observation of behavior of people with mild dementia and their carers will be used to get this in-depth understanding of the situation/context. The case-study method is used to understand complex social phenomena influencing the usability of the program and will allow the researchers to observe the holistic meaningful characteristics of real-life events, such as the context in which behaviors take place.[79] The case studies will be divided into three phases[37]: (i) the situation before the start of using the person-centred tablet program; (ii) the process of using the person-centred tablet program; (iii) the situation at the end of the intervention.

In addition, quantitative research methods will be used to get additional information from the cases, such as: background characteristics (like age, gender, type and stage of dementia, tablet experience), context characteristics (living alone or together, support from informal carers) and user behavior characteristics in relation to the intervention (amount of time interacting with the tablet and its apps, amount of time needing support by carers, kind of apps used). This information is necessary to gain insight into the characteristics of the research population and the way they use the tablet, and to take these characteristics into account in the next phase of the MRC framework: the exploratory trial. Furthermore, the Use questionnaire [42] will be used to collect additional quantitative data about the usability of the person-centred tablet program. This questionnaire consists of four topics regarding usefulness, ease of use (user-friendliness), ease of learning and satisfaction.[42]

An inductive content analysis, based on principles of grounded theory[66], will be performed to identify successful components, usability and feasibility of the program. Characteristics of the study population and data about the usability of the program will be analyzed by means of descriptive statistics (means and standard deviations for interval

variables, and numbers and percentages for nominal and ordinal data).
The outcomes of this phase are used to refine the person-centred tablet program and identify the most important and successful components of the program. Furthermore, the conditions that have to be met for adequate application of the program and the practical difficulties/consequences of the program will become evident. All together this will provide insight into the feasibility of the program. A higher feasibility will contribute to more treatment fidelity in case the program effectiveness is tested in an RCT[80] Low treatment fidelity (or implementation error) refers to the circumstance that the application of the intervention differs considerably from the original plan. This is a serious threat to the validity of the study when investigating the effectiveness of psychosocial interventions for people with dementia.[80]

Methods of Exploratory trial (phase II)

The aim of this phase is to determine the primary and secondary outcome parameters and the instruments to measure these outcome parameters, as well as to test the feasibility of the intervention and the research design for a future RCT. The following research questions will be addressed in this phase:

1. Which primary and secondary outcome parameters are suitable to measure the effect of the person-centred tablet program and which measuring instruments are suitable to measure the selected primary and secondary outcome parameters?
2. What is the feasibility of the person-centred tablet program and what factors can potentially influence the effect and implementation of the program from the perspective of the client (background, context and user behavior characteristics of the intervention), carers (adherence, treatment fidelity) and organization prerequisites (shared vision, readiness for change, financial aspects).
3. Is the research design for the RCT feasible with regard to: the recruitment of respondents, inclusion criteria, the burden on the participants (in relation to the number of measuring instruments, duration of the tests), 'sensitivity to change' of the instruments for this target group, the expected size of effects of this program, the identification of potential subgroups for subgroup-analysis in the RCT, etc.?

In the exploratory randomized trial, the person-centred tablet program will be offered to people with mild dementia *(n=12)* and their carers *(n=12)* to test the feasibility of the program and to collect practical information which can be applied in a future RCT in phase III. In addition, a control group will be used which will be offered care as usual. In this phase a combination of quantitative and qualitative research methods will be used.
Based on the knowledge gathered in the preceding phases and on an additional literature search with regard to relevant measuring instruments, the primary and secondary outcome parameters and measuring instruments will be selected for the effect study. Obviously, instruments specifically applicable for this target group will be used in this phase. Potential primary outcome parameters for people with dementia are sense of self-

efficacy, self-confidence, self-management ability, engagement in meaningful activities, and participation in daily and social activities. Potential secondary outcome parameters are quality of life of people with dementia and their carers and sense of competence of informal carers.

The results from the theoretical and modeling phase will both provide information about the amount of time required to demonstrate effects of the intervention. Three assessments of participants are planned, at baseline (T0), directly after the program has been offered (T1), and at follow-up (T2) (time depends on information from theoretical and modeling phase). MMSE [49] will be administered at baseline to measure the severity of cognitive impairment.

Information will be collected with regard to: available number of eligible participants, willingness of participants to participate and cooperation of professionals to identify and recruit participants, drop-out rates and compliance with the intervention and completion of questionnaires, standard deviation of change in the outcome measures and effect sizes which can be used in the power calculation of the RCT, time investment of participants, time needed to collect and analyze the data.

Alongside this pilot-testing of the research design a qualitative process evaluation will be performed. Interviews with people with mild dementia and their carers will take place aiming to determine factors that may influence the effect of the program on the client, carer and organization level. This information will be useful to gain insight into important additional preconditions when performing an RCT.

1. gain insight into possible barriers and facilitators for implementation.
2. gain insight into the feasibility of the tailor-made program.
3. gain insight into the context of the intervention and how this may influence the implementation and the intervention effect.

To guarantee the internal validity, we will analyze the process data before analyzing the effects.[81] A deductive content analysis, based on the framework analysis.[71] will be performed to analyze the findings from the process evaluation, as we are particularly interested in the above-mentioned topics. Baseline characteristics of the participants will be analyzed by means of descriptive statistics (percentages for nominal variables and means and standard deviations for interval variables). To test the differences between the groups on the outcome measures, depending on whether the data meet the assumption of a normal distribution, either analysis of covariance (ANCOVA) or a Mann-Whitney U test will be conducted.

The results of this exploratory trial phase are selection of the primary and secondary outcome parameters and measuring instruments, a description of the intervention and prerequisites for implementation, and the research design for a definite RCT.

Discussion and conclusion

It is generally assumed that people with dementia are not capable, or will have much difficulty, learning how to use new technologies, because they are complicated to operate and especially older people will not have been familiar with them before the onset of dementia.[82,83] Several studies conducted in the last decade, however, showed that people with mild dementia are able to learn how to use everyday technologies and new technologies, such as smartphones and a digital organizer.[84-86] Smith and Mountain (2012) argue that when people with dementia integrate the use of tablets in their daily lives, this will help focus on intact abilities instead of the constant attention to deficits, and this may also counteract the stigmatization of people with dementia regarding their incapacity to use technology and ICT.[33]

The deployment of tablets for the use in everyday life is increasing among older people to approximately 56% of the total elderly population.[87] As in several other European countries, the Dutch government further stimulates this development through the implementation of eHealth services.[12] For example, health and social care organizations in some cases offer tablets to their customers to promote eHealth services in practice e.g. care at a distance. Hence, in line with these developments, the number of people with mild dementia who use, or are willing to learn how to use, the tablet and its apps can also be expected to increase, especially because it may offer the potential to engage in enjoyable social and leisure time activities, enabling feelings of inclusivity.[33]

We will develop a person-centred tablet program to support people with mild dementia in the effective use of the tablet for self-management and meaningful activities. Our expectation is that it can improve, among other things, the self-management ability, engagement in meaningful activities and the quality of life of people with dementia (and their carers). Because of the complex nature of this new intervention we will develop and evaluate the feasibility of this program according to the MRC framework for complex interventions. The iterative process of this framework, in especially the first three phases, will make it possible to constantly optimize the person-centred tablet program according to the needs of users and its practical feasibility, and this will contribute to a tailored and easy-to-implement intervention. In addition, this study will prepare for a methodologically sound RCT to be conducted after this study.[43,44]

To date, systematic research regarding technological applications for people with dementia is very limited. The majority of the studies included small samples, and focused primarily on development rather than evaluation.[19,20,23,27-30] Large-scale studies and RCTs, preferably in 'real-life settings', are necessary to stimulate the further development and use of touch screen technology for people with dementia. We therefore plan to conduct an RCT after the present modeling and exploratory study in order to investigate the effectiveness of the intervention. This will contribute to the further acceptance and dissemination of touch screen technology among this target group.

It is important to take into account some potential threats while performing the development and feasibility study. First, the current availability of sufficient apps for meaningful activities and self-management that match the individual needs, wishes and abilities of people with dementia may be limited. Although an explorative search of the current supply resulted in enough variation of apps in several areas of self-management and meaningful activities, the extent to which these apps are usable will depend on the person's cognitive deficits. On the other hand, there is a growing number of projects that may result in the identification and development of usable apps for people with dementia. For example, the project In Touch [22] which focuses on the identification and development of happy games for people with dementia (see www.actodementia.com), and the project Memory apps for dementia, in association with the University of Worcester, and Alive which also inventoried usable apps for people with dementia (see http://memoryappsfordementia.org.uk/).[17]

A second potential risk is that independent use of the tablet may be difficult for people with dementia and consequently may lead to new demands placed on their informal and professional carers (e.g. those working in day care centers or meeting centers for people with dementia and their carers). This could increase their burden instead of relieving it. The iterative process of the MRC framework and the involvement of users in all phases of development will allow us to identify such consequences at an early stage and to find practical solutions.

Third, investigating the conditions for performing an RCT after this project requires that several methodological threats are taken into account: insufficient recruitment of people with dementia in the experimental and control group may result in insufficient statistical power to test differences between groups; and the burden as a result of participating in the research may be a motive to withdraw from the study or result in low treatment fidelity. To prevent recruitment problems, preparatory actions are required to identify health and social care organizations that already use this kind of eHealth services for their clients in practice. Also, optimal transfer of knowledge about the new person-centred tablet program is essential. Actions to decrease the burden for participants and to increase treatment fidelity will be explored in the modeling and the exploratory trial phases of our study by means of process analysis. The identification of practical difficulties in these phases will help to design the evaluation study and to develop a dedicated user-oriented implementation strategy.[80] The importance of 'hand in hand' technological development and implementation strategies is also acknowledged by[15] who developed a memory application to support the independence of clients with dementia or intellectual disabilities.

Finally, tailoring the intervention to needs, wishes and abilities of individual clients, which is the core of a person-centred approach, may threaten the standard conditions for testing an intervention in an RCT. To gain insight into the effects of the intervention in subgroups that differ on background, context characteristics and user behavior characteristics,

subgroup-analyses will be performed. Which subgroup-analyses may be appropriate will be determined in the exploratory trial.

By developing the person-centred tablet program in a user-centered and iterative way, taking into account the existing theoretical knowledge, and by testing its feasibility in practice, we expect to deliver a well-defined intervention to promote the use of apps for self-management and meaningful activities by people with dementia. When proven effective in the RCT, this person-centred tablet program can be implemented as a new service in dementia care.

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Chapter 3

User needs studies: identifying user requirements for apps enabling meaningful activities and self-management

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Abstract

Background

Touchscreen devices (e.g. tablets) can be supportive for people with mild dementia. This study identified user requirements for the development of a tool for selecting usable apps in the domains of self-management and meaningful activities.

Method

Eight focus groups with people with MCI or mild dementia and informal carers were conducted using an exploratory study design. In study one we identified meaningful activities and self-management support. In study two we explored needs, wishes, and abilities regarding the use of apps. The outcomes were analyzed using inductive content analysis based on grounded theory.

Results

Three categories were identified in study one:

1. Past meaningful activities;
2. Present meaningful activities; and
3. Self-management support.

Two categories emerged from the data of study two, with two and three themes respectively.

1. Needs and wishes of users with regard to (a) the functionality of apps and (b) technical features of apps.
2. Abilities of users in terms of (a) physical and cognitive condition; (b) independent use of apps on a tablet; and (c) skills to use the touchscreen and tablet.

Discussion and conclusion

Based on these results we will develop filters for people with mild dementia to select apps which match their individual needs, wishes and abilities.

Introduction

In 2013, 44 million people worldwide were living with dementia. This number is expected to rise to 76 million by 2030 and as high as 135 million by 2050.[1] In the early stages of the disease people experience insufficient support from professionals and health care services to stimulate self-management abilities.[2] Interventions for coping with the disease after confirmation of diagnosis are rare and there is still a focus on medical treatment instead of adopting a holistic view of the person and their needs.[3] Furthermore, people with dementia and their informal carers reported a lack of meaningful activities to carry out during the day.[4-7] This can be stressful for the person with dementia as well as for their informal carers. Approximately 50% of informal carers in the Netherlands are highly burdened and 3% of the informal carers are overburdened.[8] High burden of carers frequently results in admission of the person with dementia to a long-term care facility.[9] Nevertheless, driven by limited financial resources, the current policy of Western countries is to enable people with dementia to live in their own home as long as possible.[10] This is also in line with the new concept of social health which is described as a) the ability to fulfil one's potential and obligations, b) the ability to manage life with some degree of independence, and c) participation in social activities.[11] However, for people living with dementia to maintain social health it will be essential to create opportunities that enable them to manage their life and engage in meaningful activities, and to relieve the burden of their informal carers. Self-management in the context of dementia refers to dealing with, and adapting to the consequences caused by the disease, and maintaining a good quality of life.[12,13] To support self-management the challenge is therefore to focus on promoting meaningful positive experiences [2] by means of engaging people with dementia in meaningful activities, which are often still possible through stimulating the use of remaining capacities and compensating for deficits.[14-16] Meaningful activities have a specific value for individual persons and can be all types of daily activities in the areas of self-management*, household or leisure activities.[18]

Long-term care investments are being made in new types of health and social care services, such as eHealth. eHealth is defined as: 'the use of new information and communication technologies (ICT), especially Internet technology, to support or improve health and health care'.[19] It is expected that eHealth can support self-management and will therefore influence health care costs.[20] New applications (apps) in the field of health and social care are becoming available daily.[21] Apps are software applications specifically developed for use on smartphones or tablets. The latter have recently been introduced in health and social care organisations because they offer a good interface for eHealth purposes, e.g. care at a distance. Based on the first positive results with the use of tablets in health care.[22] organisations are exploring whether specific target groups, such

** Areas/ targets of self-management are: (1) relationship with family/ friends/ carer; (2) maintaining an active lifestyle; (3) psychological wellbeing; (4) techniques to cope with memory change and (5) information about dementia.[17]*

as people with dementia, could benefit from some apps on tablets and how to assist them in an effective usage of tablets. Although people with dementia will need support to learn how to use the touchscreen and apps [23-29], several mainly qualitative studies have shown that those who used the tablet and its apps evaluated it as user-friendly and valuable.[24-38] The tablet and its apps may therefore be promising tools in supporting self-management activities.[21,24] and engaging in meaningful activities [26,39] in the early stages of the disease.

The wide variety of available apps for a general audience combined with the limited availability of apps specifically developed for people with dementia means that careful consideration is required to select usable apps for people with dementia.[39] Usability refers to the extent to which an app is useful, user-friendly, easy to learn, and satisfying.[40] Introducing tablets for people with dementia is a new development and although some requirements for usable apps are described (see appendix I), there is no useful tool for selecting usable apps for individuals.

In the present study user requirements were identified, by having people with mild dementia and informal carers [41-44] fulfil the roles of informants and advisors.[45] User requirements can be viewed as the result of user studies [46] and in this study are defined as individual needs, wishes and abilities of people with dementia regarding functional and technical aspects of apps. In the near future, a requirements-based assessment tool for selecting usable apps in the domains of self-management and meaningful activities for people with dementia will be designed based on these user requirements. This tool will be developed as part of a person-centred program to help people with mild dementia and their carers effectively use tablets.[47] The tool aims to match important features of apps (system requirements) to individual needs, wishes and abilities of people with dementia (user requirements), also called sets of user and system requirements (filters), so that customized apps can be selected (see Figure 3.1). This tool will contribute to the inclusion of people with dementia so that they have access to the wide variety and dynamic supply of apps in a user-friendly manner.

The main question addressed in this study was:

What do people with dementia find important in their choice and use of apps?

To answer this question we formulated three subquestions:

1. What kind of self-management and meaningful activities are important to people with dementia from the perspectives of people with mild dementia and carers?
2. What are the needs, wishes and abilities of people with dementia regarding the use of apps from the perspectives of people with mild dementia and carers?
3. What user requirements can be identified based on these perceptions?

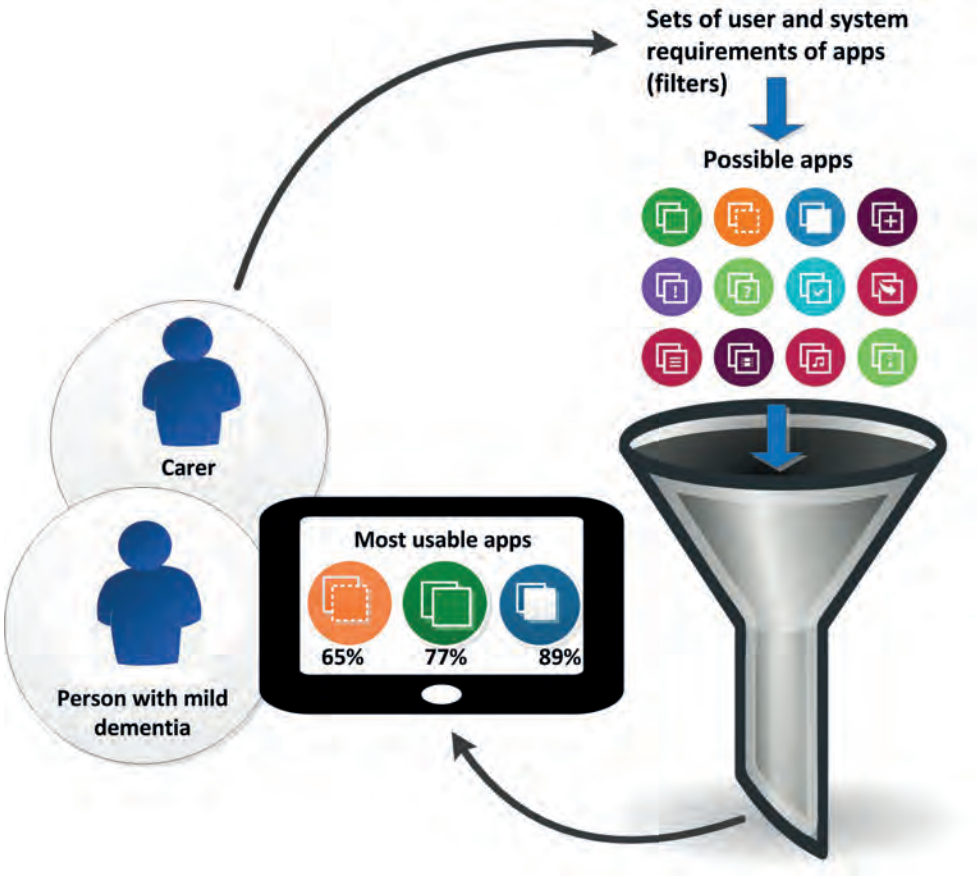


Figure 3.1 Requirements-based assessment tool

Methods

Research design

To identify the user requirements for apps for people with mild dementia a qualitative exploratory study was performed. An exploratory study design was used to gain an in-depth understanding of people's needs and wishes, and their ability to fulfil these needs and wishes.[41-44]

To ensure an adequate identification of desired activities in the context of self-management and meaningful activities we conducted two focus groups with people with mild dementia and two focus groups with informal carers in study one (subquestion 1). In study two, two focus group sessions with people with mild dementia and two focus group sessions with informal carers were held to explore the needs, wishes and abilities regarding the use of apps (subquestion 2). As a result, user requirements were listed (subquestion 3).

Setting and participants

Participants for the focus groups were recruited with help of two meeting centres located in the West and the East of the Netherlands, the Dutch Alzheimer Association and a care organisation in the East of the country that delivers community care. Inclusion criteria for people with dementia were: care-dependent people with cognitive impairments with and without a confirmed diagnosis of mild dementia. Inclusion criteria for the informal carer were: caring for a person with MCI or early dementia. In addition, participants had to be willing and able to participate actively in the focus groups, and for the focus-group sessions with regard to subquestion 2 participants were selected that according to themselves and professional carers of persons with dementia had at least some experience with the use of a tablet or smartphone and its apps.

The recruitment of the participants appeared challenging because most of the referred potential participants lacked experience with the use of tablets. We therefore consulted a care organisation that offered tablets to their customers to promote eHealth services in practice. Participants recruited via this care organisation met all criteria and most of them visited a day care centre for people with dementia or a support group for informal carers of people with young-onset dementia. The recruited people with dementia and the informal carers were not related, with the exception of one dyad.

In study one eight people with dementia and ten informal carers participated in four focus groups. In study two, the same five people with dementia participated in the first and second focus group sessions. Five informal carers participated in the first focus group session and three of them also participated in the second session. Two informal carers withdrew from participation in the second session because of illness.

Qualitative methods and study procedure

Study one

To gain insight into the target group's relevant self-management activities and other meaningful activities, the methodology of the Occupational History Performance Interview (OPHI-II-NL) was applied.[18,48] The OPHI-II-NL is a narrative person-centred interview based on the Model of Human Occupation [16] that focuses on the identification of meaningful activities and the experiences of a person with these activities in the past and the present, and what this means for the future. Focus groups with people with mild dementia and focus groups with informal carers were conducted, using a topic list based on the OPHI-II-NL interview.[18,48,49] Examples of questions asked in the focus groups were: What kind of activities were/are important for you in the past/present; what kind of activities makes you feel good; what kind of activities are important to do independently and what impeded you in performing these activities?

The focus groups were voice recorded.

Study two

Two focus group sessions were organized, seperated by two weeks. They were conducted to explore the needs, wishes and abilities of people with dementia regarding the use of apps. To avoid embarrassment due to memory problems, participants were asked to bring the tablet they normally used (own tablet or tablet of the day care centre) to capture experiences while using different kind of apps. The aim of the first session was to gain insight into the current use and types of apps, the choices made in selecting certain kind of apps, and the experiences of participants with the apps selected in advance by the researchers (Wordsearch Deluxe, WordBreaker, and a Dutch history app). In the second session the aim was to gain a more profound understanding of the experiences with the selected apps, the apps used normally, and with a newly introduced app (Dutch television app). Between the first session and the second session participants were asked to keep a diary of their experiences (advantages and disadvantages) with the selected apps and the apps they used normally. People with dementia were stimulated by an activity therapist working at the day care centre to use the tablet and the selected apps and received help from this person. The focus groups were guided by two researchers, a primary interviewer and an observer; the latter was responsible for reporting the focus group observations. Again we used a topic list, and examples of questions asked in the focus group sessions were: what kind of apps are you currently using; what do you like/dislike of the app; what is your first reaction when you see this app; is the purpose of the app clear to you, can you tell us why (not)?

The focus-group sessions were video-taped to capture the full context of the focus groups sessions, in particular the non-verbal communications and interactions of people with dementia while they were using the tablet and apps.[50]

Ethical considerations

The Medical Ethics Committee of the VU University Medical Centre in Amsterdam approved the study protocol. Prior to participation in the focus groups all participants signed an informed consent form after receiving written and oral information about the research. During the sessions with persons with dementia we performed on-going consent by regularly asking them if they still were comfortable with the procedure (51). We created a safe environment by spending time getting to know the people, giving them positive feedback, emphasizing the importance of their participation, recognizing signs of discomfort (51), and through the use of a written time schedule (A3 paper size) that allowed participants to see what was going to happen at any given time.

Data analysis

The focus groups were all transcribed verbatim. Overall, four types of data were collected and used for the analysis:

1. participant characteristics and tablet/smartphone experience;
2. transcripts of the focus groups;
3. observed behaviour of participants during the focus groups reported in notes;
4. advantages and disadvantages of used apps noted in a diary (study two).

The focus groups data were analysed using inductive content analysis based on the principles of grounded theory.[52] In this approach focus group observations and notes are also part of the analysis to capture the total context and to ensure an in-depth understanding of users' needs, wishes and abilities.[51] The procedure of 'open coding', 'axial coding' and 'selective coding' was performed to identify themes. ATLAS.ti, a software program for qualitative analysis, was used to support the further analysis. Two researchers coded the focus groups data independently (average inter-rater reliability 79% for the last focus groups we coded) and any discrepancies in coding were discussed until consensus was reached (YK and AB). The interpretation of the findings during the procedure of coding and the reporting of this qualitative study was critically discussed by four researchers (YK, AB, MG, RMD) of the research team.

To provide an in-depth understanding of the results quotes of participants were included and, to ensure confidentiality and anonymous presentation of the data, all participants were given a number (1-10 study one; 1-5 study two) with a letter to identify whether they were a person with dementia (PwD) or an informal carer (IC). It was not possible to include all the data generated from the focus groups in this paper; extracts were selected to illustrate the main content of the data based on what was most illustrative for the themes and also acknowledging the diversity of the participants.

Results

Identification of meaningful and self-management activities (study one)

For participant characteristics see Table 3.1a and Table 3.1b. The emergent coding strategy we used in the analysis of the transcripts and focus group notes resulted in categories that could be used to answer our research questions and we therefore grouped them into three categories.

1. Past meaningful activities;
2. Present meaningful activities;
3. Self-management support.

The categories were described based on different themes and subthemes. Next, user requirements were listed, see Table 3.3. This table gives an overview of categories, themes and subthemes that emerged from the different studies and user groups.

Table 3.1a Characteristics of persons with dementia (PwD)

Characteristics	PwD 1	PwD 2	PwD 3	PwD 4	PwD 5	PwD 6	PwD 7	PwD 8
Gender	male	male	male	female	female	male	male	male
Age	71	72	60	77	82	79	80	80
Marital status	married	married	married	divorced	married	married	married	married
Education	second. school	college	universi. graduate	primary school	second. school	second. school	second. school	second. school
Living situation	at home	at home	at home	at home	at home	at home	at home	at home
Health status	MCI	LB	AD	AD	AD	VD	LB	VD/AD
Tablet/PC experience	yes	yes	yes	no	no	no	no	no
Current use of apps	Solitaire, Word search, Safari, news, dice match.	Google	Google	-	-	-	-	-

MCI: Mild cognitive impairment; LB: Lewy Body Dementia; AD: Alzheimer disease; VD: Vascular dementia

Table 3.1b Characteristics of informal carers (IC)

Characterist.	IC 1	IC 2	IC 3	IC 4	IC 5	IC 6	IC 7	IC 8	IC 9	IC 10
Gender	male	female	female	female	male	female	male	female	female	male
Age	68	77	76	70	79	65	68	62	70	68
Type IC	spouse	spouse	spouse	spouse	spouse	spouse	partner	spouse	spouse	spouse
Marit. status	married	married	married	married	married	married	male partner	married	married	married
Education	second. school	primary school	primary school	college	second. school	second. school	univer. gradu.	second. school	second. school	college
Living situation spouse	home	home	home	home	home	home	home	home	home	home
Health status spouse	VD	AD	suspect. dementia	AD	AD	AD	FD	FD	LB	FD
Tablet/PC experience	yes	no	no	yes	yes	yes	yes	yes	yes	yes
Current use of apps partner	Sudoku Wordfeud			You tube					You tube	Photos, Safari

VD: Vascular dementia; AD: Alzheimer disease; FD: Frontotemporal Dementia; LB: Lewy Body Dementia

Past meaningful activities

A variety of meaningful activities in the past were mentioned by persons with dementia and informal carers. However, the most mentioned activities were reading books, practising sports, being creative and being socially active. 'Fascination' and 'to get informed' were important motives for reading books in the past. Informal carers mentioned that deficits in reasoning, empathising, imagining and giving meaning to the content were important reasons why the persons with dementia no longer read books.

"My wife she doesn't see cause and effect. When she does something that I am not pleased about and I tell her with a normal facial expression not to do that, it doesn't register. And with a book you have to be able to get into the story and this ability is completely gone. She used to read a lot, but the empathy is gone.(...). She is still sensitive to feelings, for example when I am angry and I show her that I am angry. So words do not make an impression anymore, but feelings do" (IC5).

A variety of sports were practised in the past by mostly male (eight) persons with dementia. The most frequently mentioned sports were football and bicycle racing. Important motives for participating in sports were related to the drive to win and to be socially active.

"He always went cycling with a group of friends, which was a hobby of his. He liked the combination of being active and being in the company of his friends" (IC8).

In contrast to male participants, most female (three) persons with dementia participated in creative activities such as hand-knitting, dressmaking, making jewellery and drawing. Important motives for these activities were admiration and beautiful looks.

"When I was young we were with six girls and we went dancing when we were eighteen and it was important for me to look nice and do something different. That's why I took some sewing lessons, I made dresses for myself and my sisters. I liked doing that because then I had a new dress when I went dancing" (PwD5).

Being socially active was an important motive for performing several meaningful activities in the past, but it was also an activity which in itself was perceived as meaningful, for example family meetings.

Present meaningful activities

Although a diversity of meaningful activities in the present were mentioned by persons with dementia and informal carers, most cited were socially active, listening to music, experiencing and being in nature, and watching TV. Persons with dementia found regular contact with their children and having a good relationship with them important. Furthermore, they liked to be surrounded by family members, especially their spouse, children and grandchildren. Persons with dementia who visited the meeting centres viewed their fellow visitors as a new circle of friends with whom they could share their problems, chat, and undertake all kinds of other meaningful activities, such as going out for a walk, playing shuffleboard, handcrafting, and looking at photo's of the past.

"My son arranged for me to come to the meeting centre and I am so glad to be here. Really. It is so nice to talk with my fellow visitors. This is important for me" (PwD7).

"Doing things together, for example when we play shuffleboard, that's what I like" (PwD5).

Although the types of music enjoyed by the persons with dementia differed, listening to music is a very pleasant meaningful activity for many of them. It contributes to peace of mind, expressing their emotions, helps to recall memories or provides a starting point for telling a story. For some informal carers YouTube on the computer or TV appeared supportive, for example, by making a customised playlist.

> *"My husband has these outbursts of anger, then he becomes restless and he wants to walk away. I happened to notice that music calms him and that he enjoyed it. Because these outbursts are getting worse I made a playlist with his favourite music in YouTube. Now when he becomes angry or restless I turn on the TV with that list of all those videos. Then he is quiet and calm for 2 hours, enjoying the music and saying how much he likes it over and over"* (IC4).

Experiencing and being in nature is a very welcome activity for many of the participants. They like to sit in the garden, walk or cycle in nature and enjoy the change of seasons or the beautiful weather.

> *"I put my bike to the side and I look around and I am amazed. Really. You see so much! Colours, scents, birds"* (PwD6).

Many persons with dementia, mostly men (five), liked to watch TV. Remarkably, this helped persons with dementia to calm down or feel at peace, while some informal carers interpreted this behaviour as apathetic.

> *"When I am sitting down I am calmer than when I am standing"* (PwD3).
>
> *"He mainly watches TV beginning at 10 am, and in the afternoon he bikes to the market. Then he comes home and watches TV again"* (IC8).

Many meaningful activities done in the past were shown to still be meaningful today. For example, career-related activities, such as a carpenter who still repairs chairs and tables or an art specialist who still likes to visit a museum. This was the same for participating in sports or other hobbies engaged in in the past. For example, some men who played football in the past liked to watch football matches, or a woman who drew a lot in the past and at present started drawing again.

> *"She was always very creative, but this is gone. For example, I had never seen here draw. Since she started visiting the meeting centre she has been drawing again. This is awesome because she had also become very apathetic, doing nothing"* (IC10).

Self-management support

Persons with dementia and informal carers mentioned many issues related to self-management. Those most mentioned were different kinds of memory support, such as remembering appointments and to take medication, to maintain a daily structure, to find the way and memory training.

"I would like to have an alarm system, when I am at home in the evening I need to take my medication at seven, but I never think of it, my wife arranges this" (PwD1).

They also share a lot of insights into how they cope with the consequences of their disease in terms of activities they can no longer do or that are problematic. Persons with dementia differ in how they feel and deal with the losses and changes dementia brings in their lives. Some find it very hard to accept that activities are not possible anymore while others are more resigned to their fate.

"Well, you have to live your life. Most preferably you do what you did in the past, but this is not always possible. You have to make choices" (PwD3).

This also depends on which kind of activity they have to say goodbye to or encounter problems with. For example, persons with communication problems found it hard to accept that they struggle to have and follow normal conversations.

"To join a conversation and to understand. She can't do that anymore" (IC1).

Others find it hard to accept that their freedom of movement decreased. This was particularly true when, for example, finding one's way or cycling becomes problematic. However, the most cited limitation experienced was losing their driver's license.

"Driving is not possible anymore, the car is gone and this makes him sad" (IC3).

*"It's like a piece of you has been removed" (*PwD6 about taking away his driver's licence)

Another important issue related to self-management mentioned by persons with dementia was that they feel it is important to maintain their autonomy and respect, for example in conversations with others who are not suffering from dementia.

"When I tell my wife something, and then she says: no, that's not right, this is what happened. You are seeing it wrong because of your illness. This really bothers me" (PwD6).

Needs of people with dementia with regard to the use of apps (study two)

For participant characteristics see Table 3.2a and Table 3.2b. Analysis of the transcripts, focus group notes and notes kept in a diary resulted in the identification of two categories and five themes.

1. Needs and wishes of users with regard to
   a. the functionality of apps and
   b. technical features of apps.

Table 3.2a Characteristics of persons with dementia (PwD)

Characteristics	PwD 1	PwD 2	PwD 3	PwD 4	PwD 5
Gender	male	male	male	male	male
Age	79	78	95	59	69
Marital status	married (to IC1)	married	widowed	married	married
Education	college	college	primary school	secondary school	secondary school
Living situation	at home	at home	at home	at home	at home
Health status	MCI	AD	CD	CD/ABI/ symptoms of dementia	MCI
Tablet experience	Yes	Yes	Yes	Yes	Yes
Frequency of use	once a week	daily	daily	rarely; participated in a previous research project with tablets	when visiting the day centre on tuesdays and thursdays
Own tablet	yes	yes	yes	no, day centre	no, day centre
Type tablet	Samsung	iPad	iPad	iPad	iPad
Current use of apps	Google, weather forecast, YouTube, (football) news	news, weather forecast, Safari	video calling, news, solitaire, weather forecast, checkers.	Word search, cut the rope, live rock kid, video calling, Google earth	Solitaire, Word search, Safari, dice match, news.

MCI: Mild cognitive impairment; AD: Alzheimer disease; CD: Cognitive decline; ABI: Acquired brain impairment.

Table 3.2b C-haracteristics of informal carers (IC)

Characteristics	IC 1	IC 2	IC 3	IC 4	IC 5
Gender	female	female	female	female	male
Age	79	39	51	60	64
Type of IC	spouse	spouse	spouse	partner	spouse
Marital status	married (to PwD1)	married	married	living together	married
Education	secondary school	secondary school	college	secondary school	university graduate
Living situation spouse	at home	at home	at home	at home	at home
Health status spouse	MCI	PPA	AD	MCI	AD
Tablet experience	yes	yes	yes	yes	yes
Frequency of use	daily	daily	once a week	daily	daily
Type tablet	iPad	iPad	Samsung	Acer	iPad
Current use of apps partner	games (Word search)	news, diaro (diary), DigiTaal (communication app)	-	Google	photos, WhatsApp, Alzheimer assistant

MCI: Mild cognitive impairment; PPA: Primary progressive aphasia; AD: Alzheimer disease;

2. Abilities of users with regard to
   a. their physical and cognitive condition;
   b. the independent use of apps on a tablet; and
   c. skills to use the touchscreen and tablet.

The five themes were described based on different subthemes. Next, user requirements were listed, see Table 3.3.

Needs and wishes of users for functionality of apps

Participants listed different apps they currently used to help persons with dementia engage in meaningful activities and encourage them in self-management activities, e.g. games apps, news and weather forecast apps, brain training and language exercise apps, apps that stimulate social contact and communication between the person with dementia and informal or formal carers, hobby apps (sport, music nature etc.) internet access apps, etc.

> *"I always go out in the afternoon, when it's not raining. Last summer, I got soaked twice, not nice. Nowadays I first check the weather forecast app on the tablet"* (PwD3).
>
> *"The speech therapist advised him to use the Diaro app. With this app you can take photographs of the activities you do in a day and type in what the activity was. Because talking is very difficult, this overview of activities stimulates the communication between us about what he does during the day"* (IC2).

The use of apps as well as the tablet in general, were of great benefit to the participants. It gave them feelings of pleasure, peace of mind, rest and recreation. In addition, the use of some apps such as news apps, apps for social contact, and apps for access to internet were found to be instructive, innovative and gave them access to the world, or provided social inclusion.

> *"The peace, so relaxed. Nothing else on your mind, only focusing on the solitaire app. Others can ask me something but I don't even hear them"* (PwD5).
>
> *"Well, I don't have to look at the newspaper, with this tablet I have access to the whole world. Everything I want to know I can look for and I manage reasonably well"* (PwD2).

Participants indicated that they prefered using apps that match their personal interests, hobbies and working life. For example, while using the Dutch history app or word search app, persons with dementia looked for recognizable historical information or puzzle categories that connected with their personal interests.

> *"The first railroad, interesting! I used to volunteer at the railway museum"* (PwD1).
>
> *"She dislikes playing games, so she is never going to play the word search apps"* (IC4).

Some persons with dementia were used to playing games on the tablet. They liked the competition to improve themselves or to beat the opponent. In some cases, persons with dementia chose apps for games that were to them in the past familiar (the non-digital version) out of personal interest, but also because they were more familiar with the operation of the app.

"I used to play a lot of checkers competitions with my brother. I had not played it for thirty years and now I have started again, so nice!" (PwD3).

During the focus groups we introduced new apps. Although these were not always consistent with their personal interests, participants were nevertheless enthusiastic about the functionalities of some of these apps.

"And now the Dutch television app is also on the tablet. It's such a wonderful tool, fantastic!" (PwD2).

Additional needs and wishes for special functionalities of apps were indirectly mentioned by some participants, such as the need for apps supporting daily structure and apps that remind them to take their medication.

Needs and wishes of users for technical features of apps

Participants encountered several problems in navigating the apps. The function of buttons within apps was not always clear because symbols used for the buttons were not recognizable. Sometimes navigation buttons were not big enough or missing. For example, a clear home key was not always available. Informal carers stated that this was particular so in apps built for Android. Users of these apps must use the arrow on the tablet, next to home button, to get back. According to informal carers persons with dementia find this difficult to get used. It is preferable to have a clear home key in the app. Participants also indicated that the sensitivity of the touchscreen and the use of too many links and pages within apps compromises the comfort of navigation. These issues resulted in persons with dementia having difficulty understanding the operation of some apps and getting lost in the navigation menu, the settings of apps, or visiting pages within the app and not knowing what to do there.

"Look can I make this bigger?" (PwD1).

"PwD1 felt the letters of the Dutch History app where too small. Didn't understand the function of the button to enlarge letters, in the top right corner. Experimented with different buttons, the assignments button and links to additional information. This took him to irrelevant pages outside the app" (Observation researcher) (see Figure 3.2).

"The slightest touch takes you somewhere, and you think, o dear, what am I doing here" (PwD2).

"PwD2 didn't understand the function (purpose) of the Word breaker app (similar

to 'Lingo', the Dutch word game on television). Doesn't know what to do with the letters in different colours. It might be helpful if the letters were in the same colours as the game on television. Navigation buttons were missing and he was lost in the app's navigation menu" (Observation researcher) (see Figure 3.3).

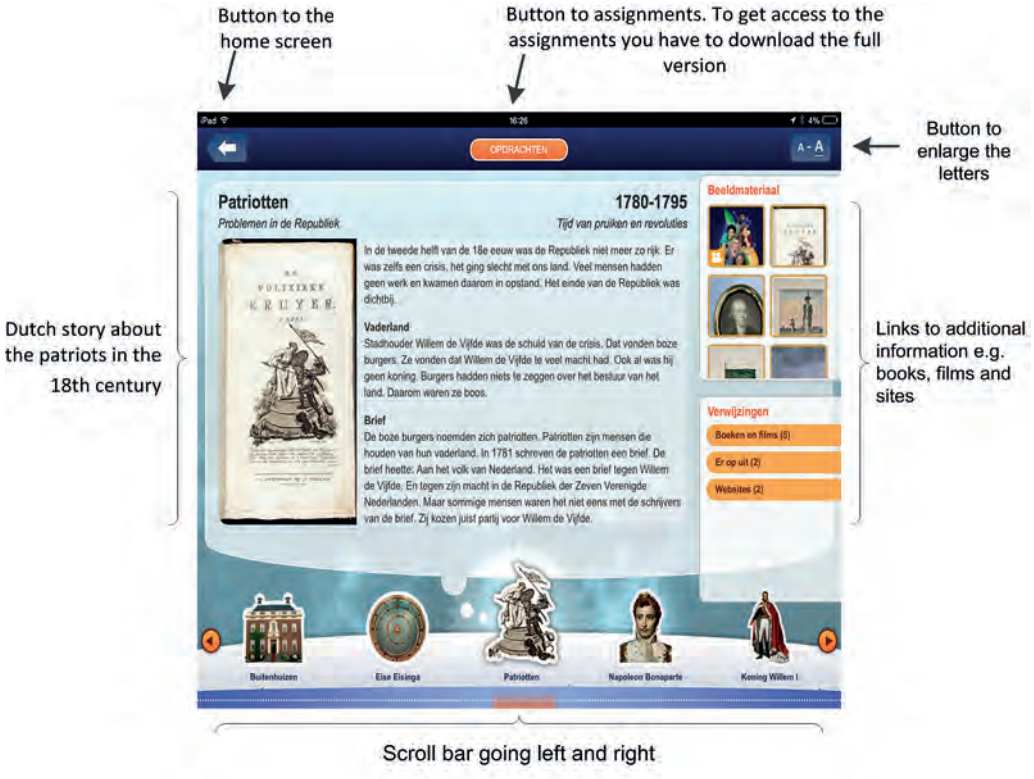
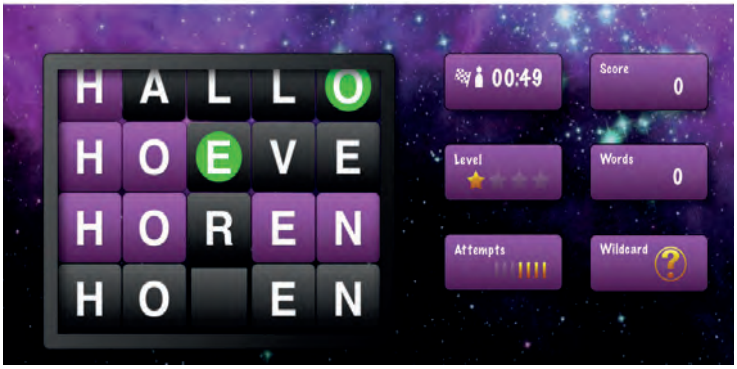


Figure 3.2 Dutch history app (en Toen Lite), ©Stichting entoen.nu.

"I was playing the word search app and when you want to go back, you have to push the pause button, I thought this was not a very clear symbol for going back. And then it might be that PwD press the advertsising pop-up window thinking that this is the button to go back" (IC2) (see Figure 3.4).

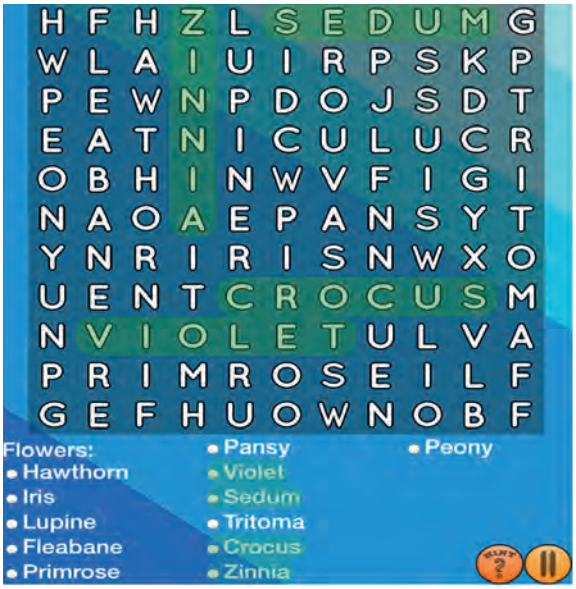
Other disadvantages impeding easy navigation were the pop-up windows used for advertising, the use of links in apps to other sites, and being asked to buy the full version of an app in cases when a light version was used. This was confusing for persons with dementia because they did not know what to do or got lost in different pages not knowing how to get back to the app they were using. In addition, updates of apps also confused them because they were used to a certain operation of apps.

Letters in purple are in the right position and letters in green belong to the word but are not in the right position.



By pressing the 'Wildcard' button a new letter of the word becomes visible.

Figure 3.3 WordBreaker HD, ©Douze Dix.



By pressing the 'Hint' button (bottom right) the first letter of a new word becomes visible.

By pressing the "||" button next to it, one goes back to the home screen.

Figure 3.4 Wordsearch Deluxe HD, ©2012-2017 Akarus.

"Previously you could see the history of sites you were visiting and then you could touch it to go back to the site, but this is gone now" (PwD5).
"Look that's strange. The competition between companies right now. I think this is horrible!" (about advertisements in apps) (PwD2).

Additional features which may improve the comfort in navigating the apps for persons with dementia indicated by informal carers were: minimize the need for scrolling, provide an easy and intuitive use, minimize the use of too many screens and clicks, present clear instructions on a step-by-step basis and use recognizable buttons supported by pictograms and text.

"The beginning of the app is important, that you instantly see what you need to do when you press the icon of the app" (IC3).

Participants mentioned many lay-out features that make apps attractive to use e.g. the use of clear pictures and photos, readable fonts, type faces and sizes, a calm interface and background, contrast between text and background, etc.

"It is nice that you can see which words are done at the bottom; in the newspaper you normally cross out the words you have found but then you can't see what you have crossed out" (PwD4).
"PwD4 was also crossing out the words he found on the tablet with his finger, maybe he was used to doing so. But the colours used in this app (blue and yellow) didn't provide a clear contrast" (Observation researcher) (see Figure 3.4).
"The world comes alive again when she sees photos. For example, I take a lot of photos of old photos. This past week a grandchild was born and she was wondering which family member the baby looks like. Then I placed the photo of the baby next to old photos of family members. So I think photos are very important in an app" (IC5).

Most of the persons with dementia preferred the possibility for a landscape presentation of apps because this was perceived as bigger and clearer, but also because most of them where used to a landscape presentation.
The use of short clear sentences and the use of easy words were preferred features of the language used by the apps, for example puzzles apps. In addition, although all the apps used in the focus groups were exclusively in Dutch, the settings were sometimes in English. Persons with dementia differ in their preferences of the language used in apps. Some, including informal carers, prefer that the app is fully in Dutch, while others mentioned that they did not mind the apps using English words, for example in the settings. However, during the focus groups, this caused confusion because the English words used in these apps were often not recognized. Persons with dementia found the use of technical terms and computer jargon, e.g. 'high definition', 'download', 'upgrade',

difficult to understand in both the Dutch and these partly English apps.

"Do you know what upgrade means? To increase the difficulty level?" (PwD1).

"I don't have a clue what this all means; when I press on Pictionary, what will happen?" (PwD5).

Additional wishes with regard to important features of apps were mentioned by persons with dementia included the possibility of a hint button in, for example, the puzzle apps. Also, both persons with dementia and informal carers found that entering codes and passwords was annoying. Persons with dementia liked the background music and the possibilities to adapt the app to personal preferences, e.g. background sounds & lay-out, difficulty level and puzzle categories of the word search app. Informal carers mentioned that the background music was annoying and the choices for different puzzle categories were confusing for people with dementia and they did not know how to operate the scroll bar.

User abilities: physical and cognitive condition

Participants mentioned different cognitive and physical disabilities which had an effect on the persons with dementia's skills to operate the tablet and its apps. Most of them have cognitive disabilities related to dementia, e.g. memory problems and language problems (speech, word recognition, meaning). Examples of physical disabilities, frequently the result of aging, include problems with the fine motor skills, and visual and hearing problems. These disabilities influenced the choices for a special functionality of the app, for example, apps that overcome language problems by supporting communication and apps for brain training, daily structure and medication alarm which compensate for memory problems. On the other hand, persons with dementia experienced problems using certain apps due to these disabilities, such as difficulties with reading and hearing, guessing and spelling the right words, not knowing how to operate the app when it was presented in portrait position, and typing and tapping.

"I cannot get out of this app" (PwD2).

"PwD2 was used to having the tablet in a landscape position, did not move the tablet to a portrait position when apps were presented this way, tilted his head so he could read the app" (Observation researcher).

"Yes, it contains difficult words, don't you think"? (PwD4).

'PwD4 could not spell and type the words correctly, so the app didn't recognize the entered words. (Observation researcher) (see Figure 3.3).

"This is useless, I cannot read it" (PwD3).

"PwD3 is keener to participate when apps contain less text" (Observation researcher).

Some informal carers mentioned that persons with dementia had difficulties using the tablet and its apps because they were not familiar with it before the onset of dementia. One of them said that his wife had resisted new technologies before the onset of dementia, one was used collecting information from Google on the tablet instead of using special apps, and another informal carer stated that a step-by-step instruction in written and oral form is needed over a longer period of time in order to get her husband used to operating the tablet and its apps.

User abilities to use the apps on a tablet independently

During the focus group sessions with persons with dementia and informal carers it became clear that the level of independence in using the tablets and its apps varied greatly between persons with dementia. Some persons with dementia could operate apps independently after becoming familiar with these apps. Some needed more support because the apps were difficult for them. The participants with dementia all received support from people around them, e.g. family members, formal carers and activity therapists at the day care centre. Two informal carers mentioned that the use of the tablet and its apps by persons with dementia placed heavy demands on them and increased the burden of informal carers.

> *"He was constantly asking, how do I do this and how do I do that. It drove me crazy "* (IC3*).*

One informal carer mentioned that the use of the tablet and its apps fully depended on how he guided his wife in using it. She merely had to look at it.

> *"I make the use of the tablet very simple for her, for example when we planned to buy a new chair I took pictures of chairs we like and when we got home I showed her the pictures again and again" (IC5).*

User abilities: touchscreen and tablet skills

Persons with dementia differed in their performance of operating the touchscreen and the tablet in general. This appeared to be related to their physical and cognitive condition but also to other factors, such as the frequency of weekly tablet use and the kind of support received by the social network. However, most of them had difficulties with touchscreen skills such as typing, unlocking the tablet by entering codes and passwords, finding apps on the screen, scrolling and navigating. This was acknowledged by the informal carers. Some persons with dementia had difficulties zooming in and out, operating the sound, and swiping and tapping. One person was used to operating the computer and automatically tapped twice, blocking the navigation of some apps. One person tapped with his nails so the screen did not react. And two people were pressing too hard resulting in apps being selected or not reacting.

Table 3.3 User requirements and user characteristics resulting from the focus groups for the requirements-based assessment tool

User requirements: needs and wishes of users related to functional and technical selection criteria of apps

Functional selection criteria of apps	
Meaningful activities present The person wants an app that is suitable for: - Moving (fitness, cycling, walking, dancing) - Being creative (carpentry, handicrafting, flower arranging, painting, drawing, photographing) - Going out (experiencing/being in nature, visiting terraces/restaurants/cinema, shopping, going on holiday). - Gastronomy (enjoying food) - Practising religion (going to church, experiencing religion) - Reminiscence related to personal life history, hobbies, holidays, working career (watching photos, watching videos, listening to music, telling stories) - Household activities (cocking, buying groceries, cleaning, doing dishes, folding laundry, taking care of each other) - Pets (taking care of pets) - Garden (gardening) - Art, culture and history (looking into history, visiting museums, looking at art) - Reading and writing (reading books, spelling, translating) - Listening to music/ making music (listening to music in general, listening to classical music, singing) - News and information (looking for information, following the news, looking at the weather forecast) - Social contact (being socially active, having company) - Games (brain training, playing shuffleboard, board games, cards, billiards and bocce, gambling, jigsaw puzzles) - TV (watching TV in general, watching sports, watching movies, watching nature movies) - Sports (playing badminton, tennis, golf, curling) - Traditions (maintaining traditions)	*Meaningful; activities past* The person wants an app that is suitable for: - Moving (cycling, walking, dancing) - Being creative (woodcrafting, hand-knitting, drawing, dressmaking, making jewellery, photographing) - Going out (driving a car, going to the cinema, going on holidays) - Gastronomy (cooking) - Practising religion (going to church) - Household activities (buying groceries) - Pets (taking care of pets) - Art, culture and history (looking into history, visiting museums, looking at art, reading about mythology) - Reading and writing (reading books, translating, writing) - Miniature trains (building miniature trains) - Listening to music/ making music (listening to music in general, listening to classic music, singing, drumming, visiting operas) - News and information (following the news) - Politics (being politically active) - Social contact (being socially active, entertaining guests) - Games (playing cards) - Sports (playing football, bicycle racing, diving, swimming, running, fitness training, doing athletics, playing badminton, golf, handball, hockey, volleyball, snowboarding, motor racing, playing table tennis, judoing)
Self-management support - The person wants an app that is suitable for: personal care support, language and communication support, social participation support, memory support (maintaining daily structure, finding the way, memory training, remembering appointments and taking medications), maintaining safety & preventing falls, maintaining freedom of movement, maintaining autonomy and respect, maintaining or increasing the living comfort and dealing with memory losses and other disabilities caused by the disease	

Technical selection criteria of apps

Navigation within apps

- The person wants an app that: uses recognizable buttons and icons supported by pictograms and text, uses large buttons and icons, uses easily accessible buttons and icons, uses a home key to return to the beginning, is obvious and intuitive to use, uses a manual or step-by-step instructions, uses a clear help button, uses the minimum number of buttons, screens and clicks (to prevent endless clicking), minimizes the use of clutter (no advertising, no light version, no link to other websites, no drop down menus), uses the same set of navigation buttons in the same location on the screens, minimizes the need for scrolling, minimizes the need for typing

Visual lay-out of apps

- The person wants an app that: uses clear colour contrast, uses visual and sound selection cues, uses clear contrast between text and background, uses clear pictures and photos, uses readable letters and sizes, uses a calm interface and background (less text, not busy, uses no unnecessary buttons/ icons, pictures or information), is not childish, have the possibility of landscape and portrait presentation (rotation)

Language used in apps

- The person wants an app that: uses short and clear sentences, uses simple words, minimizes the use of computer jargon or technical terms, provides the opportunity to adjust the language used in the app in ones own language, including the settings.

Other criteria of apps

- The person wants an app that: does not use codes or passwords, uses a voice-over, an app which use remains the same each time it is revisited, which use is familiar to the person (for example via a game in 'real life'), which use is reliable, that uses a hint button by playing games, which use can be adjusted to personal preferences, such as levels, speed and content options when playing games, background, sounds, font and type face.

User characteristics that can be used to determine user requirements addressing abilities of users in terms of their physical and cognitive condition, the independent use and skills

Abilities of users related to their physical and cognitive condition

- The person has: memory problems, visual problems, language problems (conceptual, textual and speech), hearing problems or problems with fine motor skills

Abilities of users related to the independent use of apps

- The person can use apps: independently, independently when others submit data necessary to use the app, with support of others

Abilities of users related to skills to use the touchscreen and tablet

- The person has the following touchscreen skills: entering codes and passwords, finding apps on the tablet, opening and closing apps, operating the sound, swiping, scrolling, tapping, dragging, typing, zooming in and out, navigating, connecting to the network, adjusting the app to personal preferences, downloading the apps
- The person has the following tablet skills: operating the sound, finding and operating the home-button, operating the tablet standard, rotating the tablet, switching the tablet on and off, charging the tablet

"Login and password, I don't know the password" (PwD3).

"Sometimes you don't know which side you have to swipe to, and sometimes it disappears too quickly and then you have to do it again" (PwD1).

With regard to tablet skills, most persons with dementia could find and use the home button on the tablet. When they got lost or stuck in an app, however, they also immediately used the home button, which did not solve the problem because apps were not closed. Some of them also had problems operating the sound and tablet stand. Nevertheless, most of them were motivated to learn more skills to better operate the tablet.

"I am not that handy with the tablet yet, I have to learn. I want to learn how to download apps" (PwD1).

Informal carers were sceptical about teaching persons with dementia how to download apps because they felt there are too many steps and it requires advanced skills, such as entering codes and passwords. One informal carer was also afraid that the person with dementia would download expensive apps.

User requirements (subquestion 3)

The user requirements in Table 3.3 consists of needs and wishes related to functional and technical selection criteria of apps, and of user characteristics that can be used to determine user requirements adressing abilities of users in terms of their physical and cognitive condition, the independent use of apps, and skills needed to use the touchscreen and tablet.

User characteristics that can be used to determine user requirements addressing abilities of users in terms of their physical and cognitive condition, the independent use and skills
Abilities of users related to their physical and cognitive condition
The person has: memory problems, visual problems, language problems (conceptual, textual and speech), hearing problems or problems with fine motor skills
Abilities of users related to the independent use of apps
The person can use apps: independently, independently when others submit data necessary to use the app, with support of others
Abilities of users related to skills to use the touchscreen and tablet
The person has the following touchscreen skills: entering codes and passwords, finding apps on the tablet, opening and closing apps, operating the sound, swiping, scrolling, tapping, dragging, typing, zooming in and out, navigating, connecting to the network, adjusting the app to personal preferences, downloading the apps
The person has the following tablet skills: operating the sound, finding and operating the home-button, operating the tablet standard, rotating the tablet, switching the tablet on and off, charging the tablet.

Discussion and conclusion

In this exploratory study we identified user requirements for a new, yet to be developed, interactive tool to select usable apps for meaningful activities and self-management support for people with dementia. Based on these user-requirements, filters will be developed which will enable people with dementia to select apps that match their individual needs, wishes and abilities. Most identified user requirements address needs and wishes related to functional and technical features of apps, but we also found user characteristics that can be used to determine user requirements adressing abilities of users (see Table 3.3).

Study one: user requirements related to activities

Study one resulted in the identification of a wide variety of activities perceived as meaningful for persons with dementia. Together with the inventoried needs and wishes for self-management support, this contributed to the identification of functional selection criteria of apps, or, in other words, function-related user requirements. The most frequently mentioned meaningful activity in the past and present is 'being socially active', for example having family meetings, and regular and good contact with family members. Being socially active also appears to be a motivating factor to undertake other meaningful activities. Activities seem to become more meaningful when they are undertaken together with other people, e.g. activities that take place at the meeting centre or day care facilty, such as playing shuffleboard and handicrafting, but also different kinds of sports engaged in the past, such as bicycle racing or playing football. This implies that apps that support people being socially active (e.g. Skype, Face Time, WhatsApp) or apps for other meaningful activities with a social component, such as playing games (e.g. Wordfeud) or doing sports together (e.g. football or tennis games) are desirable for people with dementia. These may also fulfil the frequently reported unmet need for social contact and company of people with dementia living at home.[4-6] Furthermore, the study showed that activities done in the past can provide relevant information for preferred activities in the present, and therefore for suitable apps. For example: career-related activities such as iHandy carpenter for a carpenter who still likes to repair chairs and tables, and 3D Virtual Art Gallery for an art specialist who still likes to visit a museum. Most of the mentioned needs and wishes for self-management were related to 'memory support' such as maintaining daily structure, finding the way, and memory training. This finding supports the results of the study by van der Roest *et al.* (2009), which showed that 32.5% of people with dementia experienced unmet needs regarding memory support.[4] Other frequently cited needs for self-management support were related to 'maintaining freedom of movement'. For example, participants reported feelings of sadness because their driver's license was taken away, or because cycling was no longer possible. This was perceived as a loss of meaningful activities. It is worth noting that people with dementia felt the need for maintaining autonomy and respect, for example when memory loss or

communication problems affected having normal conversations. The abovementioned needs are in line with findings concerning unmet needs reported in previous research in the areas of psychological distress, company and daytime activities.[4,6] Examples of apps that may be supportive in these areas of self-management are: the Pictoplanner for maintaining daily structure; Navigation apps like Blokje Om for finding the way and maintaining freedom of movement; the Diaro App for language and communication support; and brain training apps, such as Clevermind, for memory training.

Study two: user requirements related to usage

In study two focus group sessions with the same participants as they used different kinds of apps resulted in collecting diverse and rich user requirements. Part of the user requirements mentioned concerned the functional selection criteria of apps which overlapped or supplemented the inventoried user requirements in our first study. Participants mentioned different kind of apps which currently helped the person with dementia to engage in meaningful activities or supported their self-management. However, the majority of the user requirements identified in these sessions addressed needs and wishes related to the technical selection criteria of apps. Most of them were in line with the requirements for interfaces described in the literature (see Appendix I). Requirements not found in the literature, but indicated during the focus group sessions were: minimal amount of typing required to navigate within the apps; the language used in apps must be adjustable in ones own language, including the settings and apps that have the possibility of landscape and portrait presentation (rotation). Additional requirements not mentioned in the focus groups sessions but mentioned in the literature were: using warm colours [53]; placing important information first and highlighting it [54-56]; providing clear headings for text [55,57]; providing enough space between app and tablet buttons [58,59]; providing ample time to read information [54,55,60] and avoiding pronouns or any language requiring the person with dementia to recall previous information. [54, 55,60,61] The requirements for interfaces described in the literature generally incorporated a mix of different platforms, e.g. websites and web applications, and also primarily focused on elderly people in general and not on people with cognitive impairments. Although there is growing evidence that people with dementia are able to use a tablet and its apps [24,26,28,37,38] evidence of the importance of diversity regarding functional and technical features of apps for the successful use of tablets by people with dementia is still very scarce. To our knowledge this study is the first of this kind.

During the focus groups sessions we observed that persons with dementia generally chose apps for games they were already familiar with in the past, i.e. the non-digital version of checkers or solitaire, out of personal interest but also because of familiarity with the operation of these games. This was also recognized by Lim *et al.* (2013) and Groenewoud & De Lange (2014).[26,28] However, recent research shows that familiarity with the non-digital version of a game is not a guarantee of usability and that novel games

(e.g. Bubble Xplode) should not be avoided as they can be easy to use and playable.[38] This was also found in this study. Persons with dementia were enthusiastic about apps that offered the possibility of learning new games.

Informal carers stated that apps built for Android were more difficult to operate than apps built for Apple, because Android misses a clear home key. Users have to use the arrow on the tablet next to the home key to get back and this is often confusing for people with dementia. Studies into the use of touchscreen technology by people with dementia showed that the Apple iPad and its apps were primarily used because of the intuitive interface and user friendliness [24,26,28,39] and that less instructions were needed for the independent use of easy to operate apps.[26,38] This suggests that there is preference for Apple as a platform for people with dementia.

However, people with dementia still need support to learn how to use the tablet and its apps.[24,26,28] In the present study we also found that despite varying degrees of performance, persons with dementia needed support to operate the tablets and its apps. This appears to reflect to the individual physical and cognitive condition, as well as the kind of support received by the social network. Some of the informal carers said that the use of the tablet and its apps by persons with dementia put heavy demands on them. There is evidence that people with dementia are capable of learning new skills through various coaching interventions, such as Errorless learning and Trial-and-error learning.[62] It is also known that people with dementia are able to learn how to use new technologies.[63-65] Further research should focus on determining which coaching interventions would be effective to support people with dementia to use the tablet and its apps. This coaching intervention should be aimed at helping informal carers to increase independent tablet and app use by persons with dementia.

Further development

Further development of the tool requires research into how to operationalize and validate the technical selection criteria of apps. For example, what buttons are recognizable and easily accessible and what is a calm interface for people with dementia?

Secondly, it is important to determine, together with the users whether (1) a prioritization system or (2) a ranking system based on personal profiles, would be appropriate for the selection of customized apps. A prioritization system of technical criteria of apps may be suitable because applying all technical criteria together with the functional criteria of apps could result in no, or a very limited number of suitable apps. A ranking system is based on predetermined profiles of user characteristics addressing abilities of users. For example, visual problems will require some technical selection criteria of apps, such as clear colour contrast, sound selection cues and clear contrast between text and background. For the remainder of the technical selection criteria a ranking system, from 1 (less priority) to 10 (priority), could then be used.

Thirdly, it is recommended that the present supply of apps for meaningful activities and

self-management support mentioned in Table 3.3 be researched to determine how specific we must be in categorizing apps to provide sufficient supply for each category.
Fourthly, user requirements have to be translated into the system requirements of apps to enable the identification of important features of apps that match the individual needs, wishes and abilities of people with dementia. In other words, sets of user and system requirements (filters) need to be determined and apps must be rated with regard to these requirements so that customized apps can be selected (see Figure 3.1).
Fifthly, there is a possible downside of putting the needs and wants of future users at center stage. People with mild dementia may want to use a commercial app for brain training that, for example, promises to slow down cognitive decline, without any evidence of its effectiveness. It is unknown whether this will be a major challenge for a future selection tool, but it is important to pay attention to this aspect.
Finally, the tool must be designed and developed in close cooperation with the users and other important stakeholders, such as formal carers and experts (designers, developers and researchers), to ensure user-friendliness. The aim is that the tool can be used by the person with mild dementia him- or herself with or without support of a carer. Details of this planned development and design process can be found elsewhere.[47]

Strengths and limitations

The strength of this study lies in the optimal inclusion of people with dementia in the developmental process of this tool, which will enable the development of a practical and useful tool for the target group. Span *et al.* (2013) and Meiland *et al.* (2010) discussed the importance of including people with dementia in the development of user-friendly ICT applications.[42,43] Valuable strategies such as taking time, creating a safe environment, providing positive feedback and building a relationship [51], resulted in rich quotes which gave an in-depth understanding of their personal experiences, needs, wishes and abilities. The results of our study show that the needs and wishes of people with dementia and their informal carers are complementary, which contributed to a comprehensive picture of user requirements. With the inventoried user requirements we can provide valuable input for designers and builders of ICT regarding the development of usable apps for people with dementia and other vulnerable target groups with cognitive impairments. This will hopefully contribute to the inclusion of these target groups in an Internet society and thereby to their social health, as formulated by Huber *et al.*, (2011).[11]
This study has some methodological limitations. The qualitative study had an exploratory focus and we did not reach saturation in meaningful activities and self-management support because of the wealth of activities that can be classified as meaningful or supportive for self-management. Because this was the first stage in the development of the tool and because of the iterative approach to be used in the further development of the tool (47) we will continue our research on this topic in future stages of our study.
A second weakness is that we used a convenience sample of respondents. We recruited

members from a day care and two meeting centres, which may or may not have been a representative group of community-dwelling people with mild dementia that includes those who do not utilize day care facilities. More information about this group will be collected and utilized in next stages of the development of this tool. Another issue is that participants in study two had tablet experience, which may explain why we had more men than women in our sample, even though dementia is more common in females. Among the older population (age of 65 years and older), Internet use is a male-dominated activity.[66] As a result, our participants were likely more inclined to use technological solutions than people with dementia in general.

A third weakness of the study was that we included some people with MCI and cognitive decline in study two and assumed that their remarks and ideas were valid for people with mild dementia as well. However we did not test this. We also did not try to quantify the needs of people with mild dementia, but instead tried to identify a variety of important themes for the development of a requirements-based assessment tool. Further research is needed to fine-tune the user requirements and to determine the percentage of people with mild dementia for whom the tool might offer assistance in maintaining or enhancing their quality of life.

A last issue is that although we performed on-going consent and we regularly repeated what the purpose of the focus group sessions was, we could not avoid that two participants believed they were attending a tablet course. The participants stated at the end of the sessions:

"It feels like sitting in the classroom, being in school" (PwD4).

"I think I learned a lot. And that was the idea" (PwD5).

Conclusion

With the exploratory approach used in this study, user needs of people with dementia and informal carers concerning their choice and use of apps for meaningful activities and self-management support were identified. These user needs were translated into user requirements which will form the basis for a new interactive tool for a personalised selection of suitable apps. This tool will be further developed in close cooperation with potential users and other important stakeholders. We hope the tool will make it easy for people with dementia to select suitable apps for meaningful activities, which may stimulate their involvement in these activities. We expect that this will result in experiencing pleasure and enjoyment; feelings of connection and belonging; and retaining a sense of autonomy and personal identity.[67] Because apps can be selected which are supportive in the different areas of self-management [17], it is expected that using these apps will also increase self-management abilities.

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Appendix I:
Requirements of interfaces for people with dementia/elderly according to the scientific literature

	Requirements (resources)
Navigation	- Comfort in navigating the function of an app [25,28,33,34,36,55,56]
	- Use of large, easily accessible buttons and targets [25,53-56,58,60,61]
	- A home or back key to return to the beginning when someone is lost [34,57,60,68]
	- Extra and bolder navigation cues and the same set of navigation buttons in the same spot on each page (consistency on interface) [33,55,56,68,69]
	- Use of minimum number of buttons [25,38,70]
	- Provide effective prompts [33,35,36,53]
	- Use of hypermedia structure with limited options for selection. Provide too many links and number of steps. Do not use a deep hierarchy. [33,53-55,68,69]
	- Avoid drop down menus [55,60]
	- Avoid advertisements or multiple overlapping windows [55]
	- Simply structured interface [33,55-57,60]
	- Simple instructions [23,28,53,60]
	- An help tutorial should be provided [55]
	- Help button is accessible and clear [27,57,69]
	- Give specific instructions and number each step [60]
	- Minimize the need for scrolling [54,55,57,60,68,69]
	- Avoid the use of double click or make obvious what is clickable and what is not, and make easy to target and hit. [55,57,68]
Visual lay-out	- Use of relevant (not for decoration) and clear graphics and (meaningful) icons that can be personalized [23,25,36,54-57,60,68]
	- Easy, attractive and Intuitive design [23,33,36,70]
	- Use of visual (sight), auditory (sound), haptic (touch) selection cues,prompts and feedback [54,56,60,69,70]
	- Contrast between text and background and the possibility for users to fine-tune screen brightness and contrast [55-57,60]
	- Not be childish or stigmatizing [25,70]
	- Landscape presentation [33]
	- Avoid the use of animation and fast-moving objects or auto-updating content [53-55,60]
	- Minimize colour use [54,55,60]
	- Use of warm colours [53]

- Provide enough space between app buttons and tablet buttons [58,59]
- Use of high colour contrast combinations. Avoid using blue, green and yellow in close proximity [53,55,60]
- Text size: 12-14 and make it easy for people to change the text size [25,55-57,60,68]
- Use sans serif type font e.g. Helvetica, Arial. Avoid other fancy types [53,55,57,68]
- Allow sufficient white space to ensure a balanced user interface design [55,57,60,68]

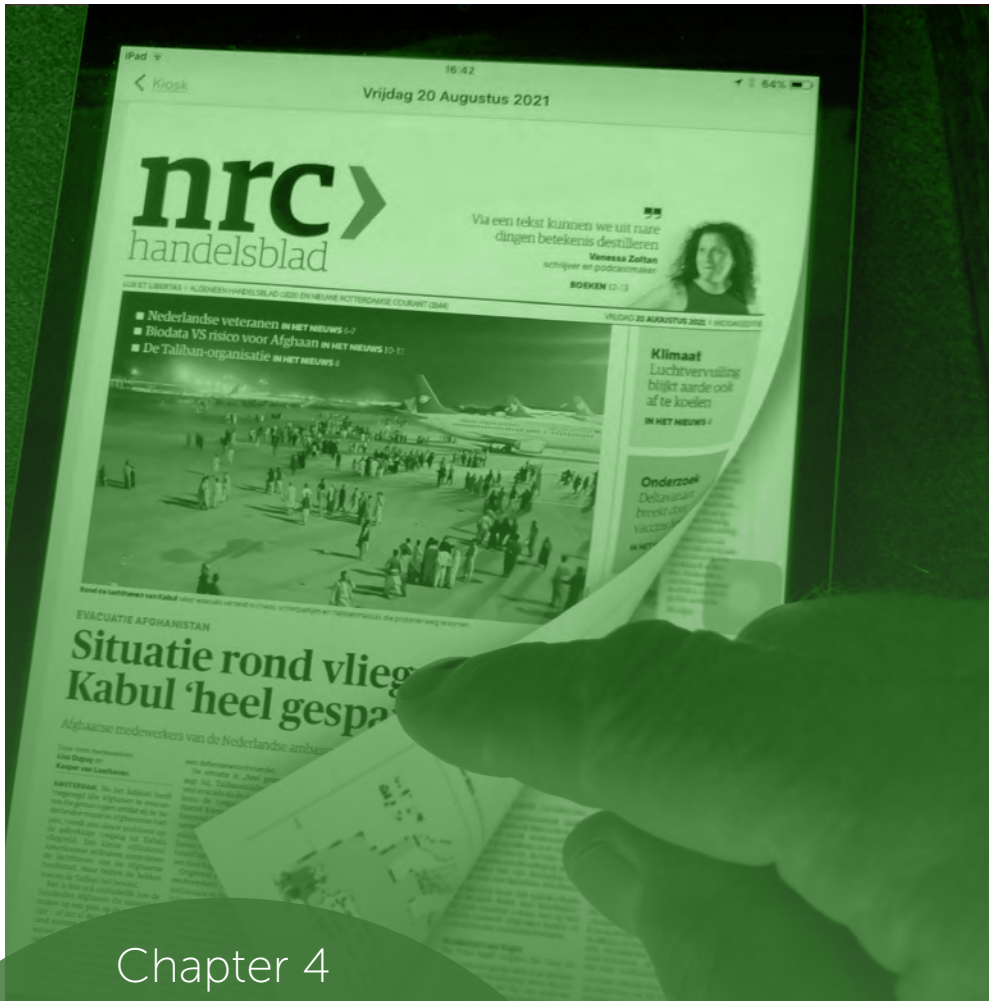
Language

- Language should be used consistently, jargon and technical terms minimized [27,54,57,68]
- Textual and sound support should be available [54,60,68]
- Provide ample time to read information [54,55,60]
- Minimal use of text [33,57,70]
- Written information should be simple and concrete (use of clear and short sentences) and where possible supported with clear visual images to aid understanding [53-57,60,61,68,69]
- Placing important information first and highlight it [54-56]
- Text should have clear headings [55,57]
- Avoid pronouns or any language which requires the person to recall previous information, support recognition [54,55,60,61]
- Use of positive active language [28,57,69]

Other

- Possibility to adjust the app to personal preferences with regard to capabilities and interests [25-27,33,70]
- amiliarity to persons with dementia, for example, a game in 'real life' [26,28]
- Provide undo facility [69]
- Absence of codes or passwords [70]
- No use of both hands [56]
- Page should remain the same each time it is revisited [55]

A1



Chapter 4
Literature review: are people with mild dementia able to (re)learn how to use technology?

Published as

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Abstract

Objective

There is growing evidence that people with mild dementia can benefit from using tablets and apps. Due to their cognitive decline people with dementia need support in learning how to use these devices. The objective of this review was to identify which training interventions work best to help people with mild dementia (re)learn how to use technologies, including handheld touchscreen devices. Because the uptake of these devices in people with dementia is quite new, training interventions for the use of other technologies were also included, such as technologies assisting people in Instrumental Activities of Daily Living (IADL).

Research design

An electronic search was conducted in the following databases: PubMed, APA PsycInfo (EBSCO) and CINAHL (EBSCO). Themes discussed include the learning effects; training method (e.g. Errorful (EF) and Errorless (EL) learning); training intensity and setting; technology task type; dementia type and severity; and study design and outcome measures.

Results

In total, 16 studies were included. All studies reported positive learning effects and improved task performance in people with dementia, regardless of dementia severity, training intensity, setting and the method used. Although the EL training method was successful more often than the EF training method, it would be inappropriate to conclude that the EL method is more effective, because the majority of studies only investigated EL training interventions with (multiple) single-case study designs.

Discussion and Conclusion

Future research should consider using more robust study designs, such as RCTs, to evaluate the effectiveness of training interventions for (re)learning technology-orientated tasks, including operating handheld touchscreen devices.

Introduction

In the early stages of the disease people with dementia and informal carers experience insufficient support for self-management [1] and a lack of meaningful activities to spend the day.[2-4] Facilitating self-management and meaningful activities for people with dementia promotes autonomy and wellbeing and relieves the burden of informal carers.[5] Technology can potentially support people in their ability to manage life and to engage in meaningful activities despite chronic diseases.[6] Handheld touchscreen devices, such as tablets and their applications (apps), provide an intuitive and user-friendly interface. The use of tablets for eHealth purposes is increasing as the availability of new apps in the field of health and social care increases.[7] In recent years many Information Communication Technology (ICT) applications that support independence in daily living have been developed, such as apps for cognitive training, calendar, games and art, which can also be used by people with dementia.[8-10]

There is growing evidence that people with mild dementia are able to use tablets and apps [11-17] which stimulate self-management activities, e.g. apps to cope with memory loss [13,18], and which engage people with dementia in meaningful activities, e.g. apps for leisure activities [19] such as gaming [16,17] or art. [14] However, people with dementia need support to learn how to use the tablet and its apps.[11-13,17]

Introducing tablets to community-dwelling people with mild dementia is a new development. It may therefore be important to take into account specific preconditions, such as related to their cognitive disabilities and living situation (e.g. cohabiting with an informal carer or living alone). To this end a person-centred tablet program to assist people with mild dementia and their carers in the effective usage of tablets will be developed in co-creation with end users.[20] This program consists of a selection tool to help users find apps for self-management and meaningful activities and a training for informal carers to support people with dementia in using the tablet. This training will be based on available evidence on effective coaching interventions for people with dementia to (re)learn the use of technologies.

Kessels and Joosten-Weyn Banningh (2008) describe that new skills can be taught to people with dementia using their implicit memory. This part of the long-term memory is responsible for performing procedural tasks which are acquired through fixed routines, such as biking and washing hands, and are conducted automatically.[21]

The review by De Werd *et al.* (2013) found that an Errorless (EL) learning approach is more effective than an Errorful (EF) learning approach to teach people with dementia a variety of daily tasks or skills. EL approaches keep errors during the learning process to a minimum, because memory limitations prevent learning from mistakes.[22,23] EL employs error-reduction methods, such as a stepwise approach with feed-forward-instruction, vanishing cues and spaced retrieval.[22,23] Another review indicates that spaced-retrieval training is effective in enabling people with dementia to learn new information and to teach associations between a cue and a specific behaviour in order to improve

performance of skills.[24] In EF approaches the idea is that skills can be learned by guessing the correct response and learning from any errors made.[25]

EL might be the best way to introduce tablets to people with dementia, but because of the broad scope of both reviews [23,24] - they included studies with a wide range of activities of daily living, such as relearning names of persons and objects – they are not conclusive about the effectiveness of EL specifically for (re)learning skills for using technologies. It is uncertain whether EL is the best approach for people with dementia to (re)learn the use of technology. For example, the stepwise approach may not be suitable when learning to use ICT applications, because the actions needed when using ICT are not as predictable as relearning names of objects or executing ADL. The (re)learning of technology is a different process. This becomes clear by acknowledging the three layers of technology significance formulated by Martins and Dal Sasso (2008): that of physical objects (such as instruments and machines); that of a form of knowledge (such as how to use it); and as it forms part of a complex set of human activities.[26] Hence, only studies with training interventions focusing on (re)learning how to use technologies have been included in this review. Because the uptake of Information Communication Technology (ICT) applications is a recent development in people with dementia and relatively few publications were therefore expected in this area, we also included training interventions for the use of other technologies, such as technologies to assist people in Instrumental Activities of Daily Living (IADL), e.g. microwaves and coffee makers.

To the best of our knowledge, no review has been conducted that examines which training interventions are most appropriate to assist people with mild dementia in (re) learning to use technologies. The purpose of this literature review is to identify which training interventions work best in helping people with mild dementia (re)learn how to use technologies, in particular the tablet. To gain insight into the context of the included studies, the following characteristics were described: a) dementia type and severity; b) technology task type; c) training intensity and setting; d) components training; e) study design and outcome measures; and f) learning effects and efficiency.

The research question is:

- *Which training interventions are effective for people with mild dementia in (re)learning how to use technologies, including handheld touchscreen devices?*

Method

Design

A literature review [27] with a systematic approach was performed in order to find training interventions for (re)teaching people with mild dementia how to use technologies. Our intention was not to get a full picture of all available evidence, but rather to understand what works best for people with mild dementia to (re)learn the use of technology, so we can include these insights in our training for the person-centred tablet program.[20] We did not perform a complete systematic review. We used systematic review methods

for transparency and reproducibility of our work, such as: methods for determining the search strategy, for setting the inclusion and exclusion criteria based on PICO, and methods for the selection of publications and the data extraction procedure as described below.[28]

Data sources and search strategy

A systematic search of the literature was conducted in 3 electronic databases (CP). PubMed, APA PsycInfo (EBSCO) and CINAHL (EBSCO) were searched from inception up to June 19th 2020 with comparable search strategies (see Table 4.1 for the search strategy used for PubMed). The complete search strategies for the other databases are available on request.

Table 4.1 Search strategy in PubMed

("Dementia"[Mesh] OR dementia* [tiab] OR alzheimer* [tiab]) AND
("Learning"[Mesh] OR "Teaching"[Mesh] OR learning* [tiab] OR relearning [tiab] OR coaching* [tiab] OR training* [tiab] OR teaching* [tiab] OR errorless* [tiab] OR error free [tiab] OR errorfree [tiab] OR spaced retrieval [tiab] OR mnemonic* [tiab] OR semantic elaboration [tiab] OR subject-performed task* [tiab] OR vanishing cues [tiab] OR cueing* [tiab] OR trial and error* [tiab] OR errorful* [tiab] OR cognitive rehabilitation [tiab] OR cognitive intervention* [tiab] OR memory rehabilitation [tiab] OR "Neurological Rehabilitation"[Mesh] OR "Memory, Long-Term"[Mesh] OR implicit memory [tiab] OR procedural memory [tiab] OR long-term memor* [tiab] OR longterm memor* [tiab]) AND
("Cell Phone"[Mesh] OR "Cell Phone Use"[Mesh] OR "Mobile Applications"[Mesh] OR "Computers, Handheld"[Mesh] OR "Self-Help devices" [Mesh] OR cell phone* [tiab] OR touch screen* [tiab] OR touchscreen* [tiab] OR computer application* [tiab] OR apps [tiab] OR iPad* [tiab] OR tablet [tiab] OR smartphone* [tiab] OR smart phone* [tiab] OR mobile phone* [tiab] OR iPhone* [tiab] OR assistive technolog* [tiab] OR self-help device* [tiab] OR assistive device* [tiab] OR memory aids [tiab] OR mobile device* [tiab] OR hand-held device* [tiab] OR handheld device* [tiab] OR palmtop computer* [tiab] OR hand-held computer* [tiab] OR handheld computer* [tiab] OR palmtop device* [tiab] OR wearable* [tiab] OR cellular phone* [tiab] OR mobile app [tiab] OR mobile application* [tiab] OR mobile technolog* [tiab] OR electronic application* [tiab] OR electronic device* [tiab] OR "Activities of Daily Living"[Mesh] OR everyday activit* [tiab] OR everyday skill* [tiab] OR ADL [tiab] OR IADL[tiab] OR daily life activit* [tiab] OR everyday life functioning* [tiab] OR skill learning [tiab] OR skills learning [tiab] OR daily activit* [tiab] OR activities of daily li* [tiab] OR activity of daily li* [tiab] OR cooking activit* [tiab] OR functional life skill* [tiab] OR daily living task* [tiab] OR self-care skill* [tiab] OR route finding [tiab] OR way finding [tiab] OR orientation skill* [tiab] OR everyday functioning* [tiab])

Inclusion and exclusion criteria

For the selection of the articles we used the inclusion and exclusion criteria presented in Table 4.2.

Table 4.2 Inclusion and exclusion criteria for this literature review

Inclusion criteria	Exclusion criteria
Population: the study population consists of people living with dementia (all types). People with mild (MMSE 21-25, GDS 4) and moderate (MMSE11-20, GDS 5) dementia were included (Perneczky *et al.*, 2006; Reisberg *et al.*, 1982), on the assumption that training interventions effective for people with moderate dementia, i.e. people with more severe cognitive disabilities, will also be helpful for people with mild dementia.	**Population:** The study population consists of people with severe dementia, who would not be capable of using touchscreen devices. We also excluded mild cognitive impairment (MCI), memory or cognitive decline without diagnosis of dementia or without MMSE/GDS score indicating mild to moderate dementia, to ensure that results were relevant for our target group.
Intervention: the study used training interventions to (re)learn technology, more specifically: learning, training or coaching strategies or rehabilitation techniques that focus on implicit/ procedural memory and explicitly target the use of technology by individuals with dementia	**Population:** The study included mixed populations (e.g. people with dementia in addition to people with stroke or traumatic brain injury or intellectual disabilities), unless the data of subgroups of people with mild to moderate dementia was specified in the analyses and results section of the paper.
Intervention: The task type described in the study is 'technology use' either related to (1) Instrumental Activities of Daily Living (IADL), such as voicemails, microwaves, answering machines, coffee makers and MP3 players, and/or to (2) new technologies, i.e. ICT applications, such as computers, memory aids, touchscreen devices, prompting or tracking devices, etc.	**Intervention:** The study included training interventions on which insufficient information was provided to reproduce the training.
Comparison and study design: The study utilized an experimental or quasi-experimental research design with comparison with a control group or control condition (comparing training interventions (e.g. EL with EF) or no treatment)	**Publication status:** The study was only published as an abstract, editorial comment, commentary, letter, congress paper, thesis or study protocol.
Comparison and study design: The study utilized (multiple) controlled (control group or control condit-ion) single-case studies or single-case studies with a measurement at baseline and after the inter-vention (e.g. multiple-baseline design or reversal design) or measurements of number of correct responses/ correctly executed steps after each learning session **Outcome:** The study evaluated the learning effects of training interventions including outcome measures related to optimising the (re)learning of skills (De Werd *et al.*, 2013) e.g. number of correct responses or correctly executed steps or functional performances according to the degree of assistance.	
Timeframe for follow-up: there were no time restrictions for follow-up.	
Publication language: The study was published in English and/ or Dutch and was published in a scientific journal.	

Selection of publications

The search results were uploaded into EndNoteX7. Duplications were removed. The Preferred Reporting Items for Systematic Reviews and Meta-Analysis flow diagram [29] were used to summarise the study selection processes (see Figure 4.1). Two researchers (YK and AB) independently screened the publications, by title and abstract, and three researchers (YK, AB and FM) independently screened the publications' full texts. In this phase further duplicates, not previously detected by EndNote, were removed. Any discrepancy between researchers regarding inclusion were resolved through discussion.

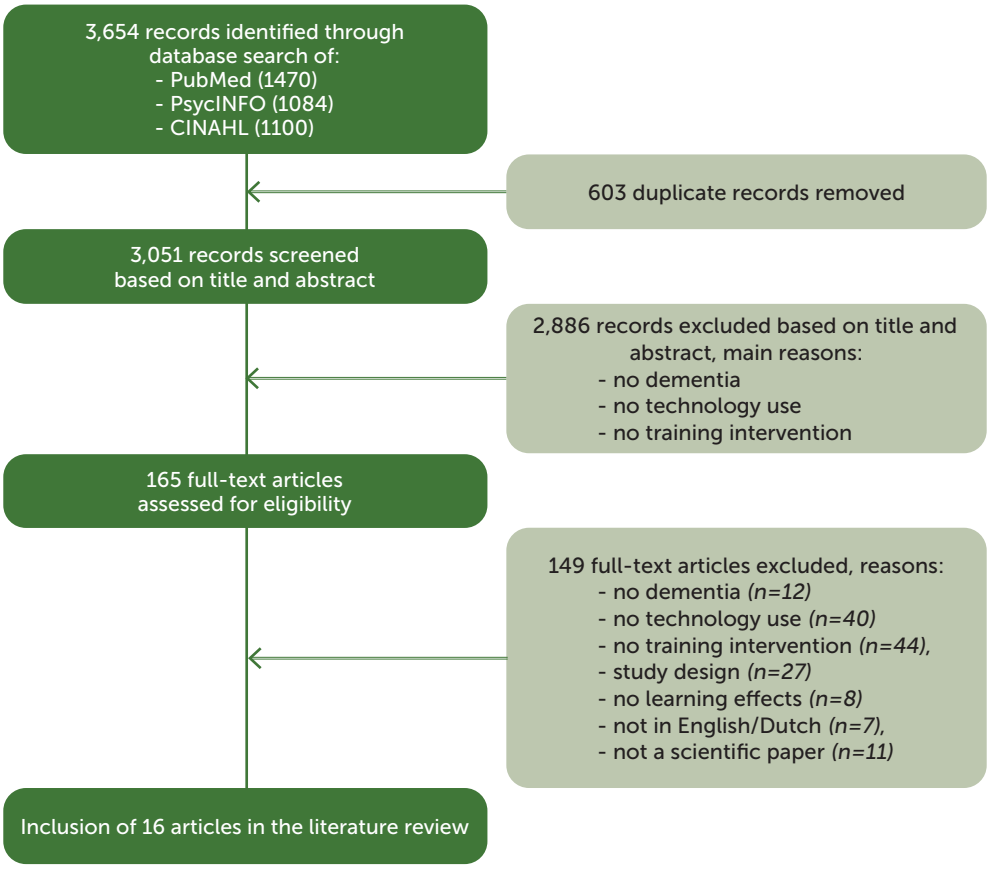

Figure 4.1 Flow diagram of the search and the selection process (Moher et al., 2009)

Data extraction and data synthesis

Initially two researchers (YK and AB) independently extracted data from one included article and this was followed by a consensus meeting. Next, data was extracted from another article by the same researchers. When this resulted in similar outcomes, it was decided to divide the remaining articles and to extract the data independently. For data extraction

concerning the effectiveness of training interventions and maintenance of treatment gains, additional consensus meetings took place (YK and AB). Small samples (n<26) were used in 13 of the 16 studies reviewed, and the training interventions and procedures, outcomes of learning effects and research designs varied considerably among studies. We therefore performed a qualitative analysis on previous described characteristics.

Results

The search in the PubMed, PsycINFO and CINAHL databases resulted in a total of 3,654 references of which 3,638 were excluded either because they did not meet the inclusion criteria (see Figure 4.1). The study selection resulted in 16 articles describing training interventions to assist people with mild dementia in (re)learning how to use technology. Table 4.3 shows a detailed description of each study.

Dementia type and severity

The most common diagnosis was Alzheimer's disease.[25,30-41] One study reported mixed type [30], others mentioned semantic dementia [42,43], and in one study the form of dementia was not specified.[44] With regard to the severity, most studies reported MMSE/MoCa scores between 11 and 25, indicating a mild to moderate dementia. Two single-case studies did not mention scores, but based on the case description we can assume it was mild dementia.[35,42]

Technology task type

The technology tasks ranged from using telephones and (mobile) ICT devices, to using music and television devices, and conducting household activities and operating household devices (IADL). Examples of telephone and (mobile) ICT devices were learning to operate a:

- voicemail and answering machine [39];
- (mobile) phone [36,37,41];
- smartphone/tablet and its apps [35,42,43];
- computer, to use e-mail, Internet search and computer games.[31,40]

Two studies described people with dementia learning to use the AP@LZ application.[33,34] AP@LZ is an electronic personal organiser application, developed for people with dementia and installed on a smartphone. The application consists of five functions: (1) Appointments; (2) Personal; (3) Medical; (4) Contacts; and (5) Notepad.[33,34]

The use of music and television devices consisted, for example, of learning to operate a:

- radio and video cassette [30,40];
- remote control [31,41];
- CD player and DVD player with leisure activities, such as Wii game and origami.[31,40]

In other studies participants with dementia focussed on (re)learning household activities such as:

Table 4.3 Detailed description of reviewed studies

Study	N	MMSE/ MoCa score	Dementia type/severity	Technology task type	Training intensity	Train. setting	Components of coaching intervention	Study design	Outcome measures learning effects	Effectiveness (+/-) [a] Performance pre- and post-intervention on scale of 0-100	Maintenance of treatment gains (+/-) [b] Performance on scale of 0-100
3a Group studies (RCTs and quasi-experimental designs) using EL and/ or EF approaches to (re)learning mostly IADLs											
Bourgeois et al., 2016	52	MMSE (mean) 17	Mild to moderate Alzheimer's dementia	3 mostly IADL tasks per person, such as using the stove, an alarm clock or preparing tea	12 sessions of two hours over 6 weeks (two sessions per week)	?	EL elements in two methods; 1. Stepwise approach 2. Modelling with SR 3. EF approach	Randomised prospective clinical trial (group study)	Number of correct responses or correctly executed steps: after each learning session at baseline and post-intervention	**EL: + (21-62)** **Modelling & SR: + (20-56)** **EF: + (23-64)**	*After 4 weeks* [c] EL: + (47) Modelling & SR: + (55) EF: + (57)
Dechamps et al., 2011	14	MMSE (mean) 15	Mild to moderately severe Alzheimer's dementia	3 mostly IADL tasks per person, such as using an electric kettle, coffee machine and remote control	6 sessions of 30 minutes within one week (per task)	Nursing home	EL elements in two methods; 1. Stepwise approach 2. Modelling with SR 3. EF approach	Within-subject design (group study)	Number of correct responses or correctly executed steps: after each learning session at baseline and post-intervention	**EL stepwise: + (49-63)** **Modelling + (44-74)** **EF: + (45-59)**	*After 3 weeks* EL stepwise: + (73) Modelling + (75) EF: + (52)
Thivierge, Jean and Simard, 2014	17	MMSE (mean) 21	Mild to moderate Alzheimer's dementia	1 task per person, such as using television or music devices and computer apps (Wii game and origami)	2 sessions of 45-60 minutes a week, over 4 weeks	At home	EL elements with SR	A block-random-ised cross-over controlled study (group study)	Functional performances according to the degree of assistance: at baseline and post- intervention	**EL & SR Group 1: + (75-90)** **EL & SR Group 2: + (77-88)**	*After 8 weeks* Group 1: + (87) Group 2: + (88)
van Tilborg, Kessels and Hulstijn, 2011	26	MMSE (mean) 20	Mild to moderate dementia	Coffee machine and microwave oven	5 sessions of 15 minutes, over 2-3 days	?	EL elements in two methods: 1. Explicit method (verbal instructions & cues) 2. Implicit method (modelling & preventing errors)	Counterbalanced self-controlled cases series (group study)	Number of correct responses or correctly executed steps: after each learning session at baseline and post-intervention	**Explicit method: + (43-80)** **Implicit method: + (36-80)**	*After 7-10 days* Explicit method: + (80) Implicit method: + (71)
Voigt-Radloff et al., 2017	161	MMSE (mean) 20	Mild to moderate Alzheimer's dementia or mixed dementia	2 tasks per person, such as performing light exercises, making a telephone call, choosing television broadcast and writing shopping list	8 sessions of 60 minutes over 8 weeks. A refresher training session in week 19 or 20	At home	1. EL elements 2. EF approach	Single blind, active-controlled design (group study)	Number of correct responses or correctly executed steps: at baseline and post-intervention	**EL: + (44-64)[d]** **EF: + (53-61)**	*After 15 weeks* EL: + (56) EF: + (56)
3b Experimental (multiple) single case studies using EL approach to (re)learning handheld touchscreen devices											
Bier, Paquette and Macoir, 2018	1	?	Semantic dementia (probable, mild)	Smartphone functions and apps	7 sessions of 1.5 hours over 7 weeks (one session per week)	?	EL elements	ABA single-case study	Number of correct responses or correctly executed steps: after each learning session at baseline and post-intervention	**+ (19-100)**	*After six months* + (80)
Bier et al., 2015	1	MoCa = 23	Mild semantic dementia	Smartphone functions and apps	5 training sessions	?	EL elements	ABA single-case study	Number of correct responses or correctly executed steps: after each learning session at baseline and post-intervention	**+ (30-73)**	*After six months* + (78)
Imbeault et al., 2014	2	MMSE 22, 29	Mild Alzheimer's dementia	Smartphone app AP@LZ, as electronic agenda	2 sessions of 30-40 minutes a week in first two phases (with a total of 19-38 sessions, including follow-up). In total AP@LZ use 11-14 months.	?	EL elements	ABA multiple single-case studies	Functional performances according to the degree of assistance: after each learning session	Case 1: +(32-90)[e] Case 2: +(36-90)[e]	*After four weeks* Case 1: + (100). Still uses AP@LZ after 14 months (end of study) Case 2: + (50-75).[f] Still uses AP@LZ after 11 months (end of study)

Study	N	MMSE/ MoCa score	Dementia type/severity	Technology task type	Training intensity	Train. setting	Components of coaching intervention	Study design	Outcome measures learning effects	Effectiveness (+/-) [a] Performance pre- and post-intervention on scale of 0-100	Maintenance of treatment gains (+/-) [b] Performance on scale of 0-100
Imbeault et al., 2018	2	MMSE 27,28	Mild Alzheimer's dementia	Smartphone app AP@LZ, as electronic agenda	2 sessions of 30-40 minutes/week in first two phases (total 19-25 sessions, incl. follow-up). In total AP@LZ use 2-10 months	?	EL elements	ABA multiple single-case studies	Functional performances according to degree of assistance: after each learning session	Case 1: +(50-90)[e] **Case 2: +(55-88)[e]**	*After 10 months* Case 1: + (100). Still uses AP@LZ after 12 months (end of the study) Case 2 not completed
Imbeault et al., 2018	1	?	Probable mild Alzheimer's dementia according to DSM-5 criteria	General functions of the tablet and functionalities of a calendar application	2 sessions a week, for 8 weeks in first two phases (17 sessions). Follow-up 23 sessions over 12 months. 75-120 minutes during the first 3 sessions, later 30-45 minutes per session	?	EL elements	Exploratory single-case study	Functional performances according to the degree of assistance: after each learning session	**+ (64-98)[e]**	*After 12 months* + (100). Still uses the tablet after 12 months (end of the study)
3c Experimental (multiple) single case studies using EL approach to (re)learning a variety of technology tasks											
Bier et al., 2008	1	MMSE 24	Mild Alzheimer's dementia with vascular aspects	Cassette radio and video cassette recorder	8 sessions of 1.5 hours for the cassette radio and 10 sessions for the video cassette recorder (VCR). Two sessions per week	At home	EL elements with VC and SR	ABA single-case study	Number of correct responses or correctly executed steps: after each learning session at baseline and post-intervention	**+ (60-87 for cassette radio & (33-100, for VCR)**	*After 9 weeks* + (70, for cassette radio & 90 for VCR). - Transfer in daily life for cassette radio and VCR).
Foloppe et al., 2018	1	MMSE 16	Moderate Alzheimer's dementia	Cooking tasks such as using the stove and microwave in a virtual situation. Using a coffee machine and toaster in a real situation	16 learning sessions in 4 weeks (four sessions in 4 days)	At home	EL elements with VC	Within single-case study	Functional performances according to the degree of assistance:after each learning session at baseline and post-intervention	**Real situation: + (83-94)** **Virtual situation: + (75-91)**	*After six months* Real situation: + (94) Virtual situation: + (95)
Kelly et al., 2019	2	MMSE 18, 20	Moderate Alzheimer's dementia	Case 1 Phone Case 2 Mobile phone	1 session of 60-90 minutes a week, over 8 weeks	At home	EL elements with (in case 1) VC	Multiple single-case studies	Number of correct responses or correctly executed steps[g]: after each learning session at baseline and post-intervention	Case 1: + (8-100) Case 2: + (50-100)	*After 6 weeks* Case 1: + (90) Case 2: + (80)
Lekeu et al., 2002	2	MMSE 21, 22	Mild probably Alzheimer's dementia	Calling somebody on a mobile telephone	1-2 sessions of 45 minutes a week, over 3 months (13-14 sessions in total)	Ambu. cognit. rehab. centre	EL elements with SR	Multiple single-case studies	Number of correct responses or correctly executed steps: after each learning session at baseline and post-intervention	Case 1: + (33-91) Case 2: + (22-77)	*After 3 months* Case 1: + (100) Case 2: + (100)
Quittre, Olivier and Salmon, 2005	1	MMSE 21	Mild probable Alzheimer's dementia	Digital clock	2 sessions a week over three months (21 sessions in total)	Memory centre	EL elements with SR	Exploratory single-case study	Number of correct responses or correctly executed steps: after each learning session	+ (43-100)	*After 3 months* + spontaneous use *After 6 months* + still uses the clock
Thivierge et al., 2008	2	MMSE 19, 25	Mild to moderate Alzheimer's dementia	Case 1 voicemail and Case 2 answering machine	2 sessions of 45-60 minutes a week, over 4 weeks	?	EL elements with SR	Multiple single-case studies	Functional performances according to degree of assistance: after each learning session at baseline and post-intervention	Case 1: + (57-94) Case 2: + (47-75)	*After 5 weeks* Case 1: + (89) Case 2: + (83)

a+ Improvement in performance of target functions between baseline and post-intervention; – is no learning effect. The entries in bold indicate a significant effect. Performance of the task refers to performance without help, cues or written instructions.
b+ Improvement in performance of target functions between baseline and follow-up; – means the learning effect has disappeared at follow-up. The entries in bold indicate a significant effect.
c After the end of the training.
d Average of two different tasks recalculated to scale of 0-100.
e At the end of acquisition and application phase.
f The application phase was with help from trainers.
g Only included objective measure of percentage of correct responses, not self-rated goal performance and satisfaction.

- making tea [25,31],
- making coffee with a coffee machine [31,32,44];
- using the oven [25,32];
- using the microwave [32,44];
- setting the alarm clock or using a digital clock.[25,38]

Training intensity and setting

The number and duration of training sessions varied considerably between the reviewed studies. In nine studies the number of training sessions was fewer than ten, ranging from 5-9 sessions.[30,31,36,39-44] In seven studies the number of training sessions was more than ten, ranging from 12-39 sessions.[25,32-35,37,38,41] The duration of each session ranged from 15-120 minutes and the total training programs were given during a period ranging from 2 days to 14 months. In three studies no duration of each session was mentioned[32,38,43], and in one study the length of the total training program was unclear.[43]

With task types relating to mobile devices, such as operating a mobile phone, smartphone or tablet and its apps, the intensity of training sessions varied among the studies. In two studies [42,43] participants attended 5 to 7 sessions to learn new (smart)phone functions and apps, whereas in other studies [33-37] 8 to14 sessions were needed.

In studies by Imbeault *et al.* (2014; 2016; 2018) a training program developed by Sohlberg and Mateer (1989) was conducted in which participants learned to operate a smartphone or tablet and a calendar app (e.g. AP@LZ). This training program consisted of three stages: the acquisition phase (i), where participants learned to operate the smartphone or tablet and calendar app; the application phase (ii), where participants learned "how" and "when" to use the app; and the adaption phase (iii), where participants were required to demonstrate their ability to use the app in a real-world setting (33-35). An average of 10, 9 and 13 training sessions of merely 30-40 minutes were needed to complete the acquisition, application and adaption phases respectively (33-35) with one missing value because the adaption phase, in one case, was not completed (34).

The training setting was at home [30,32,36,40,41], an ambulatory rehabilitation centre [37], a memory centre [38], a nursing home [31] or not specified.

Components training intervention (training method)

All reviewed studies used EL approaches and included a variety of error-reduction components for (re)teaching people with mild dementia how to use technology. Although studies varied in the level of detail of description of the training components, the following error-reduction methods, as described in the review by De Werd *et al.* (2013) were identified: no guessing; a stepwise approach; modelling; verbal instructions or visual instructions; vanishing cues and spaced retrieval.[23]

First, in some studies participants were encouraged to avoid guessing to prevent errors.[33,36,37,41] When errors occurred, the therapist/researcher intervened offering the

correct response and/or steps were repeated to prevent errors.[25,32-35,37,41-44]
Second, a stepwise approach was applied in all the studies except one (38) and this was done by dividing tasks into small steps.
Third, participants received a demonstration of how each step had to be performed (modelling), supported by verbal or visual instructions.[25,31,32,34,35,39-44] In other studies participants received verbal and/or visual instructions without physical demonstration.[30,36-38,44]
Fourth, the method of vanishing cues (VC), which refers to gradually withholding cues after successful response performance [23] was applied in three studies.[30,32,36] Last, the spaced retrieval (SR) method, referring to increasing recall intervals after reproducing the desired response [23], was applied in six studies.[25,31,37-40]
Three studies used not only EL but also EF approaches.[25,31,41] One study examined the effectiveness of EF in addition to EL approaches [25] and in two of the studies EF was applied as a control condition for EL method(s).[31,41]

Study design and outcome measures

Five studies used a group experimental design, three were randomised controlled trials (RCT) and two had quasi-experimental designs. Two RCTs compared different training interventions [25,41] and in one RCT the training intervention was compared with controls on the waiting list.[40] As to the quasi-experimental designs, one study used a within-subject design in which participants received three different training interventions.[31] the other study used a counterbalanced self-controlled cases series in which both healthy controls and participants with dementia were trained individually.[44] Eleven articles reported experimental case studies, of which six were single-case studies [30,32,35,38,42,43] and five multiple single-case studies.[33,34,36,37,39] Three single-case studies and three multiple single-case studies applied an ABA design, where A represents the measurements and B the intervention.[30,33,34,37,42,43] One single-case study [42] and three multiple single-case studies had a multiple baseline design [33,34,36], one study a multiple baseline design by activity [30] and one study a multiple-baseline across-subjects design.[39]
In all studies the number (percentages) of correct responses or correctly executed steps done without help was an important outcome measure and of these studies the number of correct responses or correct steps was assessed during the intervention with the exception of two studies.[40,41] In twelve studies the number of correct responses or correct steps was measured at baseline and at post-intervention assessments.[25,30-32,36,37,39-44] In some studies the response was scored according to the degree of assistance needed to perform the task [32-35,39,40] and in two studies performance of tasks was divided into implicit performance (or knowledge) and explicit performance (or knowledge).[25,31]
All studies reported the maintenance of treatment gains. In twelve studies follow-up assessments were performed and in the remaining four studies it was reported how participants used the learned technology in a real-life context.[33-35,38]

Learning effects and efficiency

- Group studies (RCTs and quasi-experimental designs) using EL and/or EF approaches to (re)learning mostly IADLs (Table 4.3a):

In five experimental group studies, three RCTs and two quasi-experimental designs, the training interventions contributed to significant improvements in task performance at post measures including follow-up.[25,31,40,41,44] An average of 46% in performance across studies at baseline improved to 60% at post measures, which was maintained at follow-up assessments with an average of 60% after 6 weeks (range from 1.5 to 15 weeks). The studies, one with a sample size of n=161 [41], showed that participants with dementia were able to relearn, mostly IADL-orientated tasks, regardless of the type of training intervention, i.e. EL approaches versus EF approach [25,41] or explicit (verbal instructions, with errors) versus implicit (modelling, preventing errors) training intervention methods.[44] In one study performances of the implicit training method in both the control and the experimental group decreased significantly at follow-up compared to post-intervention [44] and in another study performance in the EL group decreased the most at follow-up.[25] However, in one study with a small sample size *(n=14)* the EL approach, consisting of modelling with SR and a stepwise approach with feed forward instruction, resulted in a significantly better learning effect compared to the EF approach.[31] There was even a slight improvement after EF at post measures, which was not, however, maintained at a 3 week follow-up.[31] In another study, EL elements, such as a stepwise approach, modelling and SR versus no training intervention, resulted in significantly better performance of the experimental group.[40] In the experimental group studies participants needed an average of 8 sessions of 56 min during 4 weeks to learn and improve task performance (average intervention time across the studies).

- Experimental (multiple) single-case studies using EL approach to (re)learning handheld touchscreen devices (Table 4.3b):

The EL approach, consisting of a stepwise approach, modelling and verbal instructions, was used in three experimental single-case [35,42,43] and two multiple single-case studies.[33,34] Participants were taught to use a smartphone or a tablet. Studies found an improved task performance after learning sessions and/or at post measures. An average of 40% in performance across studies at baseline improved to 90% at post measures and was maintained at follow-up with an average of 78% after 33 weeks (ranged from 4 to 52 weeks). Transfer in everyday life was difficult in the two multiple single-case studies. In one case this was because the participant lived alone [34] and in the other case the severity of the participant's cognitive problems became an obstacle.[33] In these (multiple) single-case studies participants needed an average of 9 sessions of 47 min during 5 weeks to learn and improve task performance (intervention time across the studies).

- Experimental (multiple) single-case studies using EL approach to (re)learning a variety of technology tasks (Table 4.3c):

In one experimental single-case [38] and two multiple single-case studies [37,39] EL elements such as a stepwise approach were used in combination with the SR method, and in two (multiple) single-case studies [32,36] in combination with the VC method. Participants learned to successfully operate (mobile) telephone devices and IADL [32,36-39] and succeeded in maintaining autonomy in these tasks.[32,38,39] One single-case study used three combinations of error-reduction methods to teach the participant how to use a cassette radio and video cassette recorder.[30] The stepwise approach with VC method was successful for learning the target functions, but maintenance, transfer and spontaneous use of target functions, learned with the SR method, remained difficult.[30] In these (multiple) single-case studies, an average of 46% in performance across studies at baseline improved to 92% at post measures and it was maintained at follow-up with an average of 89% after 12 weeks (range from 5 to 26 weeks), with one missing value of performance at follow-up.[38] In addition, participants needed an average of 13 sessions of 66 min during 8 weeks to learn and improve task performance (average intervention time across the studies) with two missing values of duration of sessions in minutes.[32,38]

Discussion

All studies (25, 30-44) that were included in this review reported improvements in task performance in people with dementia (re)learning how to use technology, regardless of training intensity, setting and method they used and whether they had mild or moderate dementia. The successes were not limited to the studies that used EL and were not limited to simpler tasks, such as making tea with an electric kettle.

In the experimental group studies, we did not find evidence that EL, compared to EF, resulted in e.g. improved task performance, except in one study [31] with a smaller sample size. This is in contrast with the findings of De Werd *et al.* (2013), who concluded that EL is more effective than EF for people with dementia when learning everyday tasks. However, they also included studies that focus on (re)learning names of objects or other daily tasks instead of solely focusing on the use of technologies. In most of the studies in the review by De Werd *et al.* (2013), only error-reduction training interventions were used, which resulted in improved task performance. Also, in most of the studies included in our review, i.e. in two experimental group studies [40,44] and eleven experimental (multiple) case studies [30,32-39,42,43], only error-reduction (EL) training interventions were used. Although the EL training generally resulted in improved outcomes, the task performances in three studies using EF training interventions also improved. Hence, based on this review we cannot conclude that EL training interventions are more effective than EF training interventions. Nevertheless, our review contributes to additional evidence for the potential impact of EL training interventions when people with mild to moderate dementia (re)learn how to use technology.

Most of the studies included in this review used a combination of error-reduction training interventions, i.e. a stepwise approach with a demonstration of steps (modelling) supported by verbal or visual instructions. Unfortunately, the content of training components between the different studies is inconsistent and studies also vary regarding the details described in the training components. This makes it difficult to determine which components contribute most to learning. Also, combinations of EL elements with SR and VC were tested, which generally resulted in positive outcomes [30,32,36-39], which is in line with findings of previous reviews [23,24,45] and with studies on supporting people with mild to moderate dementia in IADL that did not meet the inclusion criteria of our search.[46,47]

When we focus on training interventions for people with mild dementia to (re)learn how to use the smartphone or tablet, which was the specific purpose of this review, studies of Bier *et al.* (2015) [42,43] showed that fewer EL sessions (5-7) were needed for learning new smartphone functions than the 8-12 sessions needed in the studies by Imbeault *et al.* (2014; 2016; 2018) [33-35]. Moreover, in studies by Bier *et al.* (2015) these sessions proved to be sufficient for continued regular use of half of the learned app functions at a six-month follow-up. In the studies by Imbeault *et al.* (2014; 2016; 2018), on the other hand, between 5 to 16 sessions were needed to learn "how" and "when" to use the app, and between 5 to 23 extra sessions were needed for transfer to/spontaneous use in daily life, and this remained difficult in two cases.[33,34] Possible explanations for these variations in training sessions may be that participants in the studies conducted by Imbeault *et al.* (2014; 2016) were older, had Alzheimer's dementia, one participant lived alone and none of the participants had touchscreen experience. In studies of Bier *et al.* (2015), participants were relatively young, had Semantic Dementia, all lived with their partner and they already had touchscreen experience. Other studies acknowledge that people are more likely to be able to engage with technology if they have learned how to use it before the onset of dementia [10,48] and that support of informal carers in the home environment must be sufficiently frequent and ongoing.[9]

Nowadays the use of ICT applications is becoming an integral part of everyday life, even among the older generation and people with dementia. Recent reviews show that touchscreen technology is feasible and can improve the well-being of people with dementia (8-10). This increases the need to design digital systems and applications that can be used by all, regardless of physical or cognitive impairments [49], along with appropriate support for learning to use them.[9]

Strengths and limitations

This is the first review that examines which training interventions are most appropriate for people with mild dementia to (re)learn how to perform technology-orientated tasks. This review contributes to the body of knowledge concerning effective training interventions to help people with dementia (re)learn how to use technology, including the use of

touchscreen technology. This is important, because so far it is unclear whether proven best learning methods for people with mild to moderate dementia are also applicable to the teaching of how to use technologies that are complex and at times may be difficult to learn.

The scarcity of available studies forced us to include different study designs with different levels of evidence. We included quasi-experimental and (multiple) single-case studies with small sample sizes in this review, because RCTs were limited for technology training interventions studies in people with dementia, which is also acknowledged in De Werd *et al.* (2013).[23]

Another potential limitation is that this review may not have included all studies that involved training interventions to assist people with mild to moderate dementia in learning to use technology, as we only searched databases related to health and social sciences, not databases specifically related to technology only. However, relevant journals focusing on a combination of healthcare and technology were also indexed in these databases. We may have missed studies due to the selected keywords we used when searching, but we made a concerted effort to be as comprehensive as possible. Although our search strategy had a broad set-up and covered a wide range of training interventions and we used a transparent selection process, all studies included in this literature review used the EL approach as a training intervention. Moreover, only studies in English and Dutch were included. This may have caused publication bias within and across studies.

Implications for research and practice

Regarding the uptake of touchscreen technology by people with mild dementia, there is a growing need to build on evidence that supports best practice and to recommend and implement meaningful activities via handheld touchscreen devices.[9] Therefore, more evidence is necessary to find the most appropriate and effective training interventions to help people with mild dementia learn these skills and informal carers how they can support this. To date high quality training intervention studies are lacking, the included studies had small sample sizes and many of them were (multiple) single-case studies. Moreover, the content of the training interventions was not consistently described and used across studies. This makes it difficult to draw conclusions on which training interventions are most successful. In addition, there was little variation in training interventions, the EL approach was included in all studies. In future studies, in addition to EL, investigation of other training interventions for (re)learning the use of technology, such as associative learning [50], is recommended. Furthermore, there is a lack of reliable information about how informal carers can successfully support their relatives with dementia during training intervention. In the studies described in this review, the researchers or therapists provided the training, but successful implementation in the home environment requires ongoing support of informal carers.[9] Although training interventions to assist those with mild to moderate dementia to (re)learn technology-driven tasks proved to be feasible, the

findings were not comparable due to the variations in study design, content of training interventions and technology tasks. Future studies should consider using more consistent training methodologies and more robust study designs, such as RCTs, to evaluate the effectiveness of training interventions for (re)learning technology-orientated tasks, including tasks to operate mobile ICT devices.

Conclusion

It is promising that people with mild dementia can (re)learn technology-driven tasks such as using handheld touchscreen devices. An increasing number of ICT applications for self-management and meaningful activities, which can also potentially support people with mild dementia, are becoming available. This may help increase their autonomy and reduce social exclusion, and thereby improve their quality of life.

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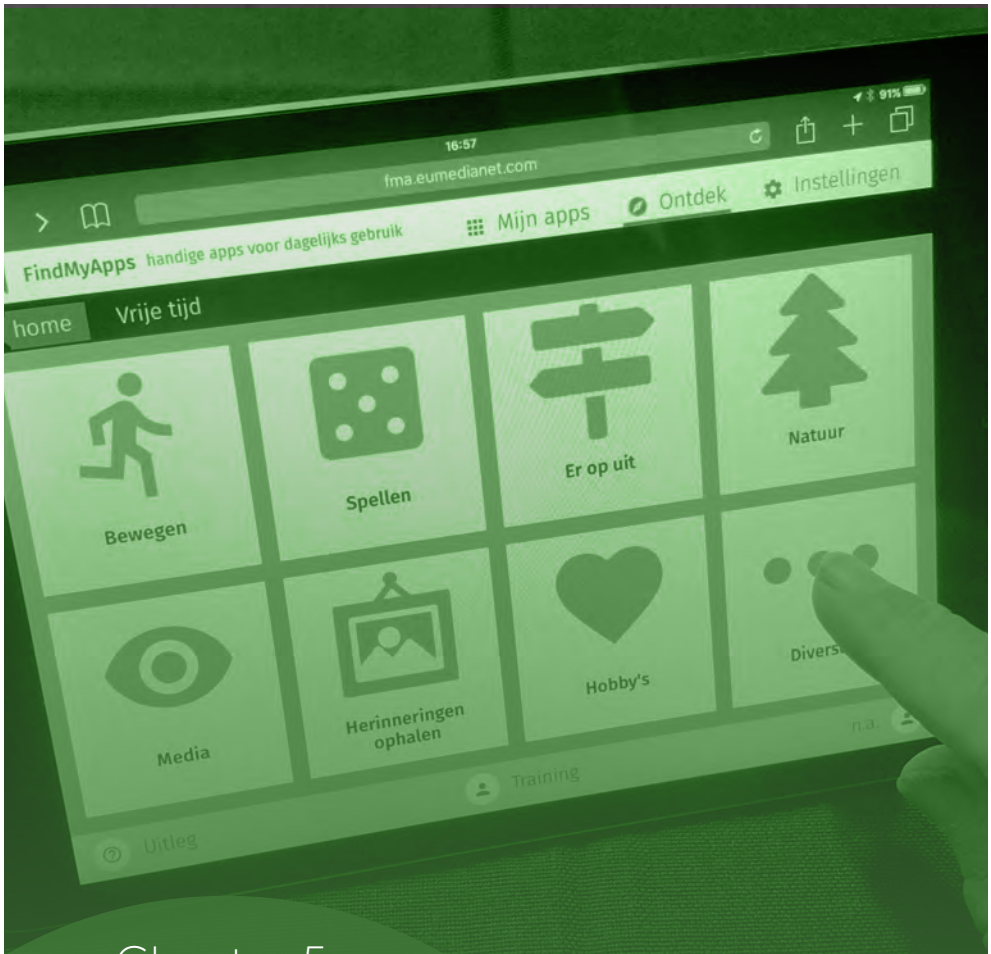

Chapter 5

User-participatory development of FindMyApps: a tool to help people with mild dementia find supportive apps for self-management and meaningful activities

Published as

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Abstract

Objective

There is growing evidence that hand-held touchscreen devices (tablets) can support people with mild dementia to manage their life and engage in meaningful activities. However, as it can be difficult to find apps that match one's personal needs, wishes and abilities, a person-centred selection tool was developed, called FindMyApps.

Methods

To ensure its usability, the FindMyApps selection tool was developed using a 'user-participatory design' in which users (persons with dementia and informal carers), and experts (designers, developers and researchers) closely collaborated. In three short iterative rounds so called 'sprints' the users were invited to test whether the prototypes harmonized with their needs, wishes and abilities.

Results

Each sprint provided insight into potential improvements of the tool. The development team gained an understanding of issues regarding usefulness (e.g. meaningful content of (sub)categories for apps in domains of self-management and meaningful activities), as well as issues to increase the user-friendliness (e.g. intuitive design with instructive navigation support).

Discussion and conclusion

The FindMyApps selection tool was conceived as a means to make it easier for people with mild dementia to select apps meeting their needs, wishes and abilities. This provisional end version will be further tested and, if necessary, improved in a feasibility study.

Introduction

Research shows that 70% of people with dementia stop engaging in activities due to lack of confidence, 50% avoid the neighbourhood and 40% hardly leave their home.[1] Community-dwelling people with dementia and their informal carers report a lack of meaningful activities during the day.[2-5] In the early stage of the disease people experience insufficient support from professional caregivers and health care services to compensate for self-management disabilities.[6] The inability to organize one's own affairs can be very difficult to accept.[7] 54% of the carers feel rather heavily burdened and 9% feel very heavily burdened or overburdened.[8] High burden of carers frequently results in admission of the person with dementia to a long-term care facility.[9]

The current policy in Western countries is to enable people with dementia to live in their own home for as long as possible.[10] This implies that they will need to adapt to and deal with the consequences of dementia in their daily life [11] in so far as is possible. Touchscreen technologies, such as hand-held touchscreen devices (tablets), are promising tools to support people with mild dementia in their ability to self-manage and engage in meaningful activities.[12,13] In the last decade, many applications (apps) for tablets were developed to support people in managing their daily life and health, staying in touch with their social network and engaging them in activities.[14] Although people with dementia need support to learn how to use touch screen devices [15-21], there is growing evidence that apps also have potential to support people with mild dementia for these purposes.[15-20,22-28] In the areas of self-management, for example, there are apps for timely medication intake (MedAlert), social contact (Nextdoor, Skype), daily structure (Dementia app, Pictoplanner), navigation (Blokje Om), language and communication support (Dario App) and a variety of apps for meaningful activities (memory training, art, history, reminiscence, music, games).

However, careful selection is required, as just a small part of the existing apps is usable for individuals with dementia.[16,20,29-31] One could formulate a top ten of most suitable apps for people with mild dementia to match the needs, wishes and abilities of the person with dementia. Yet this would make no sense since needs, wishes and abilities can differ strongly between people due to specific disabilities and personal, social and environmental factors.[32] Moreover, with the rapid development of new apps, this top ten would be quickly out of date. Nowadays, the use of apps on hand-held touchscreen devices is becoming an integral part of everyday life, also among the older generation.[33] This increases the need to design digital systems that can be used by all, regardless of physical or cognitive impairments.[34]

The present study therefore intended to develop an interactive selection tool (web application) that would be able to find apps for self-management and meaningful activities that suit individual needs, wishes and abilities of people with dementia. This paper aims to provide a clear insight into this developmental process. The specific goal of the selection tool is to match the preferences and abilities of people with dementia

to specific features and app types in order to improve and, ultimately, promote their app usage for the purposes of self-management and engaging in meaningful activities.

Within the context of self-management and meaningful activities, the tool was based on an extensive inventory of the functional selection criteria of apps that related to the activities in which persons with dementia wished to engage and an inventory of the technical selection criteria that related to their ability to use apps.[35] The tool will be used together with an introductory training to help people with dementia and family carers to learn to use the tablet, part of an innovative person-centred tablet intervention[36] called FindMyApps. To develop the FindMyApps selection tool, the following research question was addressed:

How to develop a selection tool that helps people with dementia find suitable apps for self- management and meaningful activities (selection criteria) that match their individual needs, wishes and abilities (user profile)?

Methods

Research design

To develop the FindMyApps selection tool we used a user-participatory design.[37,38] Qualitative research methods were applied to identify needs of users and usability issues (usefulness and user-friendliness). Usefulness refers, among other things, whether users believe that a website or application fulfil specific needs or whether it helps them to be more effective and productive.[39] User-friendliness (ease of use) refers, among other things, whether users believe that using a website or application will be easy and simple to use.[39] The development of the FindMyApps selection tool was inspired by the User Experience (UX) design and Agile methodology. The overall rationale behind UX design is that knowledge comes from user experience. Design decisions are made based on how users interact with the design.[40] Agile is a set of methods that help a team to think more effectively, work more efficiently, and make better decisions.[41] Derived from Agile methods, the working process was structured according to the Scrum and Kanban method. The Scrum method is an innovative method to design and evaluate a temporary product in short iterative sprints.[41] The Kanban method adds that every sprint starts with transparency about all the to do actions and the development team deciding, based on the aim to limit the work in progress which actions are to be achieved in one sprint.[41]

Three iterative sprints

Based on the Scrum method [41] and user-participatory methods [42,43], the following phases represent one sprint:

- Phase I: Design, collecting theoretical data: needs, wishes and abilities of users (user requirements) with regard to the desired design;
- Phase II: Development, converting these data (user requirements) in mock-ups;
- Phase III: Usability tests, testing to ensure that the selection tool meets the user requirements;
- Phase IV: Discover usability issues to improve the selection tool and discover needs for further development (adapting user requirements or creation of new user requirements).

The progression from one sprint to another was conducted as an iterative process, i.e. returning to the phase of design and development based on feedback or new information collected during a sprint. This provided the opportunity to optimize the selection tool constantly according to the needs, wishes and abilities of users. The three sprints were conducted over a 9-month period, from March 2017 to November 2017 (see Figure 5.1).

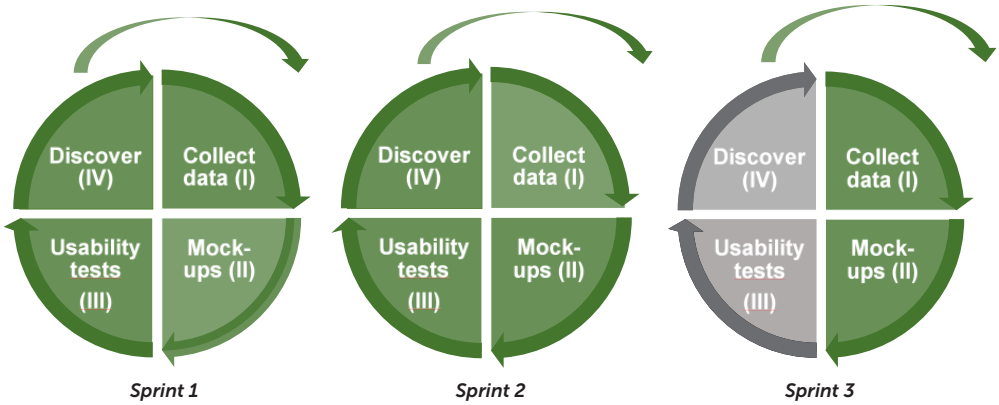

Figure 5.1 Development of FindMyApps selection tool in sprints (green phases carried out during this study)

During all sprints, researchers from Saxion University, developers and designers from a software company worked together (development team) with potential users (community-dwelling people with mild dementia, informal and formal carers), experts in person-centred dementia care and ICT experts (expert team). The result of phase II in the third sprint is a provisional end version of the FindMyApps selection tool. Although originally three complete sprints were pre-planned, sprints 1 and 2 provided us with enough rich data about how the users interacted with the tool. On the basis of these data, new improved prototypes were developed (phase I and II of sprint 3). Subsequently, additional information collection will be needed on more sustainable usability issues. It is expected that users can only provide this information after having used the tool for a longer period

of time. We will investigate these usability issues in a controlled pre-posttest feasibility study into FindMyApps (phase III and IV of sprint 3) that is yet to be conducted and will be described in a separate paper.

Methods phases I and II: Design and development

The development team used Confluence - project management software. In Confluence it is possible to plan and register the actions of sprints, to chat with each other, to share documents and notes of meetings and to present prototypes. The development team met every two weeks. They discussed the design and content of the FindMyApps tool with an expert team on a monthly basis. During the first meeting with the expert team, the major principles of the tool were established on the basis of the scientific literature [6,7,44], our previous study [35] and best practices [45-47] as well as the intended functionalities in FindMyApps. The developers and designers from the software company translated these principles into a program of requirements. Mock-ups were created in each sprint and these were tested in order to assess whether they met the requirements. The development team and expert team also discussed the additional wishes and needs and inventoried these in order to improve the tool's prototypes. This process continued until the prototype met its predetermined requirements. A cognitive walkthrough took place within the second *(n=4)* and third sprint *(n=5)* by both researchers and experts. They explored the tool by performing a series of tasks (assignments) aimed at identifying potential usability problems that could impede the successful completion of a task.[48] A task is a realistic example of how users can use the tool. This cognitive walkthrough was not performed in sprint one because we wanted to record the first spontaneous reactions of participants. After integrating all feedback from a sprint and redesigning the tool to address the usability issues from the cognitive walkthrough, the next phases started, i.e. usability testing with potential users and discovering new usability issues.

Methods phases III and IV: Usability testing and discovering usability issues

Setting and participants

Participants for the usability tests were recruited with help of two Meeting Centres for people with dementia and carers and one day care centre for people with dementia, all located in the eastern part of The Netherlands (Enschede and Doetinchem). Inclusion criteria were community-dwelling care-dependent people with mild dementia, with and without a confirmed diagnosis. Inclusion criteria for the informal carers were caring for a person with possible dementia in an earlier stage. For the usability tests of the FindMyApps selection tool participants had to be willing and able to perform a usability test on a tablet (to trial the tool). Two participants with dementia who volunteered to work with us lacked the ability to perform the tests and their input was not used in our research.

In the first and second sprint eight persons with dementia, eight informal carers and two formal carers participated in the usability tests.

Qualitative methods and study procedure

The prototypes of the selection tool that resulted from phases I and II of sprints one and two respectively were installed on tablets. The method of 'scenario-based testing' was applied during the usability tests.[48] The scenarios (three in sprint 1 and five in sprint 2) concerned realistic examples of how users may carry out tasks in a specific context with the tool.[48] An example of a scenario was: 'In your younger years you had a special interest in painting. Now you would like to paint again. We invite you to search for an app that may support you in performing this activity'. The Three Step Test-Interview (TSTI) principle was applied within each scenario to identify usability issues with regard to the content and design of the FindMyApps tool. The TSTI method consists of three steps [49]:

1. (Respondent-driven) observation of respondent behaviour as they use the tool while 'thinking aloud';
2. (Interviewer-driven) retrieval of additional data by follow-up probing aimed at remedying gaps in observational data;
3. (Interviewer-driven) validation via semi-structured debriefing aimed at eliciting experiences and opinions with regard to tool .

The TSTI method is usually performed by completing every step for each scenario and subsequently going to the next step for each scenario.[49] However, because of the memory problems of the target group, the TSTI was adapted by performing all three steps per scenario consecutively. In sprint 2 this method was further adapted as we noticed their (limited) short-term memory made it difficult for the target group to share their experiences and opinions afterwards. So, for a more natural sequence we decided to combine steps 2 and 3. Perceiving difficulties in the target group's ability to imagine the standard scenarios we adapted the scenario-based testing method in more realistic assignments closer to the individual users' preferences and interests. An example of an assignment was: 'Which activity would you like to do? Try to find an app for that activity'.

The interviews were conducted by two researchers (YK and MPK), in the roles of primary interviewer and observer, the latter being responsible for reporting the interview observations. The researchers alternated the roles of interviewer and observer. All interviews were videotaped to capture the full context of the interviews, in particular how the users interacted with the design while they were using the selection tool on the tablet.

To provide an in-depth understanding of the results, quotes supporting the observed behaviour of participants were included. To ensure confidentiality and anonymous presentation of the data all participants were given a number (1-8) with letters to identify whether they were a person with dementia (PwD), an informal carer (IC) or a formal carer (FC). For this article we selected extracts, based on what was most illustrative for the development of the selection tool, to illustrate the main content of the data.

Data analysis

Three types of data were collected during the usability tests and used for the analysis:

i) participant characteristics and tablet/smartphone experiences by means of a short questionnaire;
ii) observed behaviour of participants during the interview reported in notes and on video-tape;
iii) detailed descriptions of participant observations per scenario/assignment in Microsoft Excel.

These descriptions were based on analysis of the videos and the notes on observed behaviour of participants during the interviews. A deductive analysis was performed, as we were particularly interested in the usability (usefulness and user-friendliness) and needs for further improvement of the FindMyApps selection tool. The usability tests, which contained pre-defined scenario's and assignments for participants, led to participant reactions that required the use of a deductive analysis procedure. This approach matches the study's specific interest regarding issues that could help to improve the usability of the tool. The following observations and analyses were applied during the sprints:

1. Two researchers (YK and MPK) independently noted any relevant behaviours that were observed during the usability tests and also made notes whilst viewing the video tapes. Both the transcribed statements as noted behaviours as in free text descriptions, were then coded by both researchers. This procedure of independent coding was followed by a consensus meeting.
2. The researchers mutually grouped the codes into themes.
3. Researchers YK and MPK sent the developers and designers the so-called condensed raw data in an Excel document, which clearly explained the process from the coding to the themes. The developers and designers had instructed the researchers to only present the observed and transcribed behaviours and to refrain from providing possible solutions for the barriers that the users had faced, as this would have influenced the designers' creative solution process. An example of one such theme was called: input for improving icons.
4. As a last step, the researchers divided the inventoried themes into two main categories, i.e. themes that were relevant to the tool's content (self-management and meaningful activities) and themes that were relevant to the tool's design.

A summary of the findings of the usability tests was sent to the software company and discussed in a meeting with the development team. Subsequently, directions were formulated to improve the tool, which were converted into actions for the next sprint.[41]

Ethical considerations

The Medical Ethics Committee of the VU University Medical Centre in Amsterdam approved the study protocol. After receiving written and oral information about the research and prior to participation in the usability tests all participants signed an informed

consent form. During the tests with persons with dementia we performed an on-going consent procedure by regularly asking them if they were still comfortable with their participation.[50] We created a safe environment by spending time getting to know the people, giving them positive feedback, emphasizing the importance of their participation, recognizing signs of discomfort [50], and through the use of a written time schedule (A3 paper size) that allowed participants to see what was going to happen at any given time.

Results

Participant characteristics for sprints 1 and 2 of the usability tests

Both usability tests involved the participation of four community-dwelling persons with mild dementia or Mild Cognitive Impairment (MCI) (one female, seven males; mean age 78.6 range.[72-86] Five of these participants had Alzheimer's disease, two had Frontotemporal Dementia and one had MCI. Most of the participants were married, had graduated from college and had experience with using tablets or computers. Five informal carers participated in sprint 1 of the usability tests while three informal carers

Table 5.1 Basic conditions, content and design of the tool

Basic conditions	Content tool	Design tool
A person-centred selection of apps: The tool will ask questions about the individual needs, wishes and abilities of persons with dementia in the area of self-management and meaningful activities (user profile) and match their answers with specific apps (selection criteria).	Determine what (sub)categories of self-management and meaningful activities are most appropriate for the tool and determine how to organize these activities. This was based on functional selection criteria of apps [35], articles about self-management programs for people with early dementia [6,7,44] the Activity Card Sort [45] and daily activities for young people with dementia. [46]	Make prototypes right from the start, using a responsive (touchscreen based) website, to try what works and what does not. The website will be made for Android and iOS.
Persons with mild dementia may need help from an informal carer to set the user profile, select and download apps. They can use apps on the tablet independently.	Determine technical selection criteria for rating dementia-friendly apps for the (sub)categories of self-management and meaningful activities, based on technical selection criteria of apps [35] and the App Selection Framework Guidance Manual.[47] Next, rate available apps for self-management and meaningful activities on these determined selection criteria. Most of the apps were found on sites of organisations related to dementia.	Design and develop different prototypes not all at once, but better to develop prototypes after each other.
Persons with dementia are seen as the real experts and this means that when they can use the interface without problems, this is the best guarantee that it works.	Determine what selection criteria (personal settings) are needed for the user profile. This was based on user characteristics addressing abilities of users in terms of their physical and cognitive condition and tablet skills.[35]	The tool will consist of a front-end (looks like (in landscape mode)) and a back-end (administration and definition user profiles/app selection and user statistics). The front-end is based on essential heuristics for interfaces of people with dementia. [30,35,47]

participated in sprint 2 (four females, four males; mean age 73.1 range 58-82). Most of these participants were married to persons with dementia who had Alzheimer's disease and each of them had graduated from college and had experience with either tablets or computers. One formal carer participated in each of the usability tests (two females; aged 48 and 54). Both participants had graduated from college and had experience with using tablets.

Results, sprint 1

Results, design and development (phases I and II)

Table 5.1 presents the decisions regarding the major principles for the basic conditions, content and design of the tool, made by the development and expert teams during the first meetings. However, as user experience with the content of the tool was highly relevant, these principles needed to be confirmed and specified during the development.

In the program of requirements for the first sprint, the following user-interface aspects were prioritized:

1. The organization of (sub)categories of apps for self-management and meaningful activities and navigation within these (sub)categories;
2. The presentation of apps within a (sub)category;

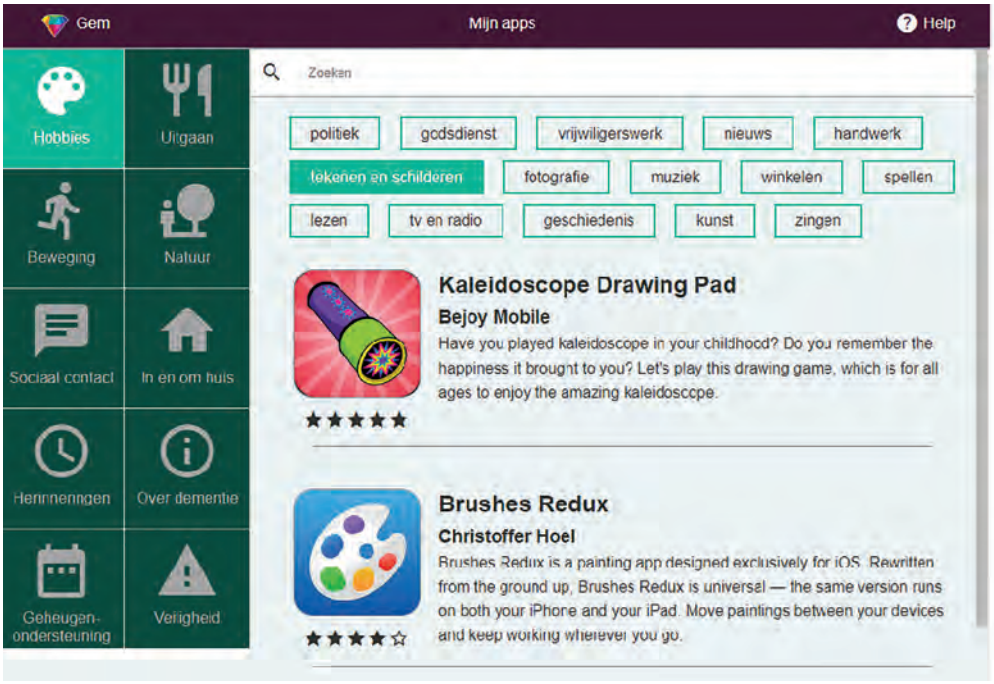

Figure 5.2 Prototype 1.3. selection tool as a result of phases I and II of sprint 1 ©Bejoy Mobil 2016 and ©Steve Sprang (Christoffer Hoel).

Table 5.2 Description of prototypes that had been provided for testing with users

Sprint 1 Prototype 1.3	**Front-end, pages** - A search page ("Zoeken") with ten categories on the left side with text, icons of self-management and meaningful activities (hobbies, going out, exercise, nature, social contact, in and around the house, memories, about dementia, memory support and safety). By pressing a category and subcategories (in text blocks) apps became visible. A (sub)category could also be searched in the search bar at the top of the screen. - A page with an overview of the most frequently used apps per category ("Mijn apps"). - A page for setting the user profile at the bottom of the screen ("Mijn profiel"). - A help button at the top right-hand corner of the screen (not functional in this prototype). - Navigation to other pages using the navigation bar at the bottom
Sprint 2- Prototype 2.4	**Front-end, pages** - A home page ("Begin") with two big buttons. One for entering the search page ("Zoeken") and one for entering the overview of most used apps ("Mijn apps"). - Search pages ("Zoeken"): - A page presenting ten categories with text and icons of self-management and meaningful activities (in and round the house, social contact, hobbies, games, exercise, nature, going out, memories, reminders and safety). - A page (after pressing a category) where subcategories with text and icons in the same colour of the overarching category become visible. - A page (after pressing a subcategory) with app selection. When pressing the image of the app, the choice to download can be made and the instruction video 'how to download an app' starts. After that a blue button becomes visible to go to Apple Store (iOS) or Google Play (Android). - A page with an overview of most used apps per category ("Mijn apps"). - A page for setting the user-profile ("Instellingen") with two big buttons that give access to the following two pages: o A page for using and changing the apps' personal settings, which contains six questions about the personal preferences for the apps, e.g. large font size; less text and plenty of pictures; only available in Dutch; real photos; simple to operate and includes instructions (Kerkhof et al., 2017). o A page for using and changing the personal settings for the FindMyApps tool, which contains questions about the personal preferences for the FindMyApps tool usage, such as choice of letter size; choice to change the icons of the categories of self-management and meaningful activities into photos, etc. - A help page where users can find the instruction video 'How to find and download an app of your interest' and where an explanation of several pages was given. A green button ("Hier") on every page offered visual and audio instructions on how to navigate the page. - Navigation to other pages using the navigation bar at the bottom with bigger and clearer navigation icons. A purple bar at the top provided on every page location information and offered the possibility to go back
Sprint 3 Prototype 3.5	**Front-end, pages** - A simple log-in page. - A page for setting the user profile containing the same six questions (see prototype 2.4) about personal preferences for apps ("Instellingen"). - A page for choosing main categories and subcategories of self-management and meaningful activities ("Ontdek"). - For each subcategory a page with a selection of apps and a sentence describing each app. The best apps will be recommended with a higher score ("Ontdek"). - For each app, a page including (a) more information about the app; (b) app score details based on personal settings; (c) button for accessing the Apple Store or Google Play ("Ontdek"). - A page with an overview of most used apps arranged by subcategory ("Mijn apps"). - A help tutorial on every page ("Uitleg"). - Navigation to other pages using the navigation bar at the top. **Back-end** Consisting of: (i) a user environment where user profiles are made and where the selection of apps is carried out; (ii) an administration environment where user profiles, apps and selection criteria are defined and (iii) a reporting environment where information about the user profiles and the use of the tool (during the feasibility study and RCT) can be automatically stored.

3. The navigation to the user profile and to change the personal settings, e.g. letter size of apps and letter size of the tool.

Mock-ups and prototypes were created and subsequently tested by the researchers. Prototype 1.3. (see Figure 5.2 and Table 5.2 for a description of the prototype) was ready to be trialled in usability tests.

Results, usability tests and discovered usability issues (phases III and IV)

Scenarios, based on the above described user-interface aspects, were formulated for the usability tests. The section below contains the main observations and quotes that were made by the users for each scenario. Lastly, some general observations and quotes about the tool are mentioned.

Scenario 1: 'In your younger years you had a special interest in painting. Now you would like to paint again. We invite you to search for an app that may support you in performing this activity'

Most users with dementia needed more support to select the right (sub)category due to three problems:

1. The category names and icons were not clear and too many and overlapping options for subcategories. *'Can I find an app for painting under art or under drawing and painting?*' (PwD1). *'Too many blocks for subcategories; is too messy and creates too many stimuli for persons with dementia'* (FC1).
2. When a category was selected, apps became visible immediately. This was distracting and users then forgot to make a further selection within the subcategories.
3. The boxes and letter sizes of the subcategories were too small. *'I have trouble reading the small letters'* (PwD4).

Scenario 2: 'You have problems with planning and maintaining overview of activities during the week. a) Could you search for an app that may support you in this?
b) Choose an app that could help you the best'

None of the users directly selected the category 'memory support' (where the planning app can be found). Most users could not decide between 'social contact', 'memories' and 'memory support'. Main reasons were that 'memory support' is a vague term and that the 'memory support' icon was not clear. *'I think it is a vague term. Can't visualize what it is. I think it is a professional term'* (IC4).

The same three problems for selecting a (sub)category were observed as in scenario 1. Most users needed more instructions to select and download an app because of three problems:

1. It was frustrating that the descriptions of apps in the tool were too long, not clear and that they were in English.
2 Most users with dementia were not aware of the possibility to scroll down in the apps

list, to see more apps.
3. Steps to be followed were not clear (i.e. enter the page of Apple Store, scroll down, download the app and go back to the tool). *"I doubt whether this app is the right choice. I should be able to tell immediately. Now the person with dementia has to search for this information and gets discouraged. The person wants to go back, but it is not clear how to go back?"* (IC4).

Scenario 3: 'You think the letter size of the app you selected is too small. You forgot to set the preferred letter size. Adjust the preferred letter size in "your profile"
None of the users pressed the button 'My profile' in the navigation bar at the bottom because of three problems:
1. The navigation bar was not noticed because users were focussing on the ten categories.
2. The term "My profile" was not recognizable for users as a page where you can change letter sizes. *'I have no idea'* (PwD3) (question researcher: do you have a clue what to find behind 'My profile').
3. The icons in the navigation bar were too small.

Once users were in the profile, most of them did not understand how to operate the personal settings and they did not understand the meaning of the personal settings. *'I am not pressing the 'little' button, because then the letter sizes become even smaller'* (IC5).

General observations and quotes about the tool:

Most users had problems operating the buttons of the prototype. They had to press more than once for buttons to react. Colour use in the prototype was experienced as clear and quiet. *'Nice quiet colours no hard colours. It has to have calm colours'* (IC3).
For most users with dementia the functionality of the tool was not immediately clear, but once they were informed they were enthusiastic about it. This was also true for the IC and FC. *'Nice tool, a progression. When you search for an app, it is already there. That's easy*' (PwD1).
One user with dementia was curious what was in the category 'about dementia'. It distracted her and kept her from continuing the usability tests. Another user with dementia found it confronting to see this category. '*I don't look at 'about dementia'; it is bad enough that I have it. It doesn't bother me, but I don't look at it*' (PwD3).
None of the users noticed the search bar at the top where they could type in (sub) categories of activities.

Results, sprint 2

Results, design and development (phases I and II)

Based on the discovered usability issues developers and designers of the software company translated these data into a new program of requirements. In the second sprint it was decided to improve the following user-interface aspects:

1. To provide the users with an instruction video and with more visual and audio instructions for operating the tool on every page.
2. To make a clear distinction between the personal settings of usable apps and the personal settings for the FindMyApps tool.
3. The organization of (sub)categories of apps for self-management and meaningful activities. Since there were too many and overlapping subcategories, it was decided to delete the subcategories for which no apps were available.
4. To present the subcategories in the same way as the categories. To make use of different colours for each category and apply those same colours to the subcategory.
5. To work on better recognizable icons/pictures for the presentation of the (sub) categories and for the navigation bar.

For point 3 we needed to start selecting dementia-friendly apps in the self-management and meaningful activities domains that were to be included in the library of the FindMyApps tool. Apps were carefully selected by students based on an assessment for dementia-friendly apps (see Table 5.3). This assessment was based on a set of important app criteria with regard to interaction, feedback, aesthetic design, app design, customization, obstacles and age appropriateness.[30,47] For each app, a maximum of 30 points could be scored; apps which scored 20 points or higher were added to the FindMyApps library.

Table 5.3 Score sheet for assessing dementia-friendly apps

Category	Criterion	Good (3 points)	Sufficient (2 pts)	Insufficient (1 pt)	Score
1.Interaction: type of gesture	What type of gesture is needed to operate the app?	Swipe and clicks	Swipe, clicks and one other type of gesture	Other types of gesture than swipe and clicks	
2.Interaction: control panel	Does de app contain large, medium or small buttons?	Large >2cm	Medium 1-2cm	Small <1cm	
3.Feedback: visual and audio	Is there visual & audio feedback when operating buttons?	Both visual and audio	Visual or audio	No visual and no audio	
4. Aesthetic design: size of text	Which size of letters is used in the app?	Large (16)	Medium (11-15)	Small (10)	
5.Aesthetic design: contrast and background	Do colours of interactive elements contrast well against background?	Both good contrast and clear background	Good contrast or clear background	Bad contrast and no clear background	
6.App design: intuitive use	How recognizable are the buttons and how user-friendly is the app?	Recognizable buttons and user-friendly	Recognizable buttons or user-friendly	No recognizable buttons and not user-friendly	
7.App design: Instructions/ help tutorial	Is there a help tutorial (instructions) and is this usable?	Usable help tutorial	Complex help tutorial	Not available	
8.Customization: language	Which language possibilities are available?	Only Dutch	Dutch and English	Only English	
9.Obstacles: adverts/ light version	Does the app contain (disrupting) adverts?	No adverts and no light version	Light version	Pop-ups and adverts	
10.Age appropriateness:childish	Is the app childish?	Not childish	For both adults and children	Childish	
				Total	

Of the approximately 400 apps that were assessed, we included 180 of these in the self-management and meaningful activities domains that were dementia friendly.

As in sprint 1 mock-ups and prototypes were created and tested by researchers of the development team. After the release of prototype 2.3., a cognitive walkthrough took place with researchers and experts to collect additional data concerning the usability of the prototype. Assignments for the cognitive walkthrough were based on the above user-interface aspects. Data was collected to improve the tool, e.g. change of icons; change of text for personal settings; workable audio instructions; the presence of a scroll bar within the presentation of apps and on the page for the overview of most used apps per category. The cognitive walkthrough also showed how to improve the assignments for the usability tests, e.g. the sequence of assignments, and to add an assignment about how the user experienced the download process of apps from the tool. Feedback was incorporated in prototype 2.4. and ready to be tested in usability tests (see Figure 5.3 and Table 5.2).

Results, usability tests and discover usability issues (phases III and IV)
Assignments of cognitive walkthrough were adapted for the usability tests. The section below contains the main observations and quotes that were made by the users for each assignment.

Assignment 1. 'Find and look at the instruction video in "Help"'
All the users with dementia and most of the IC did not find the instruction video in "help" without prompts from the researcher. For all users with dementia it was not clear that

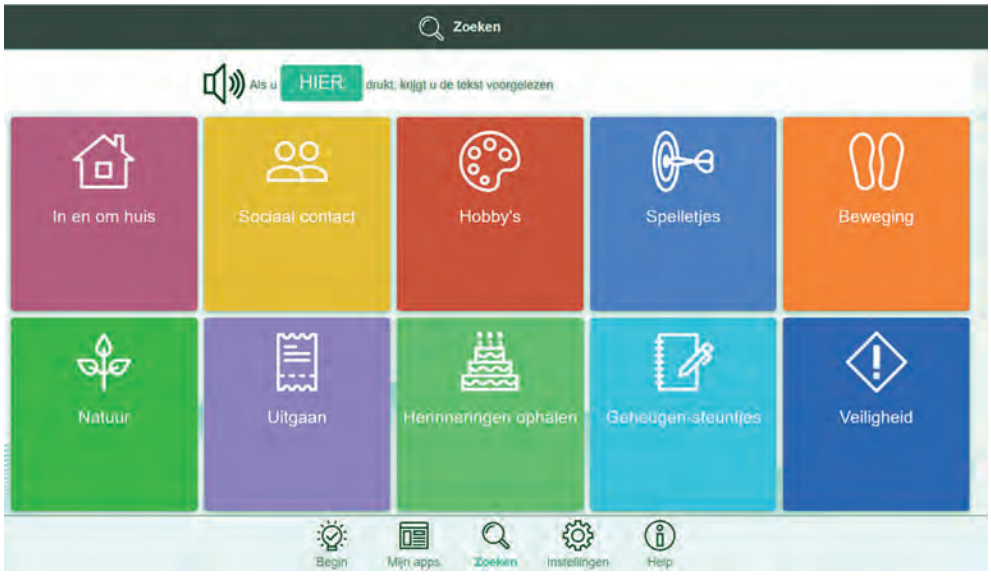

Figure 5.3 Prototype 2.4. selection tool as a result of phase I and II of sprint 2

it was an instruction video. While the video was playing the users were responding to questions asked in the video, by saying something or by pressing buttons of FindMyApps. All IC and FC felt the video contained too much information for people with dementia. That it was too fast and that the letter font used in the video was too small.
'It is complicated, too much information at once. You want to look, but it is too small and too much. You want to read but the video continues' (IC7).
Some IC noticed that other parts of the "Help" page concerning an explanation of several pages in FindMyApps offered too little support when users got stuck.

Assignment 2. a) 'Which activity would you like to do? Try to find an app for that activity'. b) 'What can you do to download the app'?
Most users did not have problems on the Home page when making a choice to enter the Search page. Most users with dementia knew that they had to press a coloured button to select an activity but had problems finding the activity of their interest because categories and related subcategories were not clear to them and there were to many options to choose for.
'Playing football is a social activity, so that's why I pressed social contact' (PwD7).
Most users needed more instructions to choose and download an app because of five problems:

1. The scroll down instruction was not noticed in the list of apps.
2. It was frustrating that the descriptions of apps in the tool were too long, not clear and that they were in English. *'It has taken more time to read than I want (refers to text of the app). It is totally unclear to me. Also, after reading the text, I don't understand the meaning of the app'* (PwD6).
3. It was not clear for some users that they had to press the image of the app.
4. The instruction video 'how to find and download an app of your interest' was confusing and not necessary. *'I am not interested in the video if I want to look at birds. I don't need it here'* (PwD8).
5. The blue button to go to Apple Store or Google Play wasn't noticed because it disappeared too quickly.

Assignment 3. The researcher is showing the page of categories of self-management and meaningful activities on the screen. a) 'In FindMyApps it is possible to change the icons of the activities into photos. The page personal settings of FindMyApps can support you with that, will you please try to do this'? b) 'Can you turn this question ON and OFF'?
All users had difficulty understanding and changing this setting because of three problems:

1. The difference between the personal settings of the FindMyApps tool and the personal settings of the apps was not clear.
2. They did not know how to operate the settings, turn it ON or OFF. *'Is the setting ON or OFF'?* (PwD5).

3. Once they turned it ON, it was not clear for them where to look for the result of their action. *'And now I don't know, it is not clear. I turned the photos on, but nothing happened'* (IC6).

Assignment 4. The researcher is opening the page for the personal settings of apps.
a) 'We are now in the page for the settings of apps. Do you have a clue what the content of these questions is'? b) 'Can you turn these questions ON and OFF'?
The same two problems occurred as in assignment 3 (see points two and three). In addition, most users had trouble understanding the content of these questions because they were not clear. '*What can I say about this setting, I don't understand'* (PwD5).

Assignment 5. The researcher is showing the page for the categories of self-management and meaningful activities on the screen. a) 'What photos are clear/not clear to you'? b) 'What icons are clear/not clear to you'?
Most users found the photos for the categories clearer than the icons. Most unclear icons for categories were those for: social contact, games, going out, memories, reminders and safety. Most unclear photos for categories were those for: exercise, going out, reminders and safety. *'I know that these are self-adhesive memos but I would not call those reminders. I do not recognize that in yellow memos'* (PwD6).

General observations and quotes about the tool

Most users had problems operating the buttons of the prototype. They had to press more than once for buttons to react.The green instruction button ("Hier") to get visual and audio instructions how to operate the pages was not noticed, not clear, distracting or confusing. Some users thought it was the home button. *'Oh, I didn't even see it'* (IC8).
Most users did not use the navigation bar at the bottom and most users did not notice the 'go back' possibility in the purple bar at the top of the screen. Colour use in the prototype was experienced as clear and calm. '*Colour use is clear. Quite visible with different colours and much better than white, black and grey'* (IC6).
The formal carer wondered whether some apps were suitable for this generation.
'The current generation is not familiar with food service at home, so what about the suitability of apps for that'? (FC2).

Results, sprint 3

Results, design and development (phases I and II)
The usability tests provided lots of ideas to improve the simplicity of the FindMyApps selection tool. It was therefore decided in the third sprint to improve the following user-interface aspects:
1. To reorganize the (sub)categories of apps for self-management and meaningful activities. This concerned work on the grouping hierarchy (with fewer possible choice

options on one page), the icons and the titles of (sub)categories.
2. To make the personal settings, help instructions and download process of apps more user-friendly.
3. To improve the supply of apps and to provide the users with short and clear information about the apps.
4. To work on the back-end of the tool where user profiles are made and defined and where the selection of apps is performed and defined so that dementia-friendly apps can be submitted. Furthermore, to work on a user-friendly presentation of tool usage by users of FindMyApps (analytics).

Due to practical issues, such as photo copyrights, it was decided to work on dementia-friendly icons instead of photos for (sub)categories of self-management and meaningful activities. So, after reorganising the group hierarchy, additional tests with ten persons with mild dementia (mostly Alzheimer Dementia, mean age 74 range 68-85) were performed to check whether the selected icons for these (sub)categories were recognized by the majority of users as representative of these activities. This was done in a Meeting Centre in Enschede. All titles and icons of a category and its subcategories were presented on tables, while the person with dementia was invited to walk by the table and try to match each title with the icon he or she thought fitted best. At the end a photo was made of the result, see Photo 5.1.

The photos of the additional tests were analyzed by counting the correct and incorrect titles given to icons of (sub)categories of self-management and meaningful activities. This was processed in tables and sent to the designer of the software company as input for improvement.

Next, mock-ups and prototypes were created and tested by researchers of the development team. After the release of prototype 3.4., a cognitive walkthrough took place with researchers and experts to collect additional needs and wishes concerning the usability of the prototype. Assignments for the cognitive walkthrough were based on the first three points of the user-interface aspects described above. Data was collected to improve the tool, e.g. change of icons for subcategories; change of text for personal settings; improve navigation to go back within subcategories so that search did not have to start from the beginning and improve the supply of apps within some subcategories. Feedback was converted in prototype 3.5. (see Figure 5.4 and Table 5.2) and ready to be tested in the feasibility study of November 2017. The FindMyApps selection tool now also includes a back-end.

First, after a simple log-in page, the FindMyApps selection tool will *create a user profile* by asking six questions about personal preferences for apps. Second, based on personal interest persons select a category in the area of self-management and meaningful activities. *Main categories* that people can choose are: in and round the house, contacts and leisure time. When persons select a main category, they will be led to *subcategories*,

Photo 5.1 Additional tests for dementia-friendly icons

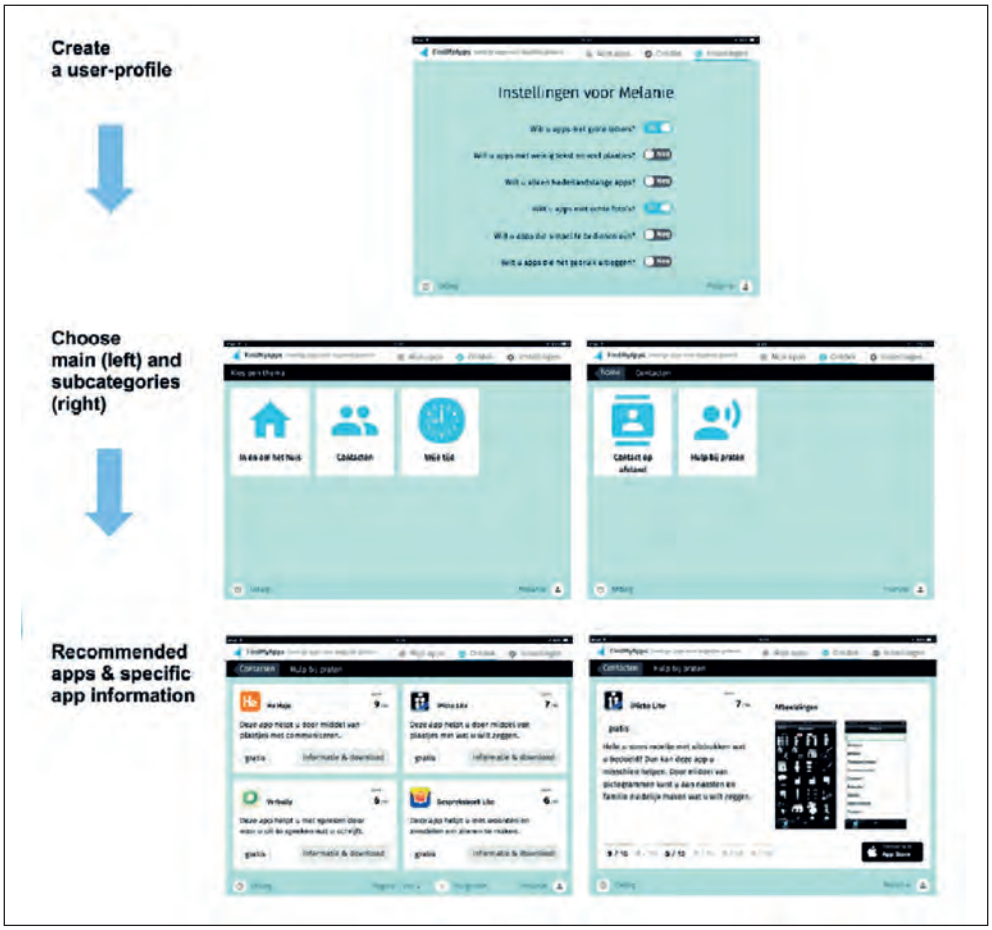

Figure 5.4 Flow of "FindMyApps" selection tool (protoype 3.5.), including personal settings, selection of main and subcategories, and app recommendation and information pages. © 2013 He Hajo; © 2011 Intuary, Inc; 2011 M&B Development and © 2013 Afasie Vereniging Nederland

where they can specify the activity of their interest. When people select a subcategory, *recommended apps* become visible. Clicking on the 'information and download' button will provide *specific app information*. The apps that best match their user profile will have a higher score. In this way apps are selected that are useful and suitable for the individual person with dementia.

Discussion and conclusion

Overall results of sprints

In this user-participatory design study the FindMyApps selection tool was developed in close collaboration with end users (persons with dementia and informal carers) and other important stakeholders. We succeeded in making a workable tool with an unambiguous routing for finding apps, which requires minimal effort from the target group to master. During sprints users tested the usability of the prototypes in several rounds, which generated important insights into useful content (i) and user-friendly design (ii) of the tool. During the development, we considered the important user-interface aspects that were mentioned in the scientific literature on designing dementia-friendly ICT applications.

One key point in the development of the content was establishing a useful group hierarchy of main and subcategories (see Table 5.I). On the one hand we wanted to meet the variety of needs regarding self-management and meaningful activities people with dementia may have [35], by offering enough apps. On the other hand, we wanted to prevent people with dementia from the need to endlessly click, which is a requirement for dementia-friendly interfaces.[22,35] At the same time, user experiences told us that combining many options for main and subcategories on one screen was not desirable. We therefore decided to incorporate more pages with fewer possible options, supported by a clear and simple navigation.

In addition, user-experiences provided relevant information on suitable dementia-friendly icons, a suitable supply of apps within subcategories, and the use of clear and short explanations of the content of apps. In addition, they clarified how to best formulate the personal settings and help instructions. Requirements about use of relevant icons, minimal use of text and using clear and short sentences for dementia-friendly interfaces were also acknowledged in other studies.[19,21,22,27,35,51]

With regard to the design, user-experiences with the tool provided us with knowledge for an intuitive design that is easy and attractive in its use. A major insight was that different user-interface elements, such as pages and interactive buttons, had to be simple and logically integrated to support users in intuitively operating and understanding the tool. In previous prototypes (1.3 and 2.4) users had problems accessing and understanding the settings and the Help page. The last version (prototype 3.5.), in addition to a Setting page, also asks about the settings during the registration into FindMyApps (immediately after having chosen a username and password) so that users do not have to access a separate setting page when they are into the FindMyApps environment. Instead of having one Help

page explaining different functions, the help function was broken down so that each page in FindMyApps has its own explanation. The design of the buttons – i.e. big horizontal and easy to access - made the interaction with the buttons very intuitive, which resulted in easy selection within the main and sub-categories. Requirements for an easy-to-use, attractive and intuitive design, and the use of large accessible buttons were also acknowledged in other studies that designed dementia-friendly applications.[19,21,22,27,35,52] Furthermore, to meet the requirement of a simple structured interface and to improve recognizability, we used the interface also used for overarching main and subcategories. Subsequently, we simplified the use of username and password [52] by asking the users to set a username and password in the beginning only; after that they stayed logged in. Other important requirements that were taken into account in the design of the tool were the use of a minimum number of buttons [19,28], minimalization of the need for scrolling [35,53,54], clear contrast between text and background [35,51,54] use of appropriate text sizes and fonts [19,35,51,54], navigation comfort and landscape presentation.[22]

Still, for some requirements, such as colour use and location of the navigation bar, practice will have to show what works best. In prototype 1.3. colour use was minimized, whereas in prototype 2.4. different colours were used. In both usability tests users were satisfied about the colours used in the tool. For prototype 3.5. we minimized the colour use again also because of literature insights.[53,54] Both usability tests showed that users hardly noticed the navigation bar at the bottom of the screen. We therefore decided for prototype 3.5. to locate the navigation bar at the top, even though according Riley *et al*.[22] it is better positioned at the bottom of the screen to reduce fatigue when users hold their arms out to press the screen

The FindMyApps selection tool makes a unique and important contribution to the field of dementia. As far as we know, this is the first tool to be designed for people with dementia that matches personal preferences and abilities (user-profile) with the specific features and types of apps in the self-management and meaningful activities domains. We hope that FindMyApps will ultimately support people with mild dementia in using the relevant apps and that this, subsequently, contributes to a better quality of life.

A similar web-based and personalized toolbox is available for young adults to prevent them from developing mental disorders with the help of mobile health apps.[55] Significant effects were found on mood, energy, rest and sleep trajectories between intervention and control groups.[55]

Strengths and limitations

The main strength of the current study is that end users were involved in developing FindMyApps. This is in contrast with the more traditional 'waterfall' method, a more top-down approach that does not include the end user in the development process, which is frequently associated with problems with usability, adoption and attrition.[56] Span *et*

al.[42] stated that the involvement of people with dementia improved the usefulness and acceptability of IT applications and that it may have empowering effects for them. In our study people with dementia and informal carers fulfilled roles of informants and advisors [57], and decisions during the designing of FindMyApps were based on how the users interacted with the design and how they experienced it.[40] Furthermore, we worked according to the Scrum method in demarcated yet iterative sprints that guided the development team in prioritizing the working agenda.[41] Also, a development team and an expert team consisting of different disciplines, i.e. researchers, experts in dementia care and developers of the software company, collaborated intensively during the development process, which created a kind of triangulation in developmental issues.

There are also limitations of the study that need to be mentioned. One limitation is that the development team had to make choices based on a limited amount of data. Establishing a useful group hierarchy and selecting suitable icons representing the main and subcategories could have been a separate study, instead of part of the current study. The development team struggled to choose the most suitable icons for people with dementia. In addition, the researchers mentioned that both persons with dementia and informal carers needed some training in the basic working principles of FindMyApps before performing the tasks prescribed by the development team. We presume, and this was also noticed by participants, that they would have performed 'better' on tasks during sprint 1 and sprint 2 if they had had the chance to get to know FindMyApps a little better before performing prescribed tasks. We therefore recommend providing instructions and giving users time to practice before starting with tasks and research data collection. These recommendations will be followed in the subsequent FindMyApps feasibility study.[36] Last, the developers gave first priority to the technical realization of the FindMyApps functionality, while design including user-friendly navigation was a second priority. During Sprint 1 it became evident that especially for people with dementia, design and technical functionalities had to be developed 'hand in hand'.

Further development

Having followed the recommendations from the Medical Research Council framework for the development and evaluation of complex interventions [58,59], future studies will involve testing the FindMyApps selection tool in one or more feasibility studies, with further improvements where needed, and finally tested in a definite RCT.[36] According to Span *et al.*[42] this is guaranteed to result in a supportive and user-friendly IT application, because it guarantees the involvement of people with dementia in four development phases:

1. Explorative phase, setting requirements, collected in previous needs studies [35];
2. Technical development phase, setting technical requirements (current study);
3. Adaption phase, pilot testing (daily operation of FindMyApps), identifying usability issues;
4. Evolution phase, measuring effects and impact of FindMyApps.

Second, if FindMyApps is effective and improved based on newly discovered usability issues, a native app will be developed (which will be also made available for other platforms e.g. a smart phone). A native app can be defined as an app downloaded to the user device.[60] From the beginning it was decided to build a responsive website, instead of a native app, because of research-driven pros: A website provides the possibility for continuous development and improvement, whereas a native app is more static and can therefore easily result in a poor-quality end product. In addition, a website is less time consuming to build and more user-friendly for updates.[60] Furthermore, a website avoids problems with the compatibility of FindMyApps on different versions of tablets. There are also some cons to mention regarding the use of a responsive website. During the usability tests it was noticed that users had problems operating the buttons. They had to press more than once for buttons to react, which was caused by a poor internet connection. A native app can be used offline, which would hopefully improve the responsiveness of buttons. In addition, users experienced the page with the overview of most used apps per category (Mijn apps) as less meaningful because the page does not fulfil its intended function, which was to launch (open) the apps downloaded through the FindMyApps tool. A responsive website does not support universal links of apps, which means that apps downloaded through FindMyApps are not automatically stored in the back-end, making it impossible to launch apps from the overview page of FindMyApps (Mijn Apps). With a native app they could be stored in the back-end and therefore launched within the FindMyApps environment.

Third, with the rapid development of new apps we have to find a way to update and maintain the FindMyApps library in a user-friendly way. For example, in future prototypes it would be desirable to add a functionality in which the users can recommend apps based on certain criteria for dementia-friendly apps. The selection of apps that are currently included in the library have not been chosen by potential users, but have been compiled by trained student volunteers.

Fourth, usability tests informed us that users struggled with the distinction between personal settings of individual apps and personal settings of the FindMyApps tool. To improve the simplicity of the tool we dropped the latter. In future prototypes we have to think of a user-friendly manner for users to meet the requirement to also adjust the FindMyApps tool to their personal preferences [17,19,35,52] e.g. to set photos or icons to represent main and subcategories; to set an extra search bar for typing the activities of their interest; to set the letter sizes, etc.

Fifth, as mentioned before, the researchers found it hard to establish a group hierarchy order for (sub)categories and to select suitable icons representing these (sub)categories. The feasibility study will identify further necessary adaptions based on new insights gained after people with dementia and their informal carers use the FindMyApps selection tool for a longer period of time.

Last, the FindMyApps selection tool may also be of benefit to other vulnerable target

groups, such as people with more severe dementia living in nursing homes, and people with intellectual disabilities, autism, psychiatric disorders or acquired brain injuries. New development sprints will be needed to adjust the tool to the specific needs, wishes and abilities of other target groups.

Practical implications

In this study, we found that people with dementia can participate in this type of research where they have to perform tasks on a tablet device. They provided us with valuable feedback to adapt the tool to their wishes, needs and abilities, which hopefully results in an increased usability. In future IT development researchers and software developers could benefit even more from outcomes of usability tests by providing a little practice/try out beforehand, regardless of which target group they built the application for. In the present study users, researchers, software developers and experts in dementia care worked closely together and this resulted in a thorough understanding of how potential users interact with the user-interface. It also contributed to a better mutual understanding of the researchers' and developers' roles, perspectives and use of each other's jargon. During the development researchers became more aware of logical steps in software development and software developers adopted a research attitude, which was supportive for researchers and of great value for the quality of the end product. This study may contribute to the development of practical guidelines for new dementia-friendly ICT tools. The authors intend to prepare a separate paper on this in the future.

Conclusion

Overall, we can say that in three sprints the FindMyApps selection tool, in co-creation with users, researchers, developers and experts, has developed towards a more intuitive design that is easy and attractive to use. The FindMyApps tool was conceived as a means to make it easier for people with mild dementia to select apps that meet their needs, wishes and abilities. It is hypothesized that the use of these selected apps will encourage self-management and meaningful activities. The tool will be further tested and improved in a feasibility study and its effectiveness subsequently evaluated in an RCT.

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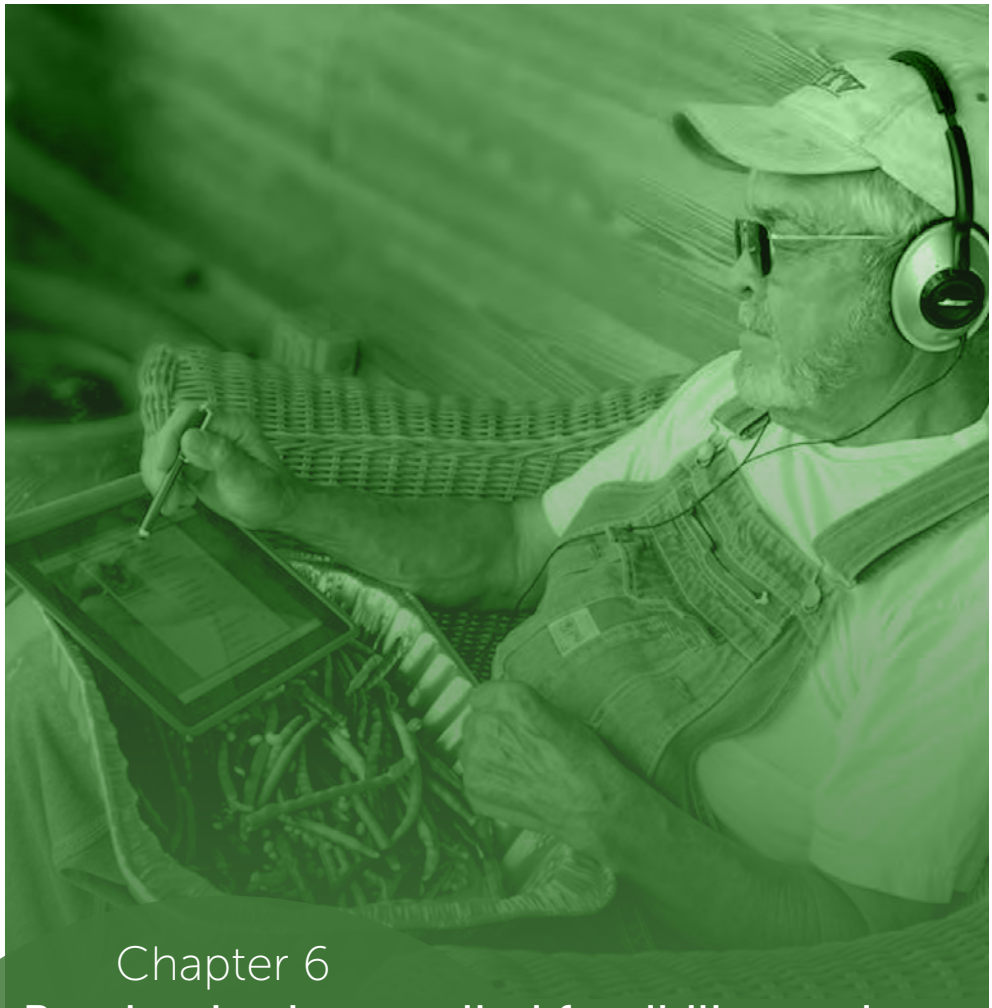

Chapter 6

Randomised controlled feasibility study of FindMyApps: first evaluation of a tablet-based intervention to promote self-management and meaningful activities in people with mild dementia

Published as

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Abstract

Objectives

We tested the feasibility, implementation strategy and mechanism of impact of FindMyApps. FindMyApps is a tablet intervention consisting of a selection tool to help people with dementia find usable apps for self-management and meaningful activities, including training to support informal carers in employing Errorless (EL) learning principles to help people with dementia learn tablet and tool usage.

Methods

We conducted an exploratory, pilot randomised controlled trial with a mixed-methods design. Twenty persons with mild dementia and carer dyads were randomly assigned to the FindMyApps group (n = 10), receiving either the FindMyApps training and selection tool, or a control condition (n = 10), receiving only a short tablet training. Pre and post-test measurements at a three month follow-up, consisted of questionnaires and post-test semi-structured interviews.

Results

The FindMyApps tool was mostly perceived as useful and easy to use. Persons with dementia were generally able to learn how to use the tool, though they regularly needed support from informal carers. Persons with dementia found apps through the tool, which they used regularly. Persons with dementia and informal carers were positive about the training and support they received, No significant differences were found on outcome measures of persons with dementia, but based on effect sizes FindMyApps is a promising intervention.

Discussion and conclusion

Qualitative results indicate that the FindMyApps intervention has the potential to positively influence the self-management abilities and engagement in meaningful activities of people with dementia. Remarks are made to improve the intervention and recommendations are given for future effectiveness studies.

Introduction

Dementia is a syndrome that describes various chronical neurodegenerative conditions with cognitive impairment in areas such as memory, thinking, judgement, orientation, language, and comprehension.[1] Dementia has a major impact on individuals and their social environment. Research shows that 70% of people with dementia stop engaging in activities due to a lack of confidence, 50% avoid their neighbourhood due to their limitations, and 40% hardly leave their home.[2] Informal carers of people with dementia often feel burdened.[3] The high burden on carers frequently results in the person with dementia being admitted to a long-term care facility.[4] The current policy in Western countries though, is to enable people with dementia to live in their own home for as long as possible.[5]

Community-dwelling people with dementia and their informal carers report a lack of meaningful activities [6-9] and a lack of support to successfully self-manage their condition, especially in the early stages.[10] Hand-held touch screen devices such as tablets have the potential to support people with dementia in managing their life and in engaging in meaningful activities.[11,12] In the last decade many applications (apps) for tablets have been developed to support people in managing their daily lives and health, staying in touch with their social network, and engaging in activities.[13] There is growing evidence that apps also have the potential to support people with mild dementia in these areas.[14-26] However, people with dementia need support to learn how to use touch screen devices.[16,19,20,23-25,27] It can also be hard to find apps that match one's own personal needs, wishes, and abilities. Support in the selection of apps is required, as just a small number of existing apps are usable for individuals with mild dementia.[16,24,28-30]

A person-centred, tailored tablet intervention, called FindMyApps, was developed in co-creation with end users, to support community-dwelling people with mild dementia in the use of apps.[31] The intervention consists of the FindMyApps training in tablet use and the FindMyApps selection tool to help users find apps for self-management and meaningful activities that fit their needs, wishes and abilities.[32]

In the FindMyApps training, informal carers are trained to use the FindMyApps tool and tablet, so that they in turn can support the person with dementia in using it. The FindMyApps training is based on the Errorless (EL) learning method.[33,34] EL refers to a learning condition involving the elimination of errors during the learning process.[35,36] The rationale behind this method is that people with dementia can be taught new skills by repetition and by using their implicit memory that is a part of the long-term memory, which is relatively spared in the early and middle stages of dementia. This memory function helps people perform procedural tasks, such as cycling and washing hands, which are acquired through fixed routines and are conducted automatically.[37] This method has been successfully applied to (re)teach people with mild to moderate dementia how to use everyday technologies [36], for example a voice mail or answering machine [38], a mobile phone [39], and a digital organizer [40].

The FindMyApps selection tool consists of a library of dementia-friendly apps, which can be matched to the user's individual needs, wishes, and abilities based on their input of personal preferences. The tool is intended for use by people with dementia with the support of their informal carers.[32] The tool was developed using needs studies to identify user requirements for desired activities in the context of self-management and meaningful activities, and by identifying the needs, wishes, and abilities related to app features.[41] Subsequently, the tool was developed in a user-participatory design process to ensure that it would meet the needs of people with dementia and informal carers.[32]
We followed the recommendations of the Medical Research Council (MRC) framework [42,43] for the evaluation of complex interventions, and accordingly conducted an exploratory feasibility study to test the FindMyApps intervention, the implementation and the research design for a future effectiveness study (RCT). Understanding the context, e.g. the implementation process, and the mechanism of impact is crucial in interpreting the outcomes of a complex intervention.[44] Therefore, we first explored the implementation strategy of the FindMyApps training and the mechanism of impact regarding the usability, i.e. the usefulness, user-friendliness, learnability, and adoption of the FindMyApps tool. The research questions addressed in this study were:

1. Is the implementation strategy for the FindMyApps training feasible?
2. Which mechanism of impact plays a role in implementing the FindMyApps tool?
3. What is the potential impact of FindMyApps on self-management and engagement in meaningful activities?
4. How feasible is the current research design and which adaptations are recommended for a future effect study?

Methods

Research design

A mixed methods design, including qualitative and quantitative research methods, was used. This feasibility study was conducted as an exploratory pilot randomised controlled trial (RCT) in order to assess the potential impact of FindMyApps and to inform the design of future studies. Participants were randomly assigned to either the FindMyApps group, receiving the FindMyApps training and tool, or the control group, receiving an introductory tablet training and links to websites that recommend apps for people with dementia in general. Randomisation was done manually by a researcher who was not involved in the eligibility screening. This was first stratified for co-habiting with informal carers, after which participants were randomised in block sizes of four with a 1:1 allocation. Assessments consisting of standardised questionnaires were performed at baseline and again after three months, to test the potential impact of FindMyApps on self-management and engagement in meaningful activities. Additional qualitative evaluation using semi-structured interviews was conducted to explore the feasibility of the implementation strategy and the mechanism of impact of the FindMyApps intervention as well as the

feasibility of the research design, methods, and procedures. Participants and assessors who conducted the baseline and post-test measurements with questionnaires, were blinded to treatment allocation.
Ethical approval was granted by the Medical Ethics Committee of the VU University Medical Centre in Amsterdam (no. 2016.030) and the Ethics Committee of the Faculty of Behavioural, Management and Social Sciences of the University of Twente (no. 17784). The trial was registered at clinicaltrials.gov (identifier NCT04026061).

Participants and procedure

From June to November 2017, dyads (people with Mild Cognitive Impairment (MCI) or dementia and informal carers) were recruited through the Dutch Alzheimer's Association, Meeting Centres for people with dementia and carers, Alzheimer's Cafés, a day care centre for people with dementia, a case manager, and a care organisation, all located in the eastern part of The Netherlands. Eligible dyads had to be community dwelling. People with dementia had MCI or mild dementia with a score of 3 to 4 on the Global Deterioration Scale (GDS) [45], with or without a confirmed diagnosis, and the availability of an informal carer or volunteer to provide support. Exclusion criteria were participation in another intervention trial and severe visual and/or physical impairment. Since this was a pilot study, we expected to require approximately 20 to 24 dyads to gain insight into all relevant feasibility factors. This number was not based on power calculation.
Dyads interested in participating received an information flyer. Informal carers were then called by the researcher (YK) to receive additional information and to verify their eligibility. Subsequently, trained assessors visited eligible dyads before randomisation to obtain written consent and perform baseline measurements.
After baseline assessments, randomisation took place and informal carers received training from researchers (GK trained the control group and MV trained the FindMyApps group) in their home setting. They were then asked to start with the intervention. If participants did not own a tablet, they could borrow one. During the three-month intervention period, informal carers kept a diary of app usage by the person with dementia. Follow-up phone calls with informal carers took place every two weeks to address possible problems and to increase adherence. In addition, informal carers could consult a help desk if they had questions or needed support.
After three months, post-test measurements were performed by blinded, trained assessors, followed by individual semi-structured interviews (carried out by GK and MV) with the dyads in their homes. All interviews were voice-recorded and transcribed verbatim. The trial ended in March 2018. All trial protocols are available from the authors on request, see also Kerkhof *et al.*[31]

The intervention

- FindMyApps group

The FindMyApps training

In the training session informal carers learned how to support persons with dementia in using a tablet and the FindMyApps tool in conformity with EL.[34] First, the method was explained at the start of the training, stating that a task has to be broken down into small steps, each step needs to be demonstrated, and then copied by the person with dementia. If that person makes a mistake, he or she should be corrected to prevent the error being consolidated in the memory. This needs to be done for all steps until the person with dementia has learned to carry out the complete task.[34] Secondly, informal carers were taught the tablet and the FindMyApps tool functions in accordance with EL (e.g. breaking each task down into steps). Using a tablet and the FindMyApps tool requires the use of different skills such as turning the power on/off, opening and closing apps or returning to the home screen. Explanation of these skills was done through the use of a step-by-step guide with accompanying screen shots. The skills were demonstrated by the researcher and then tried out by the informal carers. Thirdly, informal carers downloaded an app from the FindMyApps tool that matched the person with dementia's interests. Finally, they received tips to help them support the persons with dementia, such as using a stylus and giving positive feedback. The informal carers received a written manual with the information given in the training, as well as laminated explanation cards with the steps of the EL method and the FindMyApps tool.

The FindMyApps tool

The FindMyApps tool is the main part of the intervention. It is a web application installed on tablets consisting of a library containing 180 apps in the domains of self-management and meaningful activities which are assessed as dementia-friendly apps.[32] This was based on a set of important app criteria with regard to interaction, feedback, aesthetic design, app design, customisation, obstacles, and age appropriateness.[29,46] Usable apps are selected by matching personal preferences of persons with dementia (i.e. the user profile) with app features and by matching their needs and wishes with the different types of apps. The FindMyApps tool consists of six components, also called pages.[32]

Figure 6.1 provides an overview of the FindMyApps tool flow. On the page *personal settings* (Figure 6.1a), a user profile for the person with dementia is created by answering six questions relating to personal preferences regarding apps by means of a yes/no button. This user profile is set by informal carers during the training. The preferences offered are: large font size; less text, many pictures; only in Dutch; real photos; simple to operate; and instructions offered. After this, the home page of the tool with the main *categories*, i.e. 'in and around the house', 'contacts', and 'leisure' (Figure 6.1b), opens. From here, sub-categories (Figure 6.1c) can be chosen to find usable apps. When a sub-category is

selected, a page with an *overview of apps in each category* (Figure 6.1d) opens. Each app is presented with a brief information sentence, the costs, and an overall score is shown indicating the match of the app with personal preferences; a higher score indicates a better match. By clicking on the button 'information & download', the page with the *app description* (Figure 6.1e) is opened. More specific app information and screenshots are presented and six scores show the match of the app with all six personal preferences. A button to access the Apple Store or Play Store to download the app is provided. The page *My Apps* provides an overview of all apps that someone has shown interest in, arranged in subcategories. Finally, all pages show the *explanation button*, which gives support on how to use that particular page.

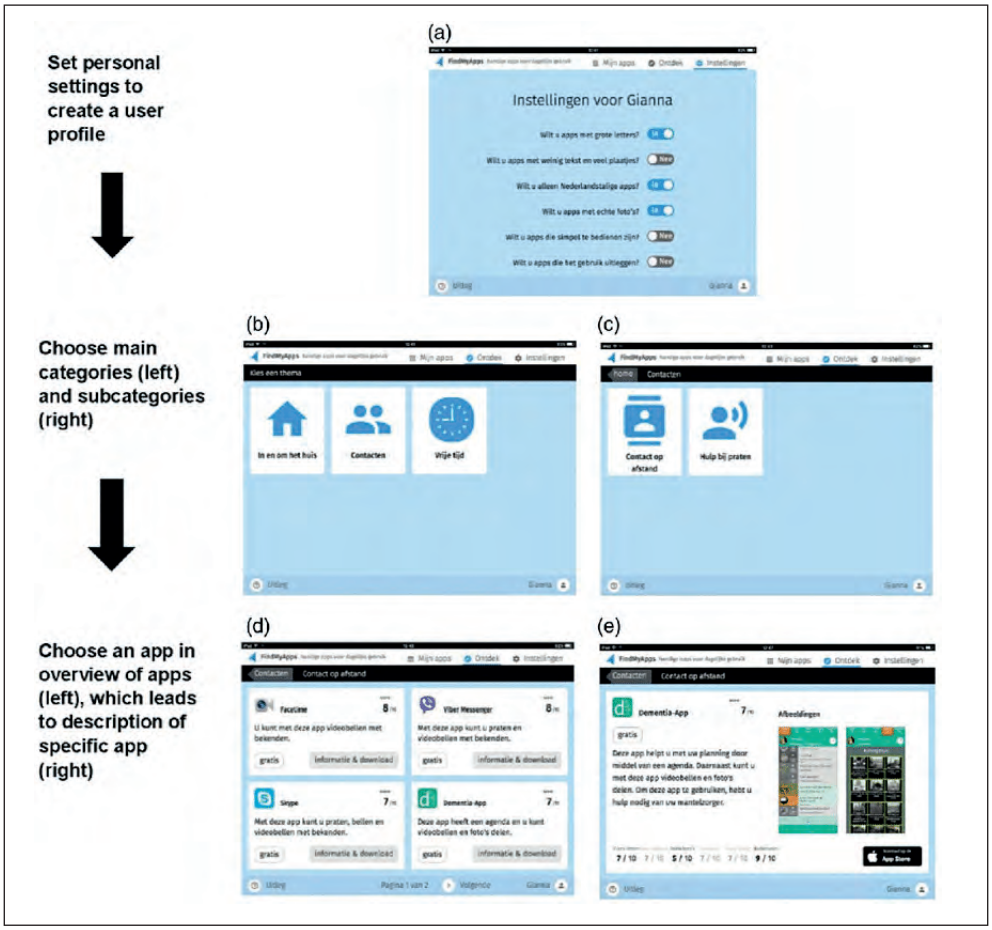

Figure 6.1 Flow of the FindMyApps tool, including setting the user profile in the personal settings (a), division into main categories (b) and subcategories (c), overview of apps in a category (d), and description of an app (e)

- Control group

Informal carers in the control group received a tablet training similar to the training of the FindMyApps group but without the use of the EL method, and they were also provided with a list of Dutch- and English-language websites containing potentially usable apps for people with dementia. The training started with an explanation and demonstration of the tablet functions. They were then asked to open one of the websites and download an app matching the interests of the person with dementia. Finally, informal carers received the same tips for tablet use as the FindMyApps group. After the training, the informal carers received a written manual containing the information from the training, as well as laminated explanation cards showing links to websites and tips.

Instruments

A variety of questionnaires and assessment procedures were used.

- Baseline characteristics

The baseline characteristics of dyads that were assessed included age, gender, education, and experience using a tablet. Additionally, the living situation (alone/with spouse or partner) of the person with dementia, as well as their relationship with the informal carer was collected. The type of dementia and the awareness of cognitive deficits of persons with dementia were determined, using the GDS [45] and the Guidelines for the Rating of Awareness Deficits [47] respectively. All baseline characteristics were acquired through informal carers.

- Feasibility implementation strategy and mechanism of impact of FindMyApps intervention *(research questions 1 & 2)*

Individual semi-structured interviews with persons with dementia and informal carers were used to explore the feasibility of the implementation strategy and mechanism of impact of the FindMyApps intervention. To get insight into the implementation strategy of the intervention, the practicality of the FindMyApps training was explored in the interviews. Bowen *et al.* (2009) define practicality for feasibility studies as the extent to which the intervention can be delivered when resources, time, commitment, or some combination thereof are constrained in some way.[48]

To get insight into the mechanism of impact of the intervention, the usability of the FindMyApps tool was explored. The interview scheme was divided into four themes: usefulness, user-friendliness, learnability, and adoption.[20] Usefulness refers to whether users believe a website or application fulfils specific needs or whether it helps them to be more effective and productive.[49] User-friendliness (i.e. ease of use) indicates whether users believe that using a website or application will be easy and simple to use.[49] Learnability (i.e. ease of learning) refers to whether users believe that using a website or application is easily learned.[49] Adoption is defined as the decision, by an organisation or

individual, to utilise and implement a technology.[50]

We also conducted individual semi-structured interviews with the control group to explore the feasibility of the tablet training and explore apps usage found on the suggested websites. Participants' quotes were included to help provide an in-depth understanding of results. Confidentiality and privacy were ensured by coding participants' data using numbers and letters, which also identified them as a person with dementia (PwD), an informal carer (IC) or a volunteer (VT).

Interviews included the use of the Usefulness, Satisfaction, and Ease of Use (USE) questionnaire [49], consisting of 30 statements measuring four dimensions of usability (usefulness, ease of use, ease of learning, and satisfaction). The statements are rated on a 7-point scale ranging from 1 (strongly disagree) to 7 (strongly agree) with higher scores indicating better usability. Total scores were calculated by determining the mean score for each subscale.

- Outcome measures *(research question 3)*

A number of measurements were used to evaluate the potential impact of the FindMyApps intervention.

Person with dementia outcomes

The primary outcomes were self-management abilities and participation in daily and social activities. Self-management abilities were measured using the revised 30-item Self-Management Ability Scale (SMAS-30).[51] In a population of independently living elderly people without dementia, the revised SMAS-30 was found to have good internal consistency with a Cronbach's alpha of .90.[51] Participation in daily and social activities was measured using two instruments: a short version of the Pleasant Activities List (PAL)[52] consisting of 31 items on a 5-point scale for frequency and enjoyability, and one item of the Adult Social Care Outcomes Toolkit (ASCOT).[53] Both the original PAL and the ASCOT show good psychometric properties.[52,54]

The secondary outcomes were perceived self-efficacy, perceived autonomy, and quality of life. Perceived self-efficacy was measured using the Dutch version of the 10-item General Self-Efficacy Scale (D-GSE scale).[55] Previous studies have confirmed high reliability, stability, and construct validity of the original GSE scale [56,57], as well as good internal consistency with a Cronbach's alpha of .85 for the D-GSE. Perceived autonomy was measured using the 12-item Experienced Autonomy List (EAL) [58], a scale consisting of relevant items from the Mastery scale [59] and the WHOQOL-100.[60] Both the Mastery Scale and the WHOQOL-100 have shown good validity and reliability in Dutch populations [61,62], though the psychometric properties of the EAL have not been investigated yet.[63] Quality of life was measured with the Dementia Quality of Life scale (DQoL) [64], which has shown good internal consistency and construct validity in a population of people with dementia.[64,65]

Informal carer outcomes

The primary outcome was a feeling of competence, which was measured using the Short Sense of Competence Scale (SSCQ).[66] The scale shows good internal consistency with a Cronbach's Alpha of .76 and a good construct validity was found in a population of community-dwelling people with dementia.[66]

The secondary outcomes were positive care experience and quality of life. Positive care experiences were measured using the Positive Experience Scale (PES) [67], a scale with good reliability with a Cronbach's alpha of .74 and validated for large groups of informal carers, as carers for people with dementia.[67] Quality of life was measured using the EQ-5D-5L.[68] The EQ-5D-5L has been used in a multitude of health conditions [69], has good test-retest reliability, and has been validated for many diseases.[70] Additionally, the quality of life topic was measured using the TOPICS-MDS [71], which was found to have good construct validity in different study settings.[72]

- Feasibility of research design *(research question 4)*

Recruitment feasibility was evaluated based on inclusion and dropout rates. Research assessment procedures were evaluated based on persons with dementias' and informal carers' feedback on clarity and perceived burden of measurements at baseline and post-test, which was logged by assessors. The duration of the visits, adherence to the assessment protocol, and other irregularities were also logged. Questions relating to the feasibility of the research design were asked during the semi-structured interviews, such as informal carers' experiences with keeping a diary of app usage and follow-up phone calls every two weeks.

Data analysis

The interviews were transcribed verbatim. The transcripts were then read multiple times to get familiar with the data. They were initially analysed using a deductive approach, meaning that relevant fragments were coded into predefined categories.[73] These fragments consisted of meaningful words, phrases, and quotes. The following categories were used: feasibility of the FindMyApps training and usefulness, user-friendliness, learnability, and adoption of the FindMyApps tool. Two sub-categories were used to make a distinction within the categories: positive and negative. Three researchers (GK, MV, YK) individually identified those categories and sub-categories within the first two transcripts and marked relevant fragments with separate colours. The researchers met to discuss the first coding scheme. Any disagreements in coding were discussed until consensus was reached and the coding scheme was revised accordingly. The remaining transcripts were then analysed by two researchers (GK, MV) in the same manner. Inter-rater reliability, assessed as percentage agreement, was 70 percent. The final coding scheme was checked by the third researcher (YK) and any further disagreements were discussed between the three researchers until consensus was reached. Afterwards,

inductive analysis – meaning that codes derived from the narrative instead of predefined categories [73] – was used. Coding each fragment was done by GK for the persons with dementia, and by MV for the informal carers. After the codes had been established, they were reviewed by YK and some codes were adjusted or merged. The codes and relevant quotes were then summarised in the categories and sub-categories. Subsequently, for each code, the number of persons with dementia and the informal carers who had been given that code were counted.

Descriptive statistics were used to summarise background characteristics of participants. Full cases analysis was carried out. No imputation techniques were used for missing data. Baseline differences between both groups were assessed with nonparametric tests due to the small sample size and non-normal distribution of the data.[74] Mann-Whitney U test was used for ordinal and continuous variables, and Pearson chi-square test was used for nominal variables. If the assumptions of the Pearson chi-square test were not met, Fisher's exact test or Likelihood ratio test were used instead.[75] Descriptive statistics were computed for all measures. Analysis of covariance (ANCOVA) was conducted to determine differences in outcome data between the groups, with treatment condition (FindMyApps group or control group) as the independent variable, post-test data as the dependent variable, and pre-test values as the covariate. Given the small sample size involved in this pilot study, we also calculated effect sizes, i.e. partial eta squared (ηp^2), to interpret the meaningfulness of the data. An effect size of .01 was considered to be small, .06 was medium, and .14 was large.[76] A value of alpha smaller or equal to 0.05 was taken to denote significant differences. All statistical analyses were performed with SPSS 24.0.

Results

Out of the 28 screened dyads, twenty dementia-informal carer dyads (71.4%; n = 10 in the FindMyApps group; n = 10 in the control group) were eligible and willing to participate in this exploratory pilot RCT (Figure 6.2). Study attrition rate was 37,5%, with six dyads dropping out during the three-month intervention period, mainly due to lack of interest using the tablet for the participants with dementia, and the additional burden for informal carers in supporting their relatives with dementia in using the tablets. In the control group, three additional participants with dementia dropped out due to lack of interest in using the tablet, institutionalisation and death. As this happened at the end of the intervention period, it was decided to keep the informal carers of these participants in the study.

Participants' characteristics at baseline are presented in Table 6.1. There were no significant differences between both groups regarding these characteristics. A Mann-Whitney U test showed that there was a significant difference (U = 16.0, p = 0.03) in the age of informal carers who completed the study (M = 61.9) compared to informal carers who dropped out (M = 72.7).

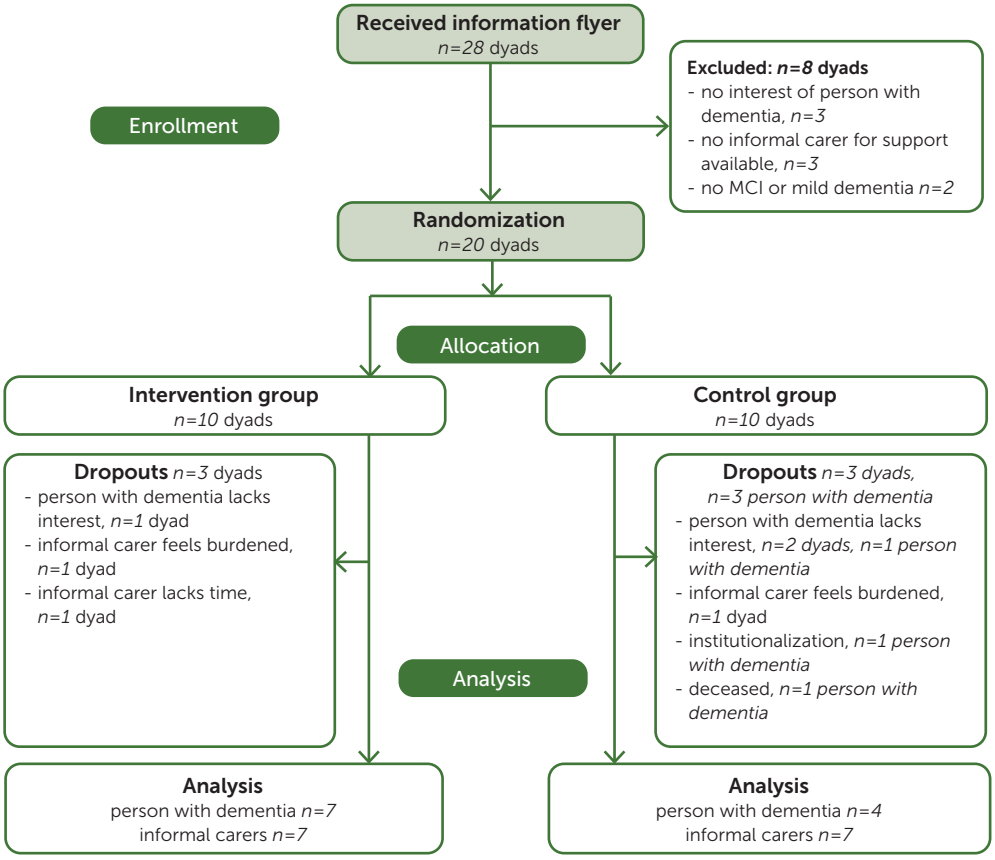

Figure 6.2 Recruitment and participant flow of exploratory pilot RCT

Feasibility implementation strategy and mechanism of impact of FindMyApps (research questions 1 and 2)

Individual semi-structured interviews took place with four persons with dementia in the control group and six of the seven persons with dementia in the FindMyApps group, since one person with dementia had not used the FindMyApps tool. Furthermore, semi-structured interviews took place with seven informal carers in the FindMyApps group and six of the seven informal carers in the control group, as one informal carer had provided less support. The interviews also took place with two volunteers, because one person with dementia in each group was trained by a volunteer. It was not possible to include all data from the interviews in this article, therefore the focus of this result section is on the feasibility of the implementation strategy of the FindMyApps training and the mechanism of impact: the usability (usefulness, user-friendliness, learnability, and adoption) of the FindMyApps tool. We only mention the control group when relevant.

Table 6.1 Baseline characteristics of Persons with Dementia & Informal Carers, by group

Characteristics persons with dementia	FindMyApps Group *(n=7)*	Control Group *(n=4)*	*p*
Gender, *n* (%)	.		49
Female	1 (14)	2 (50)	
Male	6 (86)	2 (50)	
Age, M (SD), [min-max]	68.9 (14.0), [50-87]	76.0 (4.2), [72-81]	.45
Type of diagnosis, *n* (%)			.34
Alzheimer's disease	3 (43)	1 (25)	
Vascular dementia	2 (29)	-	
Other	1 (14)	1 (25)	
Not diagnosed	1 (14)	2 (50)	
GDS stage, M (SD), [min-max]	2.8 (.3), [2.5-3.4]	3.0 (.4), [2.5-3.4]	.29
GRAD score, *n* (%)			.75
Intact	4 (57)	2 (50)	
Mildly impaired	2 (29)	1 (25)	
Moderately impaired	1 (14)	1 (25)	
Living situation, *n* (%)			1.00
Alone	1 (14)	1 (25)	
With spouse or partner	6 (86)	3 (75)	
Education level, *n* (%)			.23
Lower education	1 (14)	2 (50)	
Secondary education	2 (29)	1 (25)	
Higher education	4 (57)	1 (25)	
Use of tablet, *n* (%)			.67
Every day	4 (57)	2 (50)	
Once before	1 (14)	-	
No experience	2 (29)	2 (50)	
Characteristics informal carers	**FindMyApps Group *(n=7)***	**Control Group *(n=7)***	***p***
Gender, *n* (%)			1.00
Female	7 (100)	6 (86)	
Male	-	1 (14)	
Age, M (SD), [min-max]	63.0 (11.8), [47-79]	61.0 (11.7), [40-71]	.81
Relationship with PwD, *n* (%)			.56
Spouse or partner	6 (86)	4 (57)	
Child	1 (14)	3 (43)	
Education level, *n* (%)			.54
Lower education	1 (14)	1 (14)	
Secondary education	1 (14)	3 (43)	
Higher education	5 (71)	3 (43)	
Use of tablet, *n* (%)			.62
Every day	5 (71)	4 (57)	
Once a week	1 (14)	-	
Once or twice a month	-	1 (14)	
Once before	-	1 (14)	
No experience	1 (14)	1 (14)	

GDS, Global Deterioration Scale; GRAD, Guidelines Rating of Awareness in Dementia.
Differences between groups were tested using a Pearson chi-square test for categorical variables, and Mann-Whitney's *U* test for ordinal and continuous variables.

Feasibility of the FindMyApps training

All informal carers in the FindMyApps group were positive about the training they received. Most frequently mentioned positive remarks were:

1. clear and useful explanation of all parts of the training.
2. EL method was useful. *'For me, it was a revelation that people with mild dementia could learn new things, I thought this was not possible anymore. So, I taught her the FindMyApps tool and tablet in accordance with this method and I hope this will also work out for the long term'* (IC14).
3. Laminated explanation cards were supportive. '*The instruction cards are helpful, you can easily see what you have to do'* (IC19).

The most frequently mentioned critical remark was that the training should be given in the presence of the person with dementia. *'It might be supportive if the training was given in the presence of my mother. The mother-child relationship could have hindered her from learning from me. If a stranger emphasises that an open attitude towards me [carer] is important, that might be helpful.'* (IC14).
Other critical remarks were that the training was not sufficient for someone with no tablet experience and that the training took too long.

Overall, persons with dementia in the FindMyApps group were satisfied with the support they received from informal carers. They also thought that the support was sufficient. However, five informal carers suggested that this kind of support should be provided by someone other than the informal carer due the amount of time it took and the difficult relationship patterns between dyads that make giving and receiving support difficult at times. *'Yes, this was immediately obvious. My husband is always jumping from one subject to another and I thought VT17 would interrupt him, but he didn't, and maybe this is the right thing to do. I have less patience and that's why me supporting him is not a good idea'* (IC17, Pwd17 received support by VT17).
Also, supporting persons with dementia in small groups was mentioned as a possibility by informal carers.

Furthermore, most informal carers in the control group were positive about the training they received. Frequently made positive remarks were:

1. clear explanations;
2. useful for supporting tablet use by persons with dementia;
3. manual and laminated explanation cards were useful.

One informal carer found just one training session insufficient and needed more face-to-face support. Three informal carers mentioned that the persons with dementia showed less interest in learning to use this, for them, new device during the intervention period, and this was frustrating or an extra burden for informal carers. Persons with dementia in

the control group were satisfied with the support they received from their informal carers. Some of them already had experience with touch screen devices. Support was needed for downloading apps and operating apps which showed pop-up ads.

Usefulness of the FindMyApps tool

Five persons with dementia and seven informal carers found the FindMyApps tool useful for several reasons:

1. Apps match their personal needs and interests. *'There are [apps] in there that are very useful, you know, in my case with dementia'* (PwD13).
2. It enables tablet learning.
3. It stimulates tablet use.
4. It helps finding apps. *'I think [it's useful] to a certain extent. Because, you know, it's a good starting point to find something'* (PwD17).
5. It enables exploration of what kind of apps are being offered and it gives new ideas. *'You notice that the initiative of the person with dementia decreases and it's very useful and nice that FindMyApps gives new ideas for spending spare time'* (IC13).
6. It supports self-management and engaging in meaningful activities.*'The reason we participated in this study was to try and stimulate my husband's brain. This is because he is showing less initiative and prefers to watch television all the time. So, it would be good to activate his brain more to slow down the dementia process. And it worked'* (IC17).

One person with dementia and the informal carer stated that the tool was less useful because the apps did not match the personal interests of younger people with dementia. *'I took a quick look at 'reminiscence', but that wasn't a good match I thought'* (PwD19).

The persons with dementia and their informal carers, including the volunteer, were also asked how useful they found the different pages of the FindMyApps tool. Most pages were perceived as useful. The page 'My Apps' was perceived as less useful by the informal carers because it was not functional. The opinions about the 'explanation button' differed among persons with dementia and informal carers, as some found it useful and some found it unnecessary. *'To be honest, it is a bit redundant, because at the home page you automatically click on the main categories'* (IC13).

Finally, persons with dementia and informal carers rated the FindMyApps tool by means of the USE questionnaire as useful, with a mean score of 5.0 (SD = 1.0; range 2-7) for persons with dementia and a mean score of 4.6 (SD = 1.5; range 1-7) for informal carers. All persons with dementia and the informal carers agreed with the statement 'FindMyApps is useful' and they generally agreed that 'FindMyApps gives me (my relative) more control over activities in my (his/her) life'. Persons with dementia were less positive about the

statement: 'FindMyApps helps me to be more productive' and informal carers were less positive about the statement: 'It saves my relative time when he/she uses it'.

User-friendliness (ease of use) of the FindMyApps tool

Four persons with dementia and four informal carers were positive about the user-friendliness of the FindMyApps tool. Most frequently mentioned positive remarks were:

1. Easy to use. *'It is very user-friendly. It is not difficult at all. I am not at all technical with computers and tablets, but even I understand this'* (IC5).
2. Recognisable and clear icons. *'Icons are fine. They are recognisable'* (PwD5).
3. Colours are clear.
4. Clarity of the design.*'Sometimes I make a mistake if I click on something. I think that happens to most people, but then I just go back'* (PwD13).

Most frequently mentioned critical remarks or suggestions to improve the user-friendliness of FindMyApps were:

1. Activating touchscreen is difficult.
2. Icon of the main category 'leisure' is not recognizable. *'That clock doesn't make me think about leisure time. It's about time, but leisure time is more about things that you do rather than time itself'* (PwD19).
3. Apps on page 'My Apps' are not touchable. '*In FindMyApps a list with searched apps becomes available. But I noticed that my husband tried to click on them, that is something he got used to and it seems logical'* (IC13).
4. Too many categories and apps made it unclear. '*There are a lot of categories, you can easily get lost in FindMyApps. That is a bit unclear'* (VT17)|
   Two persons with dementia suggested it should be made clearer which subcategories are behind a main category and suggested adding a table of contents. '*Maybe you should first show a table of the apps that are being offered and which app belongs to which [category]. For example [the category] 'diary', which [apps] are in there and what you can do with them'* (PwD13).
5. Downloading apps is difficult.
6. Buttons 'Information & Download' and 'Download Appstore/Play Store' are unclear due to their colour;
7. Colour variation. '*The app is very calm and clear and you have to keep it that way, but a bit more colour diversity within the (sub)categories makes it less boring and stimulating'* (MZ14).
8. Enlarge the screenshots in the app description.
   The persons with dementia and informal carers, including the volunteer, were asked how user-friendly they found the different pages of the FindMyApps tool. Most pages were perceived as user-friendly by the people with dementia. Informal carers found the pages 'choosing main and subcategories', 'overview of apps in each category'

and 'description of an app', a bit difficult to operate for persons with dementia. *'He cannot manage to make choices in these pages, making choices is also very difficult for him in daily life. This is a major struggle for him, also with regards to the tablet'* (IC7).

Persons with dementia and informal carers also rated the FindMyApps tool by means of the USE questionnaire as user-friendly, with a mean score of 5.4 (SD = 0.6, range 2-6) for persons with dementia and a mean score of 4.9 (SD = .8; range 1-7) for informal carers. All persons with dementia and all informal carers agreed with the statement 'FindMyApps is user friendly' and they generally agreed that 'FindMyApps is easy to use' and 'FindMyApps is simple to use'. Persons with dementia were less positive about the statement 'I can quickly and easily correct mistakes I've made in FindMyApps'. Informal carers were less positive about the statement 'my relative can use FindMyApps successfully every time' and 'my relative can use FindMyApps without written instructions'.

Learnability (ease of learning) of the FindMyApps tool

The answers persons with dementia gave suggested that they did not always differentiate between the learnability of the FindMyApps tool and the learnability of the tablet.
According to persons with dementia and informal carers, 'doing it often' was the most important facilitating factor in learning how to use the FindMyApps tool. '*It's a matter of establishing a routine. If that routine is gone, you have to relearn it bit by bit'* (PwD19).
Secondly, persons with dementia mentioned 'perseverance' as a factor that facilitated learnability. '*I just keep on [working] with it until I succeed'* (PwD7).

According to the informal carers, other facilitating factors were:

1. Use of the EL method.*'I am very consistent in using this method and I also use it to train other skills. Through repetition, providing verbal prompts, and using small steps, and I hope it will remain'* (IC14).
2. Patience and listening carefully to the needs of persons with dementia;
. Previous experience of persons with dementia with a computer/tablet. *'I think he managed very well, of course we practise on a regular basis, but he was already very experienced using a computer and a tablet'* (IC5).
4. Stimulation of persons with dementia to learn something new. Persons with dementia stated that support is most needed when 'they don't know how things work'. Informal carers made this more specific by mentioning that persons with dementia needed support with the FindMyApps tool for:
   - Downloading apps. *'Downloading apps was difficult, we did this mostly together, he never did it alone'* (IC5).
   - Operating the overview of apps in each subcategory.
   - Navigating through (sub)categories. '*I helped him with that, certainly to start with'* (IC13).

Persons with dementia were also asked to indicate:

1. The difficulty in learning how to use the FindMyApps tool and the tablet, and
2. The difficulty of using the FindMyApps tool and tablet independently.

Overall, persons with dementia found learning to use the FindMyApps tool and using it independently more difficult compared to the tablet. Most needed support when using the FindMyApps tool. *'I couldn't do it by myself, someone had to be around'* (PwD7).

Finally, persons with dementia and informal carers were positive about the ease of learning of the FindMyApps tool rated by the USE questionnaire, with a mean score of 5.4 (SD = .5; range 4-6) for persons with dementia and a mean score of 4.4 (SD = 1.2; range 1-7) for informal carers. All persons with dementia agreed with the statement 'I easily remember how to use FindMyApps', whereas informal carers were most negative about this statement for their relative.

Adoption of the FindMyApps tool

Persons with dementia in both groups reported the number of apps downloaded, the source, the frequency, and the type of support those apps had provided (see Table 6.2). In the FindMyApps group most apps were found in the FindMyApps tool: five persons with dementia found more than three apps in the FindMyApps tool. One person with dementia stated that he did not download any apps from the FindMyApps tool. In the control group, three persons with dementia found apps only on the suggested websites and three found apps elsewhere as well as on the suggested websites.

In the FindMyApps group, the persons with dementia used apps found in the FindMyApps tool more often than apps found elsewhere. In the control group, persons with dementia used apps that were found elsewhere a little more frequently than apps found on the suggested websites. In the FindMyApps group, all of the persons with dementia stated that the apps found in the FindMyApps tool supported them in pursuing meaningful activities and four reported the apps supported them in self-management.

In addition, persons with dementia and informal carers made remarks regarding the impact that using the FindMyApps tool and the tablet had on their daily lives.

Most frequently mentioned remarks were:

1. Increased use of tablets. *'Not every day, but a few times per week'* (PwD7).
2. Increased interest in tablet devices. *'It definitely stimulated his interest, he said "I want a tablet of my own. Because when I am sitting outside, I enjoy using it." So, we bought a tablet'* (MZ7).
3. Becoming more digital. *'Well, I have become more digital. Before, I would have used a paper file'* (PwD13).

4. Keeping up with the times. *'You know, I grew up with pen and paper. But you can live without it nowadays'* (PwD17).
5. The world has become bigger. *'Yes, I think that my life has changed. It hasn't changed a lot, but I do think that it changes you. You know more, you hear more, and you see more, and your social environment is different. When I look at my sister, well, her world is very small. And a tablet can make it bigger'* (PwD14).

Informal carers mentioned a lack of time as an important reason that impeded the adoption of FindMyApps in daily life. *'I can get it off the ground, my husband was always against using laptops and computers. At the moment I have to deal with all kinds of family issues and in combination with my energy level necessary to take care of my husband, this makes it impossible. It is just a matter of lack of time'* (MZ2).

Overall, persons with dementia and informal carers were satisfied with the FindMyApps tool as rated by the USE questionnaire, with a mean score of 5.0 (SD = .6; range 2-7) for persons with dementia and a mean score of 4.9 (SD = 1.5; range 1-7) for informal carers. All persons with dementia and informal carers agreed with the statement 'FindMyApps is fun to use'. Fewer persons with dementia thought that 'FindMyApps works the way I want it to work' and informal carers were less positive about the statement 'My relative would recommend FindMyApps to a friend'.

Results: outcome measures (research question 3)

One person with dementia in the FindMyApps group was excluded from the analysis of outcome measures, because he did not complete the post-test measurement as he found it too stressful. Descriptive statistics of the outcomes, and results of the ANCOVAs including effect sizes are provided in Table 6.3.

Analysis of outcome measures for persons with dementia shows large effect sizes for Investing, i.e. investing in resources for long-term benefits (ηp^2 = .16), and Multifunctionality, i.e. gaining or maintaining resources or activities that serve multiple dimensions of well-being simultaneously (ηp^2 = .42) of the primary outcome measure SMAS-30. Investing was more favoured in the control group and Multifunctionality in the FindMyApps group. Additionally, a moderate effect size was found for Variety, i.e. achieving and maintaining various resources for each dimension of well-being (ηp^2 = .12), in favour of the FindMyApps group. We also found large effect sizes for both frequency and enjoyability of the social and domestic activities scale of the PAL, with ηp^2 ranging between .15 and .38, in favour of the FindMyApps group, though scores suggest some decline in both groups. Effect sizes of the secondary outcome measures D-GSE and EAL showed relative changes in the expected direction that favoured the FindMyApps group, with a ηp^2 of .34 and .24 respectively, while the scores on the EAL also improved for the control group.

Table 6.2 Overview of number and usage of apps, and type of support the apps provided for Persons with dementia (PwD) in the FindMyApps and Control Group (N = 10) during three month intervention period based on diary of app usage

	FindMyApps group *(n=6)*		Control group *(n=4)*	
Variables	FindMyApps tool *n (%)*	elsewhere *n (%)*	websites *n (%)*	elsewhere *n (%)*
Number of apps				
0	1 (17)	1 (17)	1 (25)	1(25)
1-2	-	3(25)	-	1 25)
3-4	2 (33)	-	2 (50)	1 (25)
>5	3 (50)	2 (33)	1 (25)	1 (25)
Usage [a]				
Several times per day	2 (40)	2 (33)	-	-
One time per day	-	-	1 (33)	2 (50)
A few times per week	3 (60)	1 (17)	1 (33)	1 (25)
A few times per month	-	1 (17)	1 (33)	-
Type of support [b]				
Self-management	4	3	2	2
Meaningful activities	5	4	2	3
Other	2	-	1	-

PwD who did not download any apps were not included in the description of 'usage' and 'type of support'. [a] one missing value in FindMyApps group for apps found elsewhere; [b] person with dementia could name more than one type of support, therefore the numbers do not always add up to the number of PwD.

For informal carers, a large effect size was found for the primary outcome measure feeling of competence measured with the SSCQ (ηp^2 = .18), in favour of the control group, though this declined for both groups at the post-test.

The ANCOVAs showed only one significant difference in the primary and secondary outcome measures between the FindMyApps group and the control group: scores of the PES, with pre-test scores included as covariate, showed that informal carers in the FindMyApps group reported significantly fewer positive care experiences at post-test than informal carers in the control group, $F(1, 11)=5.17$, $p=.04$, $\eta p^2=.32$. This was a large effect in favour of the control group.

Input future research design: methods and procedures (research question 4)

Of the 28 dyads that were approached or showed interest in participating, 20 took part, giving an inclusion percentage of 71,4%. Dropout rate was 37.5% *(n=15)* for individual participants. Most dropouts were in the control group. Although it was not the main reason for dropping out, two informal carers in the control group and one in the FindMyApps group mentioned that the tablet training was not sufficient enough for persons with no experience in using a tablet.

Informal carers were positive about the phone call at the start of the study, as it provided them with sufficient information about the research to give their consent. However, some noticed that the call took too long. Persons with dementia and informal carers also

Table 6.3 Descriptions of Outcome Measures and Results of ANCOVA for Persons with Dementia (PwD) and Informal Carers (IC) in the FindMyApps (FMA) and Control Group

	Pre-test, M (SD)		Post-test, M (SD)		M_{adj}	M_{adj}	*F*	*p*	ηp^2
					FMA	Cont			
FMA gr Outcome measures range	Cont. gr *(n=6)*	FMA gr *(n=4)*	Cont. gr *(n=6)*	FMA gr *(n= 4)*					
Primary outcome measures PwD									
Self-management abilities									
SMAS-30, [0-100]									
Taking initiative	58.0 (17.0)	47.0 (17.1)	57.3 (9.4)	51.0 (21.8)	53.9	56.1	.15	.71	.02
Self-efficacy	75.0 (15.8)	78.8 (9.5)	79.2 (12.0)	82.5 (8.7)	80.2	81.0	.04	.84	.01
Investing	66.7 (11.2)	54.0 (18.0)	61.3 (9.0)	59.0 (12.4)	58.3	63.6	1.30	.29	.16
Positive perspective	71.3 (17.6)	62.5 (6.5)	67.5 (15.1)	62.5 (17.1)	66.0	64.8	.01	.91	.00
Multifunctionality	48.0 (12.9)	46.0 (23.7)	58.7 (9.4)	42.0 (21.0)	58.2	42.7	5.06	.06	.42
Variety	68.7 (4.7)	60.0 (18.8)	72.7 (12.0)	63.0 (6.8)	71.5	64.7	.93	.37	.12
Total	64.6 (10.5)	58.0 (11.7)	66.1 (8.4)	60.0 (9.5)	64.2	62.8	.23	.64	.03
PAL, [1-5]									
Social activities									
Frequency	2.6 (.5)	2.4 (.6)	2.3 (.4)	1.9 (.4)	2.3	1.9	3.17	.12	.31
Enjoyability	3.3 (.6)	3.4 (.6)	3.3 (.4)	3.1 (.3)	2.7	2.2	2.42	.16	.38
Domestic activities									
Frequency	2.9 (.4)	2.7 (.8)	2.7 (.4)	2.1 (.7)	3.3	3.1	4.23	.08	.26
Enjoyability	3.6 (.4)	3.0 (.6)	3.6 (.4)	2.9 (.4)	3.5	3.1	1.25	.30	.15
Participation in social activities									
ASCOT[a], [1-4]	1.7 (.8)	2.0 (1.2)	1.8 (.8)	2.0 (.8)	1.9	1.9	.00	1.00	.00
Secondary outcome measures PwD									
Perceived self-efficacy									
D-GSE, [10-40]	30.7 (3.6)	30.8 (12.0)	31.3 (6.4)	28.0 (8.0)	31.4	28.0	1.07	.34	.34
Perceived autonomy									
EAL, [12-60]	36.0 (5.1)	38.3 (7.5)	36.5 (4.2)	40.3 (1.3)	36.5	40.2	2.25	.18	.24
Quality of life									
DQoL, [1-5]									
Self-esteem	3.8 (.7)	3.9 (.6)	3.8 (.4)	3.8 (.4)	3.8	3.8	.02	.90	.00
Positive affect	3.9 (.9)	4.0 (.6)	3.8 (.4)	3.8 (.5)	3.8	3.8	.03	.88	.00
Negative affect	2.2 (.6)	2.3 (.2)	2.0 (.5)	2.0 (.1)	2.1	2.0	.32	.59	.04
Feeling of belonging	3.8 (.6)	3.6 (.5)	3.6 (.6)	3.3 (.7)	3.5	3.4	.60	.46	.08
Sense of Aesthetics	3.5 (.7)	4.0 (.8)	3.5 (.6)	3.8 (.3)	3.5	3.6	.09	.77	.01
General quality of life	3.2 (.8)	3.3 (.5)	3.5 (.5)	3.3 (1.0)	3.5	3.2	.26	.63	.04
Outcome measures range	FMA gr *(n=7)*	Cont. gr *(n=7)*	FMA gr *(n=7)*	Cont. gr *(n=7)*					
Primary outcome measures persons with dementia									
Feeling of competence									
SSCQ, [7-35]	26.9 (6.1)	22.9 (3.9)	24.6 (7.7)	21.6 (6.6)	22.0	24.9	2.35	.15	.18
Secondary outcome measures informal carers									
Positive Care Experiences									
PES [0-8]	5.0 (2.0)	3.6 (2.1)	4.4 (1.7)	4.4 (2.6)	3.7	5.1	5.17	**.04**	.32
Quality of life									
EQ-5D-5L[a], [1-5]	1.5 (.3)	1.4 (.7)	1.4 (.3)	1.4 (.7)	1.3	1.5	.88	.37	.07
EQ-VAS, [0-100]	77.1 (12.5)	72.9 (17.0)	76.4 (11.8)	77.9 (18.7)	75.9	78.4	.09	.77	.01
TOPICS-MDS									
General [a], [1-5]	3.0 (.6)	3.1 (.7)	2.9 (.9)	3.0 (.6)	2.9	2.9	.01	.94	.00
General [a], compared to year ago, [1-5]	3.3 (.8)	2.9 (1.1)	3.1 (.9)	3.3 (.8)	3.1	3.3	.09	.77	.01
Rate, [0-10]	7.0 (.8)	6.8 (1.3)	7.0 (.6)	7.0 (.8)	7.0	7.0	.05	.83	.01

SMAS-30, Self-Management Ability Scale-30; PAL, Pleasant Activities List; ASCOT, Adult Social Care Outcomes Toolkit; D-GSE, Dutch General Self-Efficacy Scale; EAL, Experienced Autonomy List; DQoL, Dementia Quality of Life; SSCQ, Short Sense of Competence Scale; PES, Positive Experience Scale. ηp^2= 0.01 small effect size, 0.06 medium effect size, 0.14 large effect size. p <.05 is statistically significant. [a] = lower scores are better, for other measures higher scores are better.

mentioned that the measurements of primary and secondary outcomes of persons with dementia were too time consuming (*M*=58 minutes, range=40-100 minutes). Especially the PAL and SMAS were perceived as too long and confusing for persons with dementia to answer. Also, persons with dementia had problems with the D-GSE scale; in many cases they forgot what had been asked, due to the questions being too long. The test questions of the DQoL at baseline were confusing and it was therefore decided to skip them at post-test. Overall, the laminated response cards were helpful for people with dementia.

The measurements involving informal carers were less time consuming (*M*=20 minutes, range=10-30 minutes). Informal carers became sometimes emotional during the administration of the SSCQ or PES, as they found some questions to be confrontational. However, at the same time they also felt relieved to be able to express their emotions for a moment. Informal carers differed in their experiences with the follow-up phone calls that took place every two weeks. Half of them felt this was positive, that the phone calls worked as a reminder or that they were able to ask questions about problems they had encountered. Others experienced it as a burden when nothing had changed since the last phone call. Keeping a diary of app usage was difficult for informal carers, because some found it too time consuming and others did not have the discipline to do it or continue with it.

Most participants that contacted the helpdesk had questions about the research procedure or needed support with tablet use. At the start of the intervention period researchers accidently discovered that FindMyApps was not working due to technical problems of the software provider. After it was agreed with software provider, researchers were to check the functionality of the FindMyApps tool on a daily basis.

Other irregularities encountered were that measurements involving persons with dementia were not always conducted in a separate room, i.e. in absence of the informal carer, because of the living situation of participants. In some cases, informal carers appeared annoyed that answers given by the person with dementia were not in line with the carer's perception. In addition, because of informal carers' preferences, some semi-structured interviews with persons with dementia and informal carers were planned directly after the post-test measurements or on the same day. Most people with dementia experienced this as exhausting.

Discussion and conclusion

Overall results

FindMyApps is a newly developed intervention that helps persons with dementia to select and use apps for self-management and meaningful activities. This feasibility study explored the implementation strategy of the FindMyApps training and the impact of the FindMyApps tool on self-management and engagement in meaningful activities. We tested the potential effect of the intervention on persons with dementia and their informal carers. Overall, the results suggest that the FindMyApps intervention is a feasible

intervention for people with dementia and informal carers and that, based on the calculation of effect sizes, it has the potential to positively influence the self-management and engagement in meaningful activities in people with dementia. In this small sample, however, no significant differences between the FindMyApps group and control group regarding the outcome measures for persons with dementia were found. For informal carers we found a significant difference between both groups regarding the positive care experiences in favour of the control group.

The FindMyApps training was generally well-received by informal carers. The explanations were clear, and the training based on the EL method [35,36] proved helpful for informal carers in supporting persons with dementia in using the FindMyApps tool and tablet. Persons with dementia learned to use the FindMyApps tool and tablet through this method, which supports earlier findings that persons with dementia can learn how to use everyday technology like mobile phones [39,40]. Despite this positive result, it was remarked by some carers in both groups that one face-to-face training session given by a trainer was not sufficient to fully support both the person with dementia and carer in the independent use of the tablet and FindMyApps tool.

This study also investigated the mechanism of impact of the FindMyApps tool. The research indicates that the FindMyApps tool was useful and user-friendly. Persons with dementia and informal carers in this study reported that the tool was helpful in finding apps and that most apps were interesting and in line with the personal needs of the person with dementia. Given the results of prior studies emphasising that apps need to match the needs and wishes of persons with dementia [16,26], this is a positive outcome. Individuals also reported that using the FindMyApps tool had helped them become more familiar with the use of a tablet. In this pilot study, persons with dementia stated that using the tablet was an enjoyable activity in itself, which is in line with previous studies.[16,24,26]

Nevertheless, there were also some critical remarks regarding the usability and user-friendliness of the FindMyApps tool. Using the touchscreen of the FindMyApps tool was at times difficult for the participants. This confirms previous research showing that persons with dementia can have difficulties with movements such as swiping and tapping on a touchscreen.[16] Also, the FindMyApps tool was developed as a web application and at times a slow internet connection or a slow host server might have caused some of the problems. Another important criticism was that the page 'My Apps' in the FindMyApps tool was not as useful as expected, because apps presented in that list could not be directly opened from that page. Furthermore, there were too many categories and sub-categories, and buttons were not always recognizable as such due to a lack of colour contrast.

Persons with dementia were generally able to learn how to use the FindMyApps tool by using it regularly and through perseverance. For informal carers it was important to be patient when training the person with dementia. Previous experience using a tablet made the training easier for persons with dementia. Downloading apps was difficult for persons

with dementia, and many needed support in navigating categories on the FindMyApps tool. Though the persons with dementia stated that they had generally learned how to use the tool, almost all of them needed support from their informal carers in using specific parts of FindMyApps, which was expected.[32,41]

Most persons with dementia in the FindMyApps group found more than three apps in the FindMyApps tool, which they used on a daily or weekly basis. Persons with dementia in the control group also found useful apps on websites, though they used them less often than participants in the FindMyApps group. All participants reported that the apps stimulated either their self-management abilities, their engagement in meaningful activities or both. These findings confirm previous studies that show that persons with dementia can still enjoy engaging in activities and that a tablet with apps can be both an interface to do this as well as offering daily support.[15-17,19,21,24,26] For example, Cutler *et al.*[15] and Groenewoud *et al.*[16] found that playing games on a tablet can be a meaningful activity for persons with dementia.

We did not find any statistical significant effects in the FindMyApps group on the primary or secondary outcomes in persons with dementia. So there was no clear indication that the FindMyApps group had more support in tablet use than those in the control group. We did find some moderate to large effect sizes for variables of the primary and secondary outcomes for people with dementia, which are generally slightly in favour of the FindMyApps group. For example, we found a large effect size for the D-GSE with scores showing an improvement for persons with dementia in the FindMyApps group. Persons with dementia in the FindMyApps group possibly felt more optimistic that they were able to cope with their condition, because they had access to the specific intervention. Informal carers in the FindMyApps group reported significantly fewer positive care experiences than participants in the control group. A possible explanation could be that informal carers in the FindMyApps group experienced the support for their relative with dementia as too time-consuming, which was also acknowledged in the semi-structured interviews. A future RCT with a larger sample will enable us to have enough power to draw conclusions that are supported by statistical analyses.

Strengths and limitations

A strength of this study is that we used a mixed-methods design comprising qualitative and quantitative measures, which helped us gain in-depth information on the experiences and opinions of the participants. We took the time to build relationships with the participants. By building a relationship and meeting the participants in person – an important aspect of dementia-related research to maximize responses of persons with dementia [77] – we were able to find the intended amount of dyads to start this pilot study.

There are some limitations to be noted. Although we did find some moderate to large between-group effect sizes, statistical power was low due to the small sample, and we must therefore be cautious in drawing conclusions about the potential impact of

FindMyApps. Next, selection bias could have influenced the results. In our sample, the majority of persons with dementia and informal carers had a high level of education and the majority of persons with dementia were male, while the majority of informal carers were female. However, research shows that Internet use is a male-dominated activity among the older population [78], which may clarify why we had more men than women with dementia in our sample. In addition, due to the high level of study attrition, it may be that the opinions of persons with dementia and informal carers who completed the study differed from those who dropped out. This has to be considered when reviewing our findings

Recommendations for a future effectiveness study

As this study was an exploratory pilot RCT in preparation for an upcoming effectiveness study, some recommendations can be made. First, due to the high number of persons with dementia who dropped out due to a limited interest in using a tablet, we recommend that researchers check the level of motivation regarding tablet use not only with informal carers, but also with potential persons with dementia in order to reduce study attrition. This seems to be particularly important for people who have no prior experience in using a tablet. Secondly, we noticed that data collection using questionnaires was difficult and at times stressful for some persons with dementia due to the number of questionnaires and their length. We therefore recommend using shorter questionnaires. Examples are the SMAS-S [79], a shortened version of the SMAS-30 with 18 items, the Maastricht Social Participation Profile [80], an alternative to the PAL that measures social participation in older adults with 26 items, and a shortened version of the USE questionnaire consisting of 17 items as described by Lund.[49] This would make data collection from persons with dementia more feasible and decrease the likelihood of missing values. Thirdly, several informal carers reported that keeping a diary of app usage took up too much time and a lot of diaries were not completed. We think that using a diary for app usage will not be necessary in a future RCT, as data analytics tools for tracking app usage in the back-end of the FindMyApps tool, supported with the page 'My Apps' in the FindMyApps tool and the interviews, will provide enough information on app usage by persons with dementia. Fourthly, we recommend checking the status of dementia in participants and also repeating this post-test. The results of these outcomes could then be connected to the results of the outcome measures to get a clearer view on a possible relationship between a decline in the outcomes and the stage of dementia. Fifth, based on the data of this pilot study and the medium to large effect sizes found for some of the primary and secondary outcome measures, an *a priori* power calculation was performed with G*Power version 3.1 [81] to allow for a recommendation regarding the sample size for the upcoming RCT. The calculation indicates that in an ANCOVA model with a power of 80% and a significance level of 0.05 a total sample size of 128 participants would be needed to detect a medium effect and 52 participants to detect a large effect. Allowing

for a dropout rate of 37.5%, an overall sample of 176 participants, 88 participants in the experimental group and 88 in the control group, or 72 participants, 36 participants in the experimental group and 36 in the control group, will be required respectively.

Recommendations for the FindMyApps training and tool

The results of the qualitative analyses provided valuable insights into how the FindMyApps training and tool can be improved. Based on the remark made by informal carers that one training is not sufficient enough to support persons with dementia, we suggest adding demonstrational videos, an approach that has effectively been used to help people acquire new skills.[82] These videos could provide general instruction on the functions of the tablet for both groups, as well as instructions on how to use the tool in the FindMyApps group. Informal carers and persons with dementia could watch the videos any time they needed assistance. Hopefully, this would also contribute towards less time investment by informal carers in training their relatives with dementia. Secondly, qualitative analysis showed that several participants did not find the page 'My Apps' useful, because it was not possible to open apps directly from this page. The reason for this is that we built the FindMyApps tool as a responsive website instead of a native app, so that it could be easily updated and developed further, which was more feasible for our study purposes. We recommend that clicking on an app on the page 'My Apps' opens the App Store respectively Play Store, which would enable participants to open the specific preferred app. This would be an interim solution, as directly opening an app through the page 'My Apps' is not yet possible due to its development as a responsive website. Thirdly, participants reported that it was not always clear to them what kind of apps a main or subcategory entailed based on the symbols used. We therefore suggest adding a short description sentence to each category. Furthermore, the icon of the main category 'leisure' should be made more recognizable, and some buttons, like the download button, must offer more contrast in colour.

Scientific and practical relevance

To our knowledge, this is the first intervention for people with dementia designed to help them find usable apps for self-management and meaningful activities that are tailored to their needs, wishes, and abilities. Our findings are contributing towards the growing field of eHealth interventions for people with dementia, especially regarding the potential use of tablets and apps. In dementia-related research the opinions and experiences of persons with dementia are often neglected.[77] Our findings suggest that they can still provide valuable information and contribute to research, if the study procedure is fitted to suit their abilities, e.g. making use of trained assessors and interviewers and shorter questionnaires. A shift from doing research on people with dementia to doing research with people with dementia would be a fruitful direction for the development of effective interventions for people with dementia.

Conclusions

Based on the qualitative results and the effect sizes on the outcomes measured in this study, we consider that the FindMyApps intervention has the potential to positively influence the self-management and engagement in meaningful activities in people with dementia. Future studies with a larger sample should better indicate whether this expectation can be confirmed. The intervention will be further improved and tested in a larger pilot-RCT study and its effectiveness subsequently evaluated in a definite RCT.

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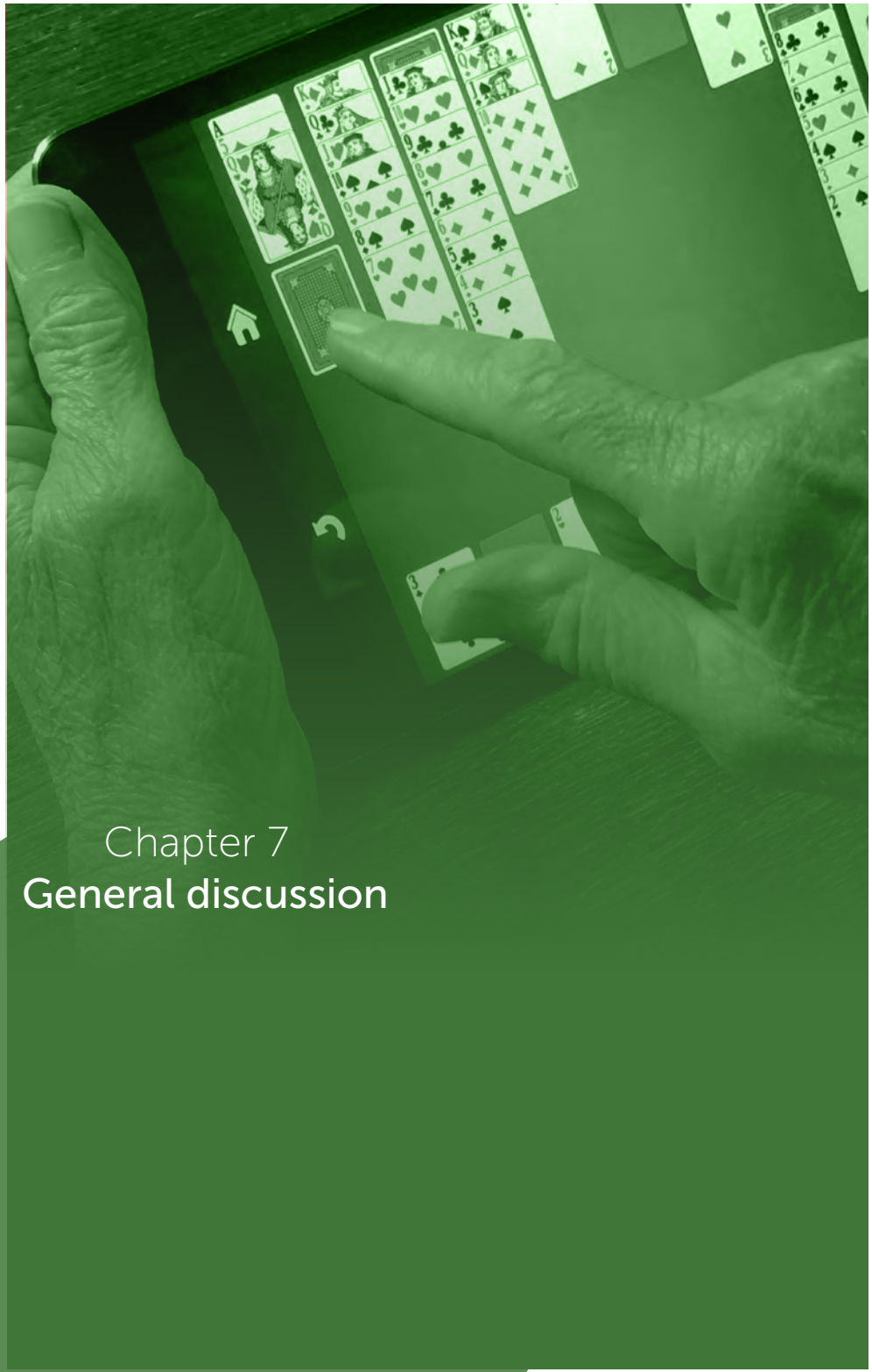

Chapter 7
General discussion

Introduction

In this thesis a person-centred tablet program, called FindMyApps, was developed and tested. The FindMyApps program consists of a training for informal carers to support people with mild dementia in using a tablet and a web-based selection tool designed to help people with mild dementia find apps for self-management and meaningful activities that fit their needs, wishes and abilities. The program was developed according to the MRC Framework for the design and evaluation of complex interventions (1-3) and in co-creation with end users. In our study we completed the first three phases of development and testing of the MRC Framework. After developing a study protocol of how FindMyApps would be developed and tested, we performed user needs studies to identify user requirements for the FindMyApps selection tool. Secondly, before developing a training for using the FindMyApps tool and tablet, we conducted a literature review into training interventions that support people with mild dementia in (re)learning the use of technologies, including handheld touchscreen devices. Thirdly, we developed a selection tool in close collaboration with users and experts i.e. designers, developers and researchers. Finally, we tested the feasibility and impact of FindMyApps in a small-scale randomised controlled exploratory trial.

In this general discussion, we shall first summarize the main findings of our studies. Next, we will discuss these findings from two perspectives: (i) the benefits/added value of the FindMyApps intervention and (ii) the factors which are essential in developing and testing a person-centred eHealth intervention for people with dementia and their informal carers. Subsequently, some methodological considerations will be discussed, as well as the scientific, clinical and societal value of the conducted study. The chapter concludes with recommendations for future research and practice.

Main findings and conclusions

The key findings and conclusions of our studies are summarized according to the main research questions of this thesis (see Introduction of the thesis):

How to develop a person-centred program that supports people with mild dementia and their informal carers in the use of hand-held touchscreen devices? (Chapter 2)

In this study-protocol we described how we planned to perform the first three phases of the MRC framework i.e.: the preclinical or theoretical phase (0); the modelling phase (I) and the exploratory trial (II). In the first phase user needs studies were planned to identify user requirements for desired self-management and meaningful activities relating to the use of apps. We also planned a literature review to find out which training interventions are most effective for people with mild dementia in (re)learning how to use technologies, including handheld touchscreen devices. The intention was to use these results to plan and develop a FindMyApps training. In the second phase of the framework we

intended to develop a first concept of a FindMyApps selection tool based on identified user requirements. In the third phase we pilot tested the FindMyApps intervention by means of individual semi-structured interviews and a pilot randomized controlled exploratory trial. Mixed methods, i.e. both qualitative and quantitative research methods, were used for designing and testing the program. People with dementia and their informal carers were involved intensively during all these phases, by means of individual interviews, focus groups, workshops and usability tests. The iterative process inherent to this framework made it possible to develop a person-centred program for the use of tablets in dementia care. The work in the first three phases of the framework aimed to complete preparations for a methodologically sound definitive randomized controlled trial (RCT) to be conducted in the near future. The ultimate goal of such a definitive RCT would be to investigate whether (i) FindMyApps contributes to better self-management and increased participation in daily and social activities of the person with dementia, resulting in more perceived self-efficacy and autonomy, (ii) an improved sense of competence and positive care experiences of their informal carer, and (iii) improved quality of life for both the person with dementia and carer.

What do people with dementia find important in their choice and use of apps and what user requirements can be identified based on these perceptions? (Chapter 3)

Chapter 3 describes the results of an exploratory study conducted to identify user requirements for the development of the FindMyApps selection tool. We performed eight focus groups in which people with mild cognitive impairment (MCI) or mild dementia *(n=13)* and informal carers *(n=15)* participated. In user study one, needs and wishes resulted in user requirements relating to apps for different aspects of self-management, such as support for memory, language and communication, and for social participation and meaningful activities, such as games, being creative, sports, news and information, gardening and reading. Based on these user requirements we created main and sub-activity categories for the FindMyApps selection tool. In user study two, needs, wishes and abilities resulted in user requirements relating to key app features such as recognisable and large buttons, large font size and being simple to operate. Firstly, based on these user requirements, we were able to set the user-profile of the tool by asking questions about personal preferences of app features. Secondly, based on these user requirements and the scientific literature we made a list of criteria for grading dementia-friendly apps to be included in the library of the selection tool. Finally, the user requirements gave us information concerning important user-interface aspects when developing the tool. In general, the user requirements collected in this study helped us to create a selection tool that works as a filter so that selected apps match the wishes and needs of the person with dementia in the domains of self-management and meaningful activities and that key features of those selected apps fit the personal preferences of people with dementia.

Which training interventions are effective for people with mild dementia in (re) learning how to use technologies, including handheld touchscreen devices (Chapter 4)?

In this literature review we identified which training interventions work best in helping people with mild dementia (re)learn how to use technologies, including handheld touchscreen devices. An electronic search was conducted in the following databases: PubMed, APA PsycInfo (EBSCO) and CINAHL (EBSCO). In total 16 studies met the inclusion criteria and the following data was inventoried and described: dementia type and severity; technology task type; training intensity and setting; components of training intervention (e.g. Errorful (EF) and Errorless (EL) learning); and study design and outcome measures. All studies reported positive learning effects and improved task performance in people with dementia, regardless of dementia severity, training intensity, setting and the method used. Although the EL training method was more frequently successful than the EF training method, it would be inappropriate to conclude that the EL method is more effective, as the majority of studies only investigated EL training interventions with (multiple) single-case study designs. Nevertheless, our review contributes to the increasing amount of promising evidence on the potential impact of EL training interventions for people with mild to moderate dementia in (re)learning how to use technology. As a result we based the FindMyApps training on the principles of EL learning, such as no guessing to prevent errors; a stepwise approach; modelling and providing verbal or visual instructions.

How to develop a selection tool that helps people with dementia find suitable apps for self-management and meaningful activities that match their individual needs, wishes and abilities? (Chapter 5)

In this study we developed the FindMyApps selection tool. To ensure its usability, the tool was developed using a 'user-participatory design' involving close collaboration between potential users, a development team (researchers, developers and designers) and an expert team (experts in person-centred dementia care and ICT). In three short iterative rounds – so called 'sprints' – the users (people with dementia *(n=8)* and (in)formal carers *(n=10)* were invited to test whether the prototypes matched with their needs, wishes and abilities. This generated important insights into (i) useful content and (ii) a user-friendly tool design. One key point in the development of the content was establishing a useful group hierarchy of main and subcategories in the domains of self-management and meaningful activities. User experience indicated that there were too many and overlapping subcategories, so it was decided to delete the subcategories where no suitable apps were available. In addition, user experiences told us that combining many options for main and subcategories on one screen was not desirable. To acknowledge the wide variety of needs and wishes for self-management and meaningful activities, we decided to incorporate more pages with fewer options, supported by clear and simple navigation. With regard to the design, user experience informed us that different user-interface ele-

ments, such as pages and interactive buttons, had to be simple and logically integrated to support users in intuitively operating and understanding the tool. One major finding was that the icons used to represent the activities and sub-activities were not all clear, so additional tests were conducted with people with mild dementia (*n*=10) to gain greater insight into which icons were clear for everyone and which icons needed to be adapted. In the end the FindMyApps selection tool was conceived as a means of making it easier for people with mild dementia to select apps meeting their needs, wishes and abilities. The front-end consisted of several pages, such as a log-in page; a page for setting the user-profile; a page for choosing main and subcategories; pages with app recommendations and information; a page with an overview of most-used apps; and a help tutorial on every page. The back-end consisted of a user environment where user profiles could be made and where app selection took place; an administration environment where user profiles, apps and selection criteria are defined and a reporting environment where information about the user profiles and the use of the tool (during the feasibility study and RCT) can be automatically stored. This provisional version was further tested in the exploratory trial.

What is the feasibility of the person-centred tablet program and research design (Chapter 6)?

In this study the feasibility, implementation strategy and mechanism of impact of FindMyApps was tested. We conducted an exploratory, pilot randomized controlled trial with a mixed-methods design. Twenty people with mild dementia and carer dyads were randomly assigned to the FindMyApps group *(n=10)*, receiving either the FindMyApps training and selection tool, or a control condition *(n=10)*, receiving only a brief tablet training. Pre- and post-test measurements at a three month follow-up, consisted of questionnaires and post-test semi-structured interviews. Qualitative results indicate that the FindMyApps intervention supports the self-management abilities and engagement in meaningful activities of people with dementia. The FindMyApps tool was mostly perceived as useful and easy to use. People with dementia found apps through the tool, which they used regularly. People with dementia and informal carers were positive about the FindMyApps training and the support they received. However, some informal carers also indicated that one training session provided by the researcher at the start was insufficient for them to effectively support the person with dementia. The participants with dementia were generally able to learn how to use the tool, though they regularly needed support from informal carers. Previous experience using a tablet made the training easier for those with dementia. No significant differences were found on outcome measures of people with dementia in this small-scale pilot study, but based on calculated effect sizes it did suggest that FindMyApps has the potential to positively influence the person with dementia's self-management and engagement in meaningful activities. For informal carers, we found a significant difference between groups regarding positive care expe-

riences in favour of the control group. Recommendations to improve the intervention included adding demonstrational videos for tool and tablet use in the FindMyApps app to offer additional support to informal carers during training and to improve the user-friendliness of the tool by adding short descriptions of activities on the (sub)category buttons (in addition to the icons) to support the understanding of the type of activities that one could expect within the main and sub-activities. In addition, recommendations were given for the future effectiveness study, such as shorter questionnaires for those with dementia and power calculation for sample size (e.g. based on the dropout rate of 37.5% in the three month pilot study, 88 participants in the experimental and control groups are needed to detect a medium effect in this period).

Discussion

Benefits/added value of the FindMyApps intervention for people with dementia and their informal carers

Based on the qualitative results and the effect sizes on the outcome measures of the exploratory trial (Chapter 6), we consider that participants with dementia were better able to find apps that match their needs, wishes and abilities regarding self-management and meaningful activities and therefore FindMyApps has the potential to contribute to better self-management and engagement in meaningful activities of people with dementia. Most participants with dementia and informal carers reported that the tool was user-friendly and useful in finding apps that matched their personal interests. These apps were supportive for either self-management abilities, their engagement in meaningful activities or both and were used on a daily or weekly basis. These findings are in line with a recent explorative evaluation study of FindMyApps with a bigger sample [4,5] and with previous studies showing that a tablet with apps can support a person with dementia's self-management [6,7] and their engagement in meaningful activities.[8-11]

The exploratory trial described in this thesis and the recent follow-up of Beentjes et al.[4] also shows that people with mild dementia can learn how to use the tool and the tablet using the EL training method (Chapter 4). This supports earlier findings that people with dementia can learn how to use everyday technology, like tablets and smartphones, with this method.[12,13] Also informal carers found the method helpful in supporting people with dementia in using the tool and tablet, and some even used it to train skills in other areas as well. Nevertheless, carers stated that one training session provided by the researcher at the start of the intervention was insufficient for them to optimally support the person with dementia. Although people with dementia generally learned how to use the tool, continuous support from informal carers was needed for some parts of the tool, as expected (Chapter 5). As a consequence they experienced the support of the person with dementia as too time-consuming. This may explain why informal carers reported fewer positive care experiences than the control group. We expect that additional demonstrational videos, an approach that has effectively been used to help people acquire new

skills [14], will support both the person with dementia and their informal carer in using the tablet and tool independently and that this will increase the positive care experiences of carers of people using FindMyApps. In the recent explorative evaluation study into FindMyApps, in which such demonstrational videos remained available after the start of the intervention, carers showed a small positive tendency on positive care experiences. This could suggests that the improved version of FindMyApps (developed after the exploratory trial), which includes the introduction of demonstration videos contributed to better supporting the person with dementia/MCI and as a consequence positively influenced the care experience of carers in the experimental group.[5]

Other positive effects reported by participants with dementia and their informal carers are that FindMyApps contributes to an increased use and interest in tablets and that they become more digitally competent. They also reported that they could keep up with times and that the world became larger (Chapter 6). Nowadays, the use of apps on hand-held touchscreen devices is becoming an integral part of everyday life, also among the older generation and this increases the need to design digital systems, such as FindMyApps, that can be used by all, regardless of physical or cognitive impairments.[15]

Essential factors for developing and testing a person-centred eHealth intervention for people with dementia and their informal carers

a. *Factors related to involving people with dementia and their carers in IT developments.*

   In this thesis people with dementia and carers were involved in different phases of technology development [16,17] and this contributed to a useful, user-friendly and person-centred IT application. According to the four developmental phases described by Span et al.[16] we involved people with dementia and carers in the explorative phase by collecting user-requirements in user needs studies (Chapter 3); in the technical phase we developed the tool by framing the user-interface aspects based on how users interacted with the tool (Chapter 5); and in the adaption phase, the exploratory trial (Chapter 6) FindMyApps was used for a longer period of time whereby users informed us of any further improvements that were needed for the last evolution phase (definitive RCT). We used different participant roles and research methods to optimally involve users in each developmental phase. For example people with dementia were involved in the explorative and technical development phases individually or in focus groups (in the absence of their carers) fulfilling the roles of informants and advisors.[18] In the exploratory trial people with dementia and carers were involved as dyads fulfilling the roles of informants and research objects.[18] However, to gain a comprehensive insight into their needs, the interviews were generally conducted independently from each other as we know from our previous studies (Chapter 3 and 5) and other studies in the literature that the needs reported by people with dementia can differ from those mentioned (about the person with dementia) by their carers.[19-21] It was

therefore important to ensure that the perspective of the person with dementia was not dominated by their carer's perspective.[22] During the development of the FindMyApps tool (Chapter 5) we used a different set of methods and instruments in a sprint, such as cognitive walkthroughs, usability tests with scenario-based tasks and Three Step Test-interview (TSTI) with the thinking-aloud method, and card sorting, which was valuable for optimal collaboration with users and other stakeholders involved.[23] For example, in sprints 2 and 3 cognitive walkthroughs took place first together with researchers and experts, in order to identify potential usability problems for developers that could hinder users from successfully completing a task during the usability tests. This was done to prevent people with dementia from unnecessary exposure to failures of the system and thus avoiding feelings of failure during the tests. Also other researchers acknowledged the importance of avoiding feelings of failure when people with dementia are unnecessary exposed to prototypes that are not working properly [24] and to perform impact evaluation when the system meets an acceptable standard of stability and reliability.[25,26]

b. *Factors related to involving people with dementia and their carers in research.*
During sessions with the person with dementia and informal carers, we found that strategies for maximizing the inclusion of people with dementia as formulated by Murphy et al., such as creating a safe environment by spending time getting to know them, performing on-going consent, giving them positive feedback, emphasizing the importance of their participation and recognizing signs of discomfort, were helpful.[22] In addition, it was important to acknowledge and repeat that it was not the person with dementia being tested but the IT system. This resulted in rich quotes which gave an in-depth understanding of their personal experiences, needs, wishes and abilities. In user study two (Chapter 3) and during the development of the tool (Chapter 5) we found that, although most of the participants with dementia were experienced in using a touchscreen or computer, it was at times stressful for them. For example, during the usability tests (Chapter 5) in sprint one we found that the method scenario-based testing and the TSTI with the thinking aloud method had to be adapted for sprint 2 due to the memory problems of the target group. Also Gibson et al. acknowledged that common usability testing protocols such as the thinking aloud method may not be suitable for evaluating app use by people with dementia.[15] We also found that some training in the basic principles of FindMyApps before performing the tasks in the usability tests could be supportive for better task performance and help avoid feelings of stress and discomfort by users with dementia and carers. Based on these findings we recommended providing instructions and giving users time to practice before starting with the semi-structured interviews during the exploratory trial (Chapter 6). In the exploratory trial we found a study attrition rate of 37.5 % mainly due to lack of interest in using a tablet among participants with dementia, and the additional burden for

carers in supporting and stimulating their relatives with dementia in using the tablet. In most cases the person with dementia or both had no prior tablet experience. Most of the participants with dementia and informal carers who completed the trial already had tablet experience at the start of the intervention and most informal carers were supportive in providing help to participants with dementia, resulting in positive FindMyApps experiences for both. Øksnebjerg et al. also acknowledged that carers who are supportive in activating app use had a significant impact on the participant adoption status. However, in their study the level of experience and skills in tablet use did not significantly differ between adopters and nonadopters.[7]

c. *Factors related to an effective collaboration between researchers and software developers.*

During the development of the FindMyApps tool (Chapter 5) researchers, software developers and experts in dementia care worked closely together and this resulted in a thorough understanding of how potential users interact with the user-interface. It also contributed to a better mutual understanding of the researchers' and developers' roles, perspectives and use of each other's jargon. During the development researchers became more aware of logical steps in software development, by following the Scrum method that guided the development team in prioritizing the working agenda. In turn, software developers adopted a research attitude, which was supportive to researchers and of great value to the quality of the end product, as is shown by these two examples: In sprint 1 it occurred that developers gave first priority to the technical realization of the FindMyApps functionality, while design including user-friendly navigation, was a second priority. It became evident that especially for those with dementia, design and technical functionalities had to be developed 'hand in hand' to avoid feelings of stress and discomfort among participants with dementia during the usability tests. Meiland et al. acknowledged that researchers involved in technology development for people with dementia must have adequate knowledge of dementia.[27] We also believe that software developers and designers can benefit from adequate knowledge of dementia when designing useful and user-friendly IT applications. The second example concerns the type of end product: at the start of the development, researchers and developers discussed the pros and cons of building a responsive website or a native app which can be defined as an app downloaded to the user device.[28] We decided to build a responsive website, because research-driven pros convinced us that this was a better option at that stage of technological development and the research phase. One important research-driven pro was that a website provides the possibility for continuous development and improvement, whereas a native app is more static and can therefore easily result in a poor-quality end product. In addition, a website is less time consuming to build and more user-friendly for updates.[28] Furthermore, a website avoids problems with the compatibility of FindMyApps on dif-

ferent versions of tablets. There are also some cons to mention regarding the use of a responsive website which were noticed during the usability tests and the exploratory trial (Chapter 5 and 6). First, users had to press more than once to get a button to react, which was caused by a poor internet connection. A native app can be used offline, which would hopefully improve the responsiveness of buttons. Secondly, users experienced the page with an overview of most used apps per category (My apps) as less meaningful, because the page did not fulfil its intended function, which was to provide the option of directly launching (open) each of the apps downloaded through the FindMyApps tool. A responsive website does not support universal links of apps, which means that apps downloaded through FindMyApps were not automatically stored in the back-end, making it impossible to launch apps directly from the MyApps page. With a native app these downloaded apps would have been stored in the back-end which would allow launching within the FindMyApps environment and would also give insight into app usage statistics.

Methodological issues and limitations

A strong point of this thesis is that we have followed the recommendations from the Medical Research Council framework for the development and evaluation of complex interventions.[1-3] The iterative process of this framework allowed us, in the first three phases of development and testing, to constantly optimize the FindMyApps intervention to the needs, wishes and abilities of the end users and to recommend further improvements for future feasibility and effectiveness studies, which have already been conducted [4,5] and are currently being executed.[29] We managed to give the end users a voice by involving them in all phases of technology development [16,17] in participatory designs [30] which contributed to a useful, user-friendly and person-centred IT application. People with dementia and informal carers fulfilled the roles of research objects, informants and advisors.[18] Decisions during the designing and pilot testing of FindMyApps were based on how users interacted with the design and how they experienced it.[31] We used valuable strategies for maximizing responses of people with dementia, such as building a relationship by taking time, creating a safe environment, performing on-going consent and providing positive feedback.[22] This resulted in rich quotes which helped us gain in-depth information on the experiences and opinions of users.

Although we actively involved people with dementia and carers, we did not involve them as co-designers which would have stimulated an equivalent cooperation and an even more active involvement.[18] Consequently, this could have improved the understanding of their specific wishes, needs and abilities directing us to an even better tailored-made intervention. Although this is challenging, it is in line with person-centred care [32], reduces the stigma that adheres to dementia and, most importantly, results in technologies which are experienced as more meaningful and suitable by the target group.[16,17]

Another limitation was that we had to make choices based on a limited amount of data

and that selection bias for the activities included in the content of FindMyApps may have occurred. The qualitative study (Chapter 3) had an exploratory focus and we did not reach saturation in self-management support and meaningful activities due to the wealth of activities in these domains and the restricted time we had for this explorative phase. This means that not all activities people would prefer are represented in FindMyApps. In addition, we could not cover all needs and wishes of people with dementia by categories and subcategories for the FindMyApps selection tool because of the lack of suitable apps. We therefore may have included an incomplete and selective content of activities (Chapter 5).

A third limitation is that in our studies a convenience sample of respondents (Chapter 3, 5 and 6) was used and that selection bias based on selective recruitment also may have influenced the results. We recruited most members from one day care and two meeting centres, which is not a representative group of community-dwelling people with mild dementia, as it does not include those who do not make use of day care facilities. Also, the fact that most of the participants with dementia included in our exploratory trial (Chapter 6) had tablet experience indicates that there was indeed selection bias, as this will not be the case in people with dementia in the general population. This is also confirmed by the fact that more men than women participated, whereas dementia is more common in females.[33] On the other hand, also in community dwelling people with dementia who do not utilize day care facilities, there will probably be a higher percentage of men with tablet experience, as it is known that among the older population (age of 65 years and older), Internet use is a male-dominated activity.[34] In addition, the majority of people with dementia and informal carers also have a high level of education and due to the high level of study attrition, it may be that the opinions of people with dementia and informal carers who completed the study differed from those who dropped out.

Fourthly, the scarcity of available studies in our literature review (Chapter 4) forced us to include different study designs with different levels of evidence. We included quasi-experimental and (multiple) single-case studies with small sample sizes, because RCTs into technology training interventions in people with dementia were scarce, which is also acknowledged by De Werd *et al*.[35] Moreover, the content of the training interventions was not consistently described and used across studies and there was little variation in training interventions, i.e. the Errorless (EL) learning approach was included in all studies. This makes it impossible to draw conclusions regarding which training interventions are most successful. Further research into a variety of training methods is needed to decide on this.

Finally, in the exploratory trial (Chapter 6) we did find some moderate to large between-group effect sizes. The statistical power was low due to the small sample, and we must therefore be cautious in drawing conclusions on the potential impact of FindMyApps, which was also not the main focus of this explorative study. This has to be considered when reviewing our findings.

Relevance

Scientific relevance

It has been acknowledged that designing 'one size fits all' applications for an entire population, such as people with dementia, cannot adequately address the barriers to engagement in meaningful activity for all people with dementia. Therefore a customised approach, such as FindMyApps, is necessary to match technology to the individual.[27,36] FindMyApps is the first touchscreen intervention that has been developed and tested by people with mild dementia and their informal carers that enables users to match personal preferences and abilities with the specific features and types of apps in the domains of self-management and meaningful activities.

With our literature review (Chapter 4) and exploratory feasibility trial (Chapter 6) we contribute to the body of knowledge concerning effective training interventions to help people with dementia (re)learn how to use technology, including touchscreen technology. This is important, because so far it was unclear whether proven effective training methods supporting people with mild to moderate dementia in their daily functioning are also applicable to teaching them how to use complex technologies.

Our findings also contribute towards the growing field of eHealth interventions for people with dementia, especially regarding the potential use of tablets and apps for self-management and meaningful activities, and meets the growing need for evidence-based practice.[36]

Clinical and societal relevance

From the new positive health perspective, as formulated by Huber *et al.*[37] and specified for social health in people with dementia by Dröes *et al.*[38], (see Introduction of this thesis), the FindMyApps intervention can be seen as an innovative intervention that aims to contribute to the social health of community-dwelling people with mild dementia - and thereby to their quality of life - by teaching them how to use a tablet and a person-centred selection tool. Our study showed that FindMyApps helps people with mild dementia and their carers to find apps for self-management and meaningful activities that fit their needs, wishes and abilities. It is expected that the use of such apps will contribute to improved self-management and social participation resulting in more self-efficacy, autonomy and a better quality of life for the person with dementia. For their carers it is expected that the use of FindMyApps contributes to a higher sense of competence, resulting in a more positive care experience and quality of life. Once proven effective, FindMyApps has the potential to be widely and easily adopted as a practical aid for people with dementia in person-centred dementia care, and so contributing to a greater experiencing of pleasure and enjoyment; retaining a sense of autonomy and personal identity; and feelings of connection and belonging.[39]

FindMyApps benefits the inclusion of people with dementia in an Internet society, as it enables them to get access to the wide variety and dynamic supply of apps in a user-

friendly and person-centred manner. It contributes to the need for digital systems, that can be used by all, regardless of physical or cognitive impairments.[15] Moreover, with the inventoried user requirements (Chapter 3) and insights into user-interface aspects (Chapter 5) we have provided valuable input for designers and builders of ICT regarding the development of usable apps for people with dementia and other vulnerable target groups with cognitive impairment.

The results from our literature review (Chapter 4) and the feasibility results of our exploratory trial (Chapter 6) show that people with mild dementia, by means of the Errorless (EL) learning training method, still can (re)learn using handheld touchscreen devices. This reduces the stigma that adheres to dementia and will hopefully challenge informal carers and professionals to support people with dementia also with (re)learning other kinds of activities in daily life.

Recommendations

To be able to draw conclusions about the effectiveness of FindMyApps, we recommend carrying out a sufficiently powered definitive RCT in the near future according to phase III of the MRC framework. Based on user experiences in the exploratory trial (Chapter 6), the following recommendations can be made with regard to the research protocol, the FindMyApps intervention and for additional development and future research into the FindMyApps intervention and dementia care practice.

Recommendations for the research protocol

1. Given the relatively high number of participants with dementia who dropped out during the exploratory trial into FindMyApps (37.5%), often due to limited interest in using a tablet *(n=4)*, we recommend that researchers check the level of motivation regarding tablet and app use not only with informal carers, but also with potential participants with dementia before including them in the study, in order to reduce study attrition. This seems to be particularly important for people who have no prior experience in using a tablet.
2. We noticed that data collection using questionnaires was difficult and at times stressful for some participants with dementia due to the number of questionnaires and their length. We therefore recommend using fewer and shorter questionnaires. In addition, before starting with the semi-structured interviews for exploring the usability of the FindMyApps tool, we recommend summarizing and visualising the functions of FindMyApps.
3. Several informal carers reported that keeping a diary of app usage took up too much time. To reduce the additional burden for carers in supporting their relatives with dementia in using the tablets, we recommend data analytics tools for tracking app usage in the back-end of the FindMyApps tool. In addition to the semi-structured interviews for process evaluation, this will provide, enough information on app usage

by people with dementia.
4. Taking into account a dropout rate of 37.5%, we recommend including 176 participants in a definitive trial, to detect at least medium effects (Cohen's d=0.5) on the outcome measures.

Recommendations for the FindMyApps intervention:

1. We recommend adding demonstrational videos to the FindMyApps app. These videos should provide general instruction on the functions of the tablet, as well as instructions on how to use the FindMyApps selection tool. This recommendation is based on the experiences of informal carers who found one training session, provided by the researcher at the start of the intervention, insufficient to effectively support the person with dementia. Demonstrational videos will also contribute towards less time investment of informal carers in training their relatives.
2. We recommend making the page 'My Apps' more useful by building a native app which will make it possible to launch apps within the FindMyApps environment via the page 'My Apps'. Storage of app usage in the back-end will also make it possible to observe individual app behaviour. We recommend discussing the pros and cons of a responsive website versus a native app again at this stage of technology development and research. An interim solution could be that clicking on an app on the 'My Apps' page would directly open the App Store or Play Store which would then enable participants to open their preferred app.
3. User experiences informed us that it was not always clear what kind of app a main or subcategory referred to based on the symbols used. We therefore recommend adding a short description under the icon of each category. Furthermore, we suggest making the icon of the main category 'leisure' more recognizable, and bringing more colour contrast into some buttons, such as the download button.

Recommendations for additional development and future research into the FindMyApps intervention:

1. With the rapid development of new apps a way needs to be found to update and maintain the FindMyApps library in a user-friendly way. For example, in future prototypes it may be desirable to add a functionality letting users recommend new apps based on certain criteria for dementia-friendly apps.
2. In future prototypes, we recommend considering a more user-friendly manner to adjust the personal settings of the FindMyApps tool itself such as, to set photos or icons that represent main and subcategories, to set letter sizes, etc. Usability tests informed us that users confused the personal settings of the FindMyApps tool with the personal settings of preferred apps to create a user profile. To improve the simplicity of the tool we therefore dropped the use of the personal settings for the FindMyApps selection tool itself, but the personal settings for preferred apps were useful

and should remain included in the user-profile.
3. The FindMyApps selection tool may also be of benefit to other vulnerable target groups, such as people with moderate dementia and people with a migration background, intellectual disabilities, autism, psychiatric disorders or acquired brain injuries. New development sprints will be needed to adjust the tool to the specific needs, wishes and abilities of other target groups.
4. More evidence is necessary to find the most appropriate and effective training intervention to help people with mild dementia (re)learn touchscreen skills and to teach informal carers how they can support this. Future studies should consider using more consistent training methodologies and more robust study designs, such as RCTs, to evaluate the effectiveness of training interventions for (re)learning technology-oriented tasks, including tasks to operate mobile ICT devices.

Recommendations for dementia care practice:

1. It is promising that people with mild dementia can, by means of the Errorless (EL) learning training method, still (re)learn technology-driven tasks such as using handheld touchscreen devices. An increasing number of ICT apps for self-management and meaningful activities, which can also support people with mild dementia, are becoming available. We recommend welfare and care organizations to help in stimulating the uptake of these apps in dementia care by using FindMyApps.
2. The results of our literature review also show that people with moderate dementia can (re)learn to use handheld touchscreen devices. We suggest to pilot in dementia care practice in what way this can be a meaningful activity for this target group. Our list of criteria for grading dementia friendly apps and the Errorless (EL) learning training method for teaching people with dementia how to learn tablet and app use, can be supportive.
3. To increase the autonomy of people with mild dementia we recommend formal and informal carers to also use the Errorless (EL) learning method for (re)learning other kinds of activities in daily life.
4. In the future development of usable apps for people with dementia and other vulnerable target groups with cognitive impairment, we recommend designers and builders of ICT to take into account the inventoried user requirement results from our user-needs studies as well as the insights into user-interface aspects collected during the development of the selection tool and exploratory trial.
5. We recommend the use of FindMyApps to support community-dwelling people with mild dementia and their informal cares, in the use of tablets and a person-centred selection of dementia-friendly apps in the domains of self-management and meaningful activities.

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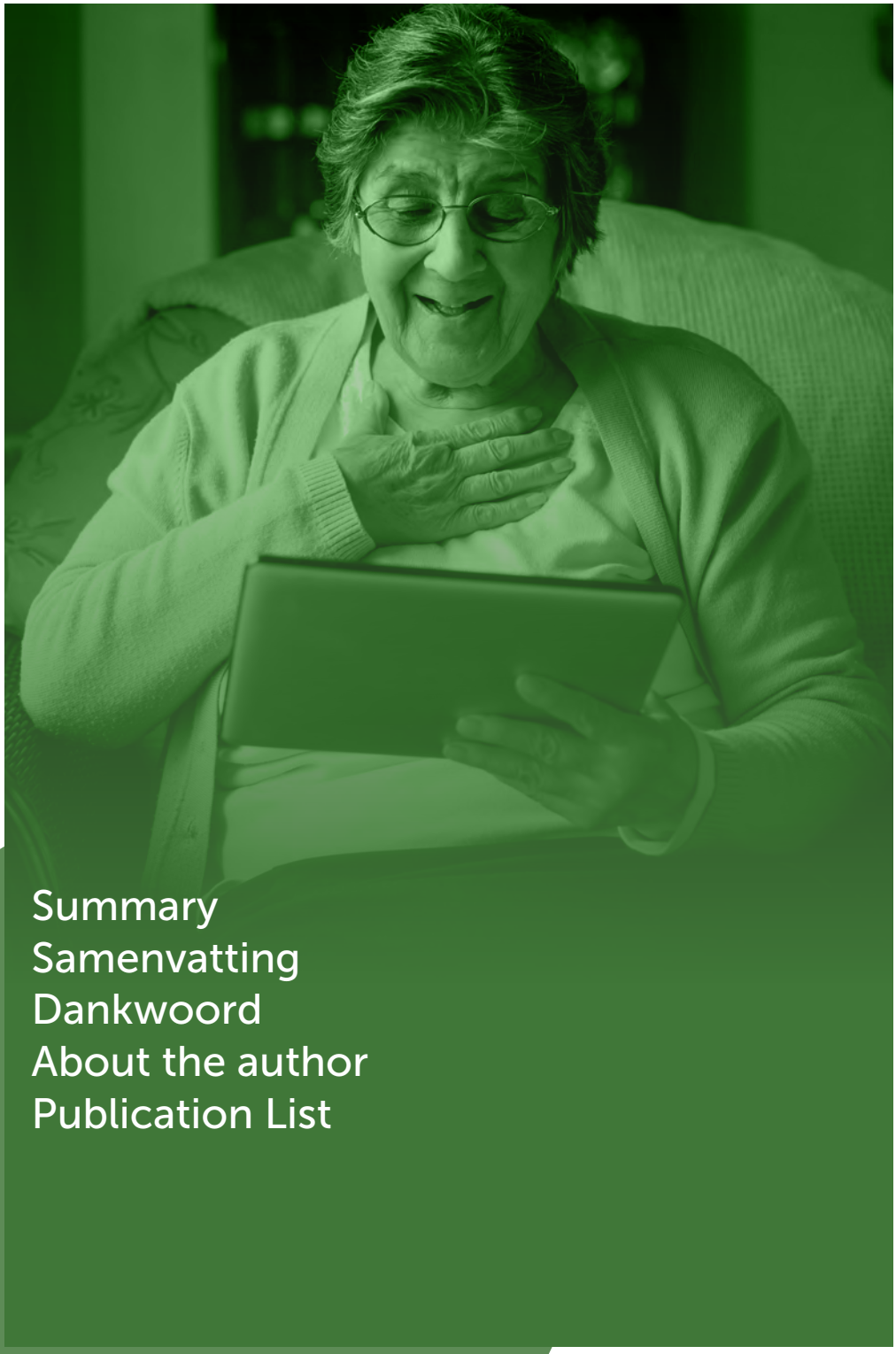

Summary

This thesis reports on the research that was conducted to develop and pilot test a person-centred touchscreen-based program that supports people with mild dementia and their informal carers in how to use a tablet and apps for self-management and meaningful activities.

Chapter 1: General introduction

The introduction describes the background of why the person-centred touchscreen-based program was developed and tested, what the program entails and what the research questions were. The primary reason for developing the program was to address the lack of support experienced by community-dwelling people with dementia and their informal carers regarding self-management, and the lack of meaningful daily activities. Hand-held touchscreen devices such as tablets have the potential to support people with dementia in their social health which can stimulate self-management e.g. apps to cope with memory loss and which engage people with dementia in meaningful activities e.g. apps for leisure activities. However, people with dementia may need support in learning how to use touchscreen devices and a careful selection of apps is required in order to find the most appropriate ones that match the user's personal needs, wishes, and abilities. Therefore, a person-centred tablet program, called FindMyApps, was developed and tested. The program consists of a training for informal carers in supporting people with mild dementia in using a tablet and a web-based selection tool to find apps for self-management and meaningful activities that fit their needs, wishes and abilities. The program was developed following the Medical Research Council (MRC) Framework for the design and evaluation of complex interventions and in co-creation with end users. The chapters of this thesis describe the first three phases mentioned in this framework, i.e.: the preclinical or theoretical phase (0); the modelling phase (I) and the exploratory trial (II).

Chapter 2: How to develop a person-centred program that supports people with mild dementia and their informal carers in the use of hand-held touchscreen devices?

This chapter describes how we planned to perform the first three phases of the MRC Framework. In the first phase user needs studies were planned to identify user requirements for desired self-management and meaningful activities and related to the use of apps. We also planned a literature review to explore which training interventions are most effective for people with mild dementia in (re)learning how to use technologies, including handheld touchscreen devices. Based on these results we planned to develop a FindMyApps training. In the second phase of the framework we intended to develop a first concept of the FindMyApps selection tool based on identified user requirements. In the third phase we pilot tested the FindMyApps intervention by means of individual semi-structured interviews and a pilot randomized controlled exploratory trial. People

with dementia and their informal carers were involved intensively during all these phases, by means of individual interviews, focus groups, workshops and usability tests. The work carried out in the first three phases of the framework was aimed at preparing for a methodologically sound, definitive randomized controlled trial (RCT) to be conducted in the near future, with the intention of investigating whether FindMyApps contributes towards:

1. better self-management and increased participation in daily and social activities of the person with dementia, resulting in more perceived self-efficacy and autonomy,
2. an improved sense of competence and positive care experiences of their informal carer, and
3. improved quality of life for both the person with dementia and carer.

Chapter 3: What do people with dementia find important in their choice and use of apps and what user requirements can be identified based on these perceptions?

Chapter 3 describes the results of an exploratory study conducted to identify user requirements for the development of the FindMyApps selection tool. We performed eight focus groups in which people with mild cognitive impairment (MCI) or mild dementia *(n=13)* and informal carers *(n=15)* participated. In user study one, the expressed needs and wishes were used to determine user requirements relating to apps for different aspects of self-management and meaningful activities. We used these user requirements to create main and subcategories of activities in the FindMyApps selection tool. In user study two, the needs, wishes and abilities led to the creation of user requirements relating to key features of apps, such as recognisable and large buttons, large font size and being simple to operate. We used these user requirements to set up a tool user-profile and we made a list of criteria for grading the dementia friendly apps to be included in the selection tool's library. It also gave us valuable information about the key aspects of a user-interface while developing the tool. In general, the user requirements collected in this study helped us to create a selection tool that works as a filter, so that the selected apps match the person with dementia's wishes and needs in the domains of self-management and meaningful activities and key features of the selected apps fit their personal preferences.

Chapter 4: Which training interventions are effective for people with mild dementia in (re)learning how to use technologies, including handheld touchscreen devices?

Chapter 4 describes the literature review conducted to identify which training interventions work best in helping people with mild dementia (re)learn how to use technologies, including handheld touchscreen devices. An electronic search was conducted in the following databases: PubMed, APA PsycInfo (EBSCO) and CINAHL (EBSCO). In total 16 studies met the inclusion criteria and the following data was inventoried and described: dementia type and severity; technology task type; training intensity and setting;

components of training intervention (e.g. Errorful (EF) and Errorless (EL) learning); and study design and outcome measures. All studies reported positive learning effects and improved task performance in people with dementia, regardless of dementia severity, training intensity, setting and the method used. Although the EL training method was more frequently successful than the EF training method, it would be inappropriate to conclude that the EL method is more effective, as the majority of studies only investigated EL training interventions with (multiple) single-case study designs. Nevertheless, our review contributes to the growing amount of promising evidence on the potential impact of EL training interventions for people with mild to moderate dementia in (re)learning how to use technology. This is why we based the FindMyApps training on the principles of EL learning, such as no guessing to prevent errors; a stepwise approach; modelling and providing verbal and visual instructions.

Chapter 5: How to develop a selection tool that helps people with dementia find suitable apps for self-management and meaningful activities that match their individual needs, wishes and abilities?

This chapter describes the development of the FindMyApps selection tool. To ensure its usability, the tool was developed using a 'user-participatory design' involving the close collaboration of potential users, a development team (researchers, developers and designers) and an expert team (experts in person-centred dementia care and ICT). In three short iterative rounds – so called 'sprints' – the users (people with dementia *(n=8)* and (in)formal carers *(n=10)*) were invited to test whether the prototypes were in line with their needs, wishes and abilities. This generated important insights into user-interface aspects relating to (i) useful content and (ii) a user-friendly tool design. In the end the FindMyApps selection tool was conceived as a means of making it easier for people with mild dementia to select apps meeting their needs, wishes and abilities. The front-end consists of several pages, such as a log-in page; a page for setting the user-profile; a page for choosing main and subcategories; pages with app recommendations and information; a page with an overview of most used apps; and a help tutorial on every page. The back-end consists of a user environment where user profiles are made and where the selection of apps is carried out; an administration environment where user profiles, apps and selection criteria are defined and a reporting environment where information about the user profiles and the use of the tool (during the feasibility study and RCT) can be automatically stored. This provisional version was further tested in the exploratory trial.

Chapter 6: What is the feasibility of the person-centred tablet program and research design?

This chapter describes the results of the exploratory feasibility trial which tested the implementation strategy, mechanism of impact and potential impact of FindMyApps as

well as the research methods in preparation for a definitive trial. We conducted a pilot randomized controlled trial with a mixed-methods design. Twenty people with mild dementia and informal carer dyads were randomly assigned to the FindMyApps group *(n=10)*, receiving either the FindMyApps training and selection tool, or a control condition *(n=10)*, receiving only a short tablet training. Pre- and post-test measurements at a three month follow-up, consisted of questionnaires and post-test semi-structured interviews. Qualitative and quantitative results indicated that the FindMyApps intervention could support the self-management abilities and engagement in meaningful activities of people with dementia. The FindMyApps tool was mostly perceived as useful and easy to use. Participants with dementia found apps through the tool they regularly used and participants learned how to use these apps, though they regularly needed support from informal carers. Participants with dementia and informal carers were positive about the FindMyApps training and the support they received. For informal carers, we found a significant difference between groups regarding the positive care experiences in favour of the control group. Recommendations to improve the intervention were a) adding demonstrational videos for tool and tablet use in the FindMyApps app to additionally support informal carers in training the person with dementia, and b) improving the user-friendliness of the tool by adding short descriptions of the included activities on the (sub) category buttons to improve the understandability of the type of activities that could be expected within these (sub)categories. In addition, recommendations were given for the proposed effectiveness study.

Chapter 7: General discussion

In the final chapter we summarize the main findings of our studies and discuss them from two perspectives: (i) the benefits/added value of the FindMyApps intervention and (ii) the factors which are essential in developing and testing a person-centred eHealth intervention for people with dementia and their informal carers (such as factors relating to involving people with dementia and their carers in IT development and research and factors relating to the effective collaboration between researchers and software developers). Subsequently, methodological considerations are discussed, as well as the scientific, clinical and societal value of the conducted study. A strong point was that we managed to give end users a voice by involving them in the first three phases of development and evaluation recommended by the MRC framework in participatory designs, which contributed to a useful, user-friendly and person-centred IT application. Important limitations were that a selection bias for the activities included in the content of FindMyApps may have occurred due to the limited number of people with dementia involved in the requirements study (see Chapter 3) and that a selection bias based on selective recruitment in the explorative trial (see Chapter 6) may also have influenced results. The chapter concludes with recommendations for the definitive RCT in the near future according to phase III of the MRC framework.

Recommendations are given regarding:

- the research protocol, such as using shorter questionnaires for people with dementia and power calculation for needed sample size;
- the FindMyApps intervention, such as adding demonstrational videos and adding short descriptions of activities on the (sub)category buttons;
- additional development and research into the FindMyapps intervention in the future, such as a functionality where users can recommend dementia-friendly apps and exploring the potential benefit of FindmyApps for other vulnerable target groups;
- dementia care practice, promoting usage of FindMyApps by community-dwelling people with dementia and stimulating its uptake by welfare and care organisations/ services.

Samenvatting

Dit proefschrift beschrijft een onderzoek dat is uitgevoerd om een persoonsgericht tabletprogramma te ontwikkelen en te testen. Dit programma ondersteunt mensen met beginnende dementie en hun mantelzorgers bij het gebruik van de tablet en apps voor zelfmanagement en betekenisvolle activiteiten.

Hoofdstuk 1: Algemene inleiding

De inleiding beschrijft de achtergrond en de aanleiding voor het ontwikkelen en testen van een persoonsgerichte tabletprogramma, de inhoud van het programma en wat de onderzoeksvragen waren. De voornaamste reden voor het ontwikkelen van het programma was het gebrek aan ondersteuning dat mensen met dementie en hun mantelzorgers ervaren bij het stimuleren en behouden van zelfmanagement activiteiten en het ontplooien van betekenisvolle activiteiten. Mobile touchscreen-apparaten, zoals tablets, hebben de potentie om mensen met dementie te ondersteunen in hun zelfmanagement, bv. apps om met geheugenverlies om te gaan, en bv. apps voor vrijetijdsbesteding en om betekenisvolle activiteiten te ontplooien. Mensen met dementie hebben echter hulp nodig bij het leren omgaan met een tablet en een zorgvuldige selectie van apps is nodig om de meest geschikte te vinden die aansluiten op de persoonlijke behoeften, wensen en capaciteiten van de gebruiker. Daarom werd een persoonsgericht tabletprogramma, genaamd FindMyApps, ontwikkeld en getest. Het programma bestaat enerzijds uit een training voor mantelzorgers in het ondersteunen van mensen met beginnende dementie bij het gebruik van een tablet (FindMyApps-training). Anderzijds biedt het de mogelijkheid om met een web-based selectietool apps te vinden voor zelfmanagement en betekenisvolle activiteiten die passen bij individuele behoeften, wensen en capaciteiten (FindMyapps-selectietool). Het programma is ontwikkeld volgens de fasen van het Medical Research Council (MRC) raamwerk voor het ontwerpen en evalueren van complexe interventies in co-creatie met eindgebruikers. De hoofdstukken van dit proefschrift beschrijven de eerste drie fasen van dit raamwerk, te weten: de preklinische of theoretische fase (0); de modelleringsfase (I) en de exploratieve fase (II).

Hoofdstuk 2: Hoe ontwikkel je een persoonsgericht programma dat mensen met beginnende dementie en hun mantelzorgers ondersteunt in het gebruik van een tablet?

Dit hoofdstuk beschrijft de planmatige aanpak van de eerste drie fasen van het MRC-raamwerk. In de eerste fase stonden behoefteonderzoeken gepland. De gebruikerseisen voor gewenste zelfmanagement en betekenisvolle activiteiten en voor het gebruik van apps werden geïdentificeerd. We planden ook een literatuurstudie om te onderzoeken welke trainingsinterventies het meest effectief zijn voor mensen met beginnende dementie bij het (opnieuw) leren gebruiken van technologieën, waaronder tablets. Op basis van deze

resultaten ontwikkelden we de FindMyApps-training. In de tweede fase van het raamwerk waren we van plan een eerste concept van de FindMyApps-selectietool te ontwikkelen op basis van de eerder geïdentificeerde gebruikerseisen. In de derde fase testten we de FindMyApps-interventie in een pilot door middel van individuele semigestructureerde interviews en een gerandomiseerde gecontroleerde exploratieve trial. Mensen met dementie en hun mantelzorgers werden intensief betrokken bij al deze fasen, door middel van individuele interviews, focusgroepen, workshops en bruikbaarheidstesten. Het werk dat werd uitgevoerd in de eerste drie fasen van het raamwerk was gericht op de voorbereiding van een methodologisch verantwoorde, definitieve gerandomiseerde gecontroleerde trial (RCT) die in de nabije toekomst wordt uitgevoerd. De intentie van deze trial is te onderzoeken of FindMyApps bijdraagt aan een:

1. beter zelfmanagement en meer participatie in dagelijkse en sociale activiteiten van de persoon met dementie, resulterend in meer waargenomen zelfeffectiviteit en autonomie;
2. verbeterd gevoel van competentie en positieve zorgervaringen van hun mantelzorger;
3. verbeterde kwaliteit van leven voor zowel de persoon met dementie als de mantelzorger.

Hoofdstuk 3: Wat vinden mensen met dementie belangrijk in hun keuze en gebruik van apps en welke gebruikerseisen kunnen op basis van deze percepties worden geïdentificeerd?

Hoofdstuk 3 beschrijft de resultaten van een exploratief onderzoek dat is uitgevoerd om gebruikerseisen te identificeren voor de ontwikkeling van de FindMyApps-selectietool. Acht focusgroepen vonden plaats waaraan mensen met milde cognitieve stoornissen (MCI) of beginnende dementie *(n=13)* en mantelzorgers *(n=15)* deelnamen. In behoefte-onderzoek 1 werden de behoeften en wensen gebruikt om gebruikerseisen te bepalen met betrekking tot apps voor verschillende zelfmanagement en betekenisvolle activiteiten. We gebruikten deze gebruikerseisen om hoofd- en subcategorieën van activiteiten te creëren in de FindMyApps-selectietool. In behoefteonderzoek 2 leidden de behoeften, wensen en capaciteiten tot het opstellen van gebruikerseisen met betrekking tot belangrijke kenmerken in het gebruik van apps, zoals herkenbare en grote knoppen, grote lettertypes en een eenvoudige bediening. We gebruikten deze eisen ook om een gebruikersprofiel van de tool op te stellen. Ook stelden we een lijst op met criteria voor het beoordelen van dementievriendelijke apps die in de bibliotheek van de selectietool zouden worden opgenomen. Het gaf ons ook waardevolle informatie over de belangrijkste aspecten van een gebruikersinterface voor de tool. In het algemeen hielpen de in dit onderzoek verzamelde gebruikerseisen ons bij het maken van een selectietool dat werkt als een filter. Zo konden de geselecteerde apps overeenkomen met de wensen en behoeften van de persoon met dementie op het gebied van zelfmanagement en betekenisvolle activiteiten. Tevens konden de belangrijkste kenmerken van de geselecteerde apps aansluiten bij persoonlijke voorkeuren.

Hoofdstuk 4: Welke trainingsinterventies zijn effectief voor mensen met beginnende dementie bij het (opnieuw) leren gebruiken van technologieën, waaronder tablets?

Hoofdstuk 4 beschrijft het literatuuronderzoek dat is verricht om vast te stellen welke trainingsinterventies het beste werken om mensen met beginnende dementie te helpen bij het (opnieuw) leren gebruiken van technologieën, waaronder tablets. Er is gezocht in de volgende databases: PubMed, APA PsycInfo (EBSCO) en CINAHL (EBSCO). In totaal voldeden zestien studies aan de inclusiecriteria en werden de volgende gegevens geïnventariseerd en beschreven: type en ernst van de dementie, type technologie-taak, trainingsintensiteit en setting, componenten van de trainingsinterventie (bijvoorbeeld Trial and error-leren (TEL) en Foutloos leren (FL)), onderzoeksdesign en uitkomstmaten, leereffecten en efficiency. Alle studies rapporteerden positieve leereffecten en verbeterde taakprestaties bij mensen met dementie, ongeacht de ernst van de dementie, de trainingsintensiteit, de setting en de gebruikte methode. Hoewel de FL-trainingsmethode vaker succesvol was dan de TEL-trainingsmethode, zou het ongepast zijn om te concluderen dat de FL-methode effectiever is, omdat de meerderheid van de studies alleen FL-trainingsinterventies onderzochten met (multiple) single-case study designs. Desalniettemin draagt onze review bij aan de groeiende hoeveelheid veelbelovend bewijs over de potentiële impact van FL-trainingsinterventies voor mensen met beginnende tot matige dementie bij het (opnieuw) leren omgaan met technologie. Daarom hebben we de FindMyApps-training gebaseerd op de principes van FL-leren, zoals een stapsgewijze aanpak; het modelleren van de stappen en het geven van verbale en visuele instructies.

Hoofdstuk 5: Hoe ontwikkel je een selectietool die mensen met dementie helpt bij het vinden van geschikte apps voor zelfmanagement en betekenisvolle activiteiten die aansluiten bij hun individuele behoeften, wensen en capaciteiten?

Dit hoofdstuk beschrijft de ontwikkeling van de FindMyApps-selectietool. Om de bruikbaarheid te garanderen werd de tool ontwikkeld met behulp van 'participatief onderzoek', waarbij nauw werd samengewerkt met potentiële gebruikers, het ontwikkelteam (onderzoekers, ontwikkelaars en ontwerpers) en een expertteam (experts op het gebied van persoonsgerichte dementiezorg en ICT). In drie korte iteraties - zogenaamde 'sprints' - werden de gebruikers (mensen met dementie *(n=8)* en (in) formele zorgverleners *(n=10)*) uitgenodigd om te testen of de prototypes aansloten bij hun behoeften, wensen en capaciteiten. Dit leverde belangrijke inzichten op voor gebruikersinterface aspecten met betrekking tot (i) een bruikbare content en (ii) een gebruiksvriendelijk design van de tool. Uiteindelijk werd de FindMyApps-selectietool ervaren als een middel dat het voor mensen met beginnende dementie makkelijker maakt apps te selecteren die aan hun behoeften, wensen en capaciteiten voldoen. De front-end bestaat uit verschillende pagina's, zoals een inlogpagina; een pagina voor het instellen

van het gebruikersprofiel; een pagina voor het kiezen van hoofd- en subcategorieën; pagina's met app-aanbevelingen en informatie; een pagina met een overzicht van de meest gebruikte apps; en helpinstructies op elke pagina. De back-end bestaat uit een gebruikersomgeving waar gebruikersprofielen worden aangemaakt en waar de selectie van apps plaatsvindt; een administratieomgeving waar gebruikersprofielen, apps en selectiecriteria worden vastgelegd en een rapportageomgeving waar informatie over de gebruikersprofielen en het gebruik van de tool (tijdens de haalbaarheidsstudie en de RCT) automatisch kan worden opgeslagen. Deze voorlopige versie van de tool wordt uitgetest in de exploratieve fase.

Hoofdstuk 6: Wat is de haalbaarheid van het persoonsgerichte tabletprogramma en de onderzoeksopzet voor de definitieve trial?

Dit hoofdstuk beschrijft de resultaten van de haalbaarheidsstudie waarin de implementatiestrategie, het werkzame mechanismen en de potentiële impact van FindMyApps in een pilot zijn getest, evenals de onderzoeksmethoden ter voorbereiding van een definitieve trial. We voerden een gerandomiseerde, gecontroleerde exploratieve trial uit met een mixed-methods design. Twintig mensen met beginnende dementie en mantelzorgers werden willekeurig toegewezen aan de FindMyApps groep *(n=10)*, die de FindMyApps-training en selectietool kregen, of een controlegroep *(n=10)*, die alleen een korte tablet training kregen. Pre- en post-testmetingen bij een follow-up van drie maanden, bestonden uit vragenlijsten en post-test semigestructureerde interviews. Kwalitatieve en kwantitatieve resultaten gaven aan dat de FindMyApps-interventie de zelfmanagementvaardigheden en betrokkenheid bij betekenisvolle activiteiten van mensen met dementie ondersteunden. De FindMyApps-selectietool werd over het algemeen als nuttig en gebruiksvriendelijk ervaren. Deelnemers met dementie vonden via de tool apps die ze regelmatig gebruikten en deelnemers leerden hoe ze deze apps moesten gebruiken, hoewel ze daarbij regelmatig ondersteuning nodig hadden van mantelzorgers. Deelnemers met dementie en mantelzorgers waren positief over de FindMyApps-training en de ondersteuning die ze kregen. Bij mantelzorgers vonden we een significant verschil tussen de groepen wat betreft de positieve zorgervaringen in het voordeel van de controlegroep. Aanbevelingen om de interventie te verbeteren waren a) het toevoegen van demonstratievideo's voor het gebruik van de tool en de tablet in FindMyApps om mantelzorgers extra te ondersteunen bij het trainen van de persoon met dementie, en b) het verbeteren van de gebruiksvriendelijkheid van de tool door het toevoegen van korte beschrijvingen op de categorieknoppen. Het type activiteiten dat binnen deze categorieën te vinden is, wordt daardoor overzichtelijker. Daarnaast werden aanbevelingen gedaan voor de definitieve trial (RCT).

Hoofdstuk 7: Algemene discussie

In het laatste hoofdstuk vatten we de belangrijkste bevindingen van onze studies samen en bespreken we deze vanuit twee perspectieven: (i) de voordelen/toegevoegde waarde van de FindMyApps-interventie en (ii) de factoren die essentieel zijn bij het ontwikkelen en testen van een persoonsgerichte eHealth interventie voor mensen met dementie en hun mantelzorgers. Het gaat hier om factoren die te maken hebben met het betrekken van mensen met dementie en hun mantelzorgers bij IT-ontwikkeling en onderzoek en factoren die bepalend zijn voor een effectieve samenwerking tussen onderzoekers en software-ontwikkelaars. Vervolgens worden methodologische overwegingen besproken, evenals de wetenschappelijke, klinische en maatschappelijke waarde van het uitgevoerde onderzoek. Een sterk punt was dat we erin slaagden de eindgebruikers een stem te geven door hen te betrekken bij de eerste drie fasen van het MRC-raamwerk. Dit, droeg bij aan een bruikbare, gebruiksvriendelijke en persoonsgerichte IT-toepassing. Belangrijke beperkingen waren dat selectiebias voor de activiteiten opgenomen in de inhoud van de FindMyApps-selectietool kan zijn opgetreden door het beperkte aantal mensen met dementie dat betrokken was bij het behoeftenonderzoek (zie Hoofdstuk 3). Ook selectiebias voor de werving van respondenten in de exploratieve trial (zie Hoofdstuk 6) kan de resultaten hebben beïnvloed. Het hoofdstuk sluit af met aanbevelingen voor o.a. de definitieve RCT volgens fase III van het MRC-raamwerk. Aanbevelingen worden gegeven ten aanzien van:

- het onderzoeksprotocol, zoals het gebruik van kortere vragenlijsten voor mensen met dementie en powerberekening voor benodigde steekproefgrootte;
- de FindMyApps-interventie, zoals het toevoegen van demonstratievideo's en het toevoegen van korte beschrijvingen van activiteiten op de categorieknoppen;
- doorontwikkeling van en onderzoek naar de FindMyApps-interventie in de toekomst, zoals een functionaliteit, waarbij gebruikers zelf dementievriendelijke apps kunnen aanbevelen en het onderzoeken van het potentiële nut van FindMyApps voor andere kwetsbare doelgroepen;
- dementiezorg in de praktijk, het bevorderen van het gebruik van FindMyApps door thuiswonende mensen met dementie en het stimuleren van de implementatie ervan door welzijns- en zorgorganisaties/diensten.

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In mijn geboortestreek, Enter ('s werelds meest gebruikte computertoets dankt zijn naam aan dit pittoreske dorp), zegt men, in dialect: *'Kan 'k met daank'n tou?'* Dat is Twents voor: *'Is een bedankje voldoende?'*
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About the author

Yvonne Kerkhof was born on 19 September 1969 in Enter, Twente, the Netherlands. After graduating from secondary school (MAVO & HAVO) she started her nursing training in the hospital of Deventer. After that she combined working in different healthcare settings with studying for a bachelor's degree in nursing and teaching nursing at the University of Applied Sciences in Utrecht. Since May 2003 she is a lecturer and researcher at the School of Health of Saxion University of Applied Sciences. She completed her Master of Health Care and Social Work at Saxion University of Applied Sciences in 2005, and in 2010 she completed her Master of Science in Advanced Nursing Practice at Birmingham City University. Since 2009 she has been a member of research groups that focus on innovating healthcare practice, and she combines this with lecturing at the bachelor of nursing programme. In March 2014 she started as a PhD candidate at VU University medical centre. Her study focused on the development and pilot-testing of a person-centred tablet programme (FindMyApps) to support people with mild dementia in their self-management and meaningful activities. In February 2019 she started a new line of research for participatory research projects to support healthy ageing of people with a migration background. In November 2021 she will start with a two-year funded postdoc study which will focus on improving social health of older persons with a Turkish migration background.

Yvonne lives in Zwolle with her partner Henk. They have two sons, Jens and Brend.

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Yvonne Kerkhof (1969) conducted the research presented in this thesis at the Amsterdam University Medical Centres, location VUmc, Department of Psychiatry and within the Amsterdam Public Health Research Institute. She is a lecturer and researcher at the School of Health of Saxion University of Applied Sciences.

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