Innovating Long-Term Care for Older People
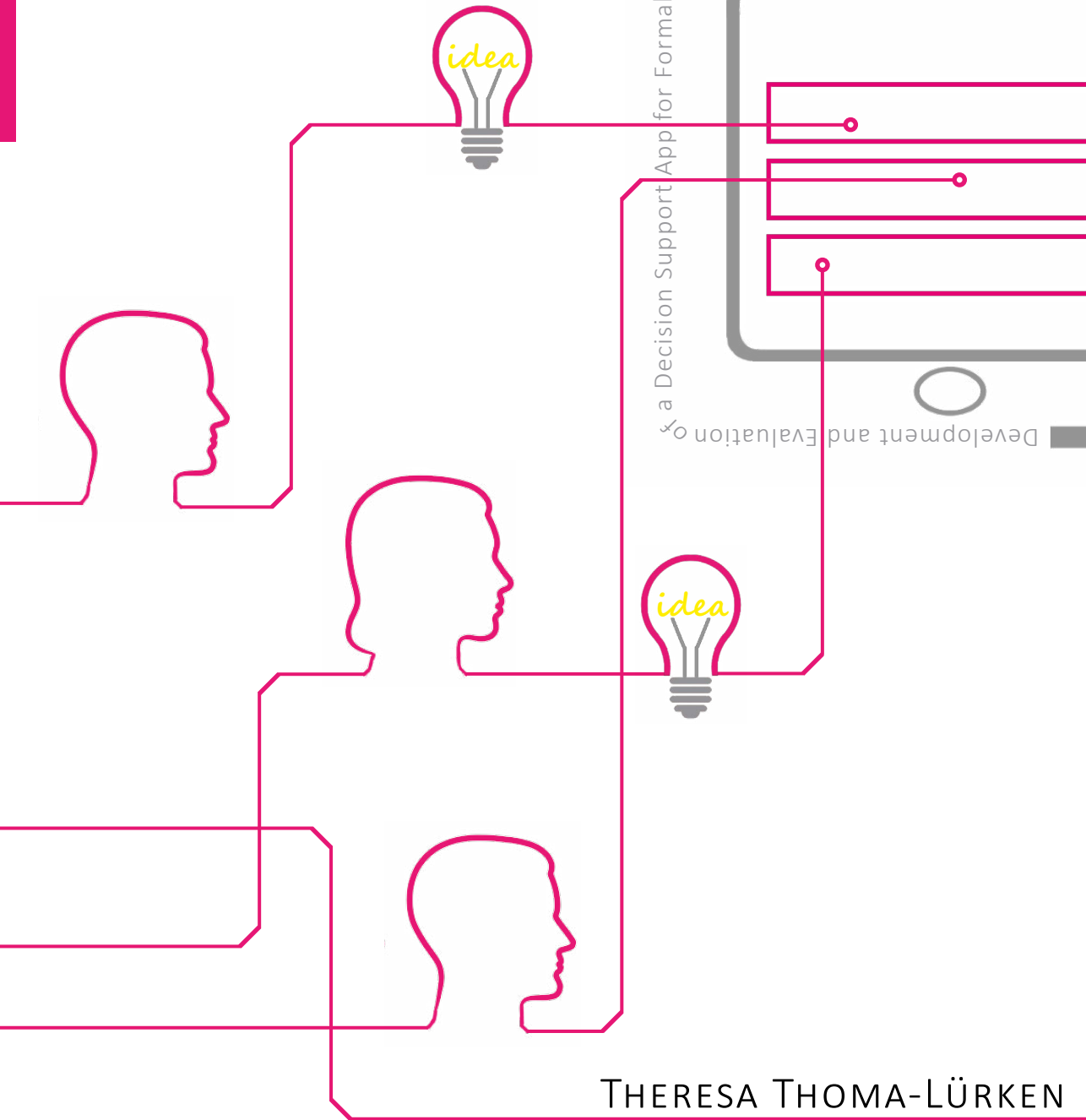
Development and Evaluation of a Decision Support App for Formal Caregivers in Community Based Dementia Care

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Innovating Long-Term Care for Older People

Development and Evaluation of a Decision Support App for Formal Caregivers in Community-Based Dementia Care

DISSERTATION

to obtain the degree of Doctor at Maastricht University,
on the authority of the Rector Magnificus, Prof. dr. Rianne M. Letschert
in accordance with the decision of the Board of Deans,
to be defended in public
on Wednesday 19th of September 2018, at 14.00 hours

by

Theresa Thoma-Lürken

Contents

Chapter **1**

General Introduction

BACKGROUND

The studies presented in this dissertation are conducted within a project entitled '(Labor-saving) innovations in long-term care for older people'. In the light of the future challenges of long-term care (LTC), the aim of this project was to inventory potential labor-saving and quality improving innovations which are currently developed and/or used by organizations providing LTC for older people in the region of Limburg in the Netherlands. By providing an overview of innovations used within one region it was aimed to stimulate discussion about existing innovations and to facilitate better usage of promising innovations. After gaining insight into the variety of innovations currently developed and/or used in the region, the focus of the project shifted towards the development and evaluation of a decision support tool for formal caregivers helping them to make better use of the available innovations.

FUTURE CHALLENGES OF LONG-TERM CARE

The world's population is aging due to an increase in life expectancy and a decrease in fertility rate.[1] Between 2015 and 2030, the number of people in the world aged 60 years or over is expected to grow from 901 million to 1.4 billion.[1] An expected consequence of the aging of the population is the increase in demand for LTC as older people and people with chronic diseases are the major recipients of long term care.[2] At the same time a decrease in availability of skilled workers (such as nurses and doctors) to deal with the increased demand in LTC can be expected due to the aforementioned demographic changes.[3]

Long-term care comprises "a range of services required by persons with a reduced degree of functional capacity, physical or cognitive, and who are consequently dependent for an extended period of time on help with basic activities of daily living (ADL)".[4] Long-term care for older people can be provided in different settings ranging from care in the community to care in health facilities such as nursing homes.[5] Care at home is often preferred as older people tend to have strong emotional ties to their home environment.[6,7] Moreover, independence and freedom of choice with regard to care and support arrangements are also increasingly important for older people nowadays.[4] The preference for "aging in place" (defined as the ability to live in one's own home and community safely and independently as one ages."[8]) is also a policy aim in many Western countries aiming to deal with the future challenges of LTC. [9,10] The underlying assumption of these policies is that besides the expected preference for aging in place, care at home is less costly and labor-intensive compared to care in institutional settings by making better use of the person's resources such as self-care ability and network support. However, living at home

can become extremely challenging for older people with functional and cognitive impairments, such as people with dementia (PwD), as these impairments are important predictors of nursing home admission.[11] Thus comprehensive care and support arrangements are needed to facilitate aging in place of individuals with impairments. Hence, solutions are needed to ensure the delivery of high quality LTC services in the future as all the aforementioned developments can seriously threaten the sustainability and quality of LTC.[5,12,]

INNOVATIONS AS MEANS TO DEAL WITH FUTURE CHALLENGES OF LONG-TERM CARE

Innovations are often seen as the key to deal with the future challenges of LTC.[2] A widely used definition of an innovation is, "an idea, practice, or object that is perceived as new by an individual or other unit of adoption."[13] This means that innovations do not always need to be entirely new, revolutionary, or disruptive, but could also be incremental changes to existing products or procedures as long as they are perceived as new. This also implies that objective measures of innovations hardly exist, as an innovation might be new for one person but already a regular practice for another one. There are different challenges which need to be addressed by innovations to ensure the sustainability and quality of long term care. With regard to increased demand and decreased availability of workforce, there are different ways in which innovations can have an impact on this imbalance. Innovations can either reduce the demand for care (e.g. facilitating more self-management of patients), or increasing the productivity (e.g. reorganizing care processes or by introducing technologies which have the potential to substitute labor-intensive tasks).[2] Moreover, innovations can also be targeted at improving the quality of care which might indirectly reduce labor-intensity over time. Many research institutes and LTC organizations are working on the development and implementation of potential labor-saving and quality-improving innovations. Examples include introducing companion or telepresence robots in care for older people,[14] implementing new care concepts such as case management in community-based dementia care,[15] or e-health applications to improve self-management of people with chronic diseases.[16] As the policies aiming to deal with the future challenges of LTC strongly focus on aging in place, it is especially important to focus on solutions to enable also vulnerable groups such as PwD to live longer in their own homes.

THE CHALLENGES OF AGING IN PLACE OF PEOPLE WITH DEMENTIA

For PwD living at home can become extremely challenging. Dementia is a syndrome which combines different symptoms associated with memory decline and deterioration

of other neuro-psychological functions which lead to disability in everyday life.[17] Even though the course of dementia is different for each individual, it is characterized by an increased need for support, and loss of independence.[18,19] In its early stages, dementia often goes undetected. During this stage PwD show signs of forgetfulness, lose their sense of time, and get lost in familiar places; symptoms that will worsen over time.[20] During the course of their disease, PwD often experience problems in daily life such as the inability to conduct instrumental activities of daily living (IADL) (e.g. handling finances or preparing hot drinks).[21] Also basic activities of daily living (ADL) (e.g. toileting, dressing and continence) and behavioural problems (e.g. agitation, night time behaviour, or eating difficulties) can have a severe impact on daily living of PwD.[22] Moreover, PwD might lose their sense of time and place or can have trouble with balance which can have serious safety consequences for living at home.[23] Finally, PwD in the late stage of dementia often become nearly totally dependent and inactive. In the Netherlands about 70% of all PwD live at home and are often supported by family members or other people from their social network.[24] However, providing informal care for PwD can be very burdensome. Especially, dealing with behavioural problems and neuropsychiatric symptoms were found to be most burdensome for informal caregivers.[25] In situations where the burden exceeds the personal limit of the informal caregivers this might contribute to a situation in which care at home is no longer possible. All these factors may lead to a situation in which aging in place is extremely difficult for PwD. Research shows that PwD are particularly susceptible to nursing home admission and general predictors include functional impairments of the PwD, caregiver stressors, and behavioral or psychological symptoms of the PwD.[26-28] At the same time PwD often wish to live as normal as possible and to live at home for as long as possible.[29,30] Thus, to facilitate aging in place for PwD, it is important to have an overview of and to gain insight into the daily struggles PwD and their families are experiencing, and to find ways to solve these problems in order to make living at home a real and safe alternative to nursing home admission.

COMMUNITY-BASED DEMENTIA CARE AND THE ROLE OF NURSES AND CASE MANAGERS IN THE NETHERLANDS

In the Netherlands various care and support options are available to facilitate aging in place for PwD. Community-dwelling PwD in the Netherlands often receive professional home care (providing support with ADL and IADL activities) and use services such as personal safety alarms or transport services.[31] A broad variety of additional (technological) solutions for practical problems PwD and their caregivers experience in daily life are currently available. Such solutions include smoke detectors, global positioning systems (GPS) or drug dispensers with reminder functions, and new solutions are constantly being developed.[32,33] It is challenging for PwD and their informal caregivers to be aware of all pos-

sible solutions and to choose the solutions that fit best to their individual needs.[34,35] For- mal caregivers can play an important role in supporting PwD and informal caregivers in finding appropriate care and supporting services and products.[36] According to the Dutch professional standard for community-based dementia care, the care and support needs of PwD and their informal caregivers need to be assessed to introduce adequate combi- nations of interventions to facilitate aging in place.[37] These tasks are often fulfilled by district nurses and case managers. To develop a tailored care and support plan, district nurses and case managers need to have insight into the care needs and practical prob- lems PwD and their informal caregivers are experiencing in daily life which prevent them from living at home. This means that they need to conduct a proper problem assessment and make a clinical judgment about the problems to be solved and have insight into pos- sible solutions to deal with them. Then they need to determine the most suitable solu- tions they could recommend to their clients. Both are complex and challenging tasks for nurses and case managers, as there is no clear guidance in the assessment of problems and it is their responsibility to keep themselves up to date with regard to the interven- tions/services available. Clinical judgment and decision-making might therefore depend on the knowledge and experience of the individual caregiver, though this is not desirable.

SUPPORT IN CLINICAL JUDGMENT AND DECISION- MAKING

Different measures such as education, guidelines and computerized decision support tools can be used to support nurses and case managers with the complex tasks of clinical judgment and decision- making.[38] The main aim of those measures is to increase the ac- curacy of decision-making, and to reduce the variance caused by different knowledge and experience levels in the decision-making of professionals. Computerized decision support tools, defined as "[tools] providing clinicians (nurses) with computer-generated clinical knowledge and patient-related information which is intelligently filtered and presented at appropriate times to enhance patient care,"[39,p.441] have several advantages. First, they can provide tailored information right at the point of care. Second, they provide the pos- sibility to present tailored information based on large amounts of information by building in complex algorithms, hidden behind the screen of a user-friendly interface. Third, they can help to make decision-making more transparent by logging the data that is entered.[38] In community-based dementia care, such a tool could guide the nurses through a struc- tured problem assessment that focuses on the most important practical problems pre- venting PwD from living at home and providing them with an overview of possible solu- tions. So far there is relatively little scientific evidence about the ability of computerized decision support tools to improve nursing practice.[38,40] Moreover, a computerized deci- sion support tool specifically developed for district nurses and case managers to facilitate aging in place is currently lacking.

AIM AND OUTLINE

Aim

The aim of this dissertation is twofold. The first aim is to provide an overview of innovations used and/or developed in long-term care organizations to deal with the expected workforce shortages and to improve quality of care. The second and major aim of this dissertation is to provide insight into the development of a computerized decision support tool for nurses in community-based dementia care and to describe its efficacy and potential added value.

Outline

Chapter two presents a cross-sectional study resulting in an overview of different types of potential labor-saving and quality-improving innovations developed and/or currently used in Dutch long-term care organizations and the level of evidence supporting their effectiveness. **Chapter three** describes a qualitative study with the aim to identify the most important practical problems preventing PwD from living at home. **Chapter four** reports on a mixed methods study about the co-creative development and usability evaluation of a decision support application (App) for district nurses and case managers in community-based dementia care to facilitate aging in place for PwD. The aim of the randomized controlled laboratory experiment presented in **chapter five** was to evaluate the efficacy of a decision support App for district nurses and case managers in terms of improved clinical judgment and decision-making. **Chapter six** describes a qualitative study aiming to explore the added value of a decision support App for district nurses and case managers in community-based dementia care, and to study its fit with the work processes of these professionals. In **chapter seven** the main findings of all studies are summarized followed by methodical and theoretical considerations, resulting in recommendations for further research and practice.

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Chapter **2**

An Overview of Potential Labor-Saving and Quality-Improving Innovations in Long-Term Care for Older People

ABSTRACT

Objectives: Increasing demands in long-term care for older people and a decrease in workforce availability can be expected in the future. These developments challenge the sustainability and quality of long-term care for older people. To address these challenges, long-term care organizations are forced to innovate. The aim of this study is to provide an overview of potential labor-saving and quality-improving innovations long-term care organizations are working on and to assess the self-reported extend of effectiveness.

Design: This is a descriptive cross-sectional study.

Methods: In total, 32 long-term care organizations in the region of Limburg in the Netherlands were invited to participate in the study. The inventory was performed by means of semi-structured interviews with chief executive officers, managers and staff members of the long-term care organizations. Based on the interview data, all innovations were described in a standardized form and subsequently checked by the participants. All innovations were clustered into product, process, organizational and marketing innovations.

Results: In total, 26 long-term care organizations delivering home and/or institutional long-term care for older people participated in the study. Overall, 228 innovations were identified; some innovations were described in a similar way by different organizations. The majority of innovations were product innovations (n=96), followed by organizational innovations (n=75) and process innovations (n=42). In addition to the main types, 15 other innovations incorporating characteristics of different types of innovations were detected. Little evidence about the effectiveness of the innovations was reported by the organizations.

Conclusion: This study shows that a large number and a broad variety of innovations have been implemented or are currently being developed in long-term care organizations for older people. However, according to the organizations, there is relatively little (scientific) evidence confirming the effectiveness of these innovations. More research is needed to evaluate the effects of the innovations and to indicate whether they provide real solutions to future challenges.

INTRODUCTION

The demand for long-term care (LTC) is set to increase in the future due to the aging of the population and the increase in chronic and degenerative diseases.[1-3] At the same time, a decrease in the availability of a skilled workforce in health care can be expected in the upcoming years, while a larger workforce would be needed to deal with the increase in demand.[4] Nowadays, it is a frequently reported concern in developed countries that these developments challenge the sustainability and quality of LTC for older people.[5]

LTC comprises "a range of services required by persons with a reduced degree of functional capacity, physical or cognitive, and who are consequently dependent for an extended period of time on help with basic activities of daily living (ADL)."[5] LTC can be delivered in the home environment or in institutional LTC facilities either by informal caregivers or formal caregivers, who mostly work for LTC organizations.

In addition to demographic changes, the expectations of older people regarding LTC have changed over the years.[5] According to the "aging in place" principle, older people prefer to live in their own home environment, making their own choices and living a self-determined life for as long as possible.[5,6] Traditional modes of care delivery, for instance in "large" institutional care organizations, often do not comply with these expectations because they restrict the freedom of choice of their clients.[7,8] Furthermore, a preference for care in the home and avoiding the institutionalization of care-dependent older people for as long as possible is now a common policy aim of many European governments.[9]

To be able to deal with these developments, LTC organizations need to reconsider their service supply. To anticipate or to adapt to these societal changes, organizations can introduce innovations. There are various possibilities, for example the introduction of product innovations in care (e.g., camera monitoring or movement sensors), the reorganization of care by process innovations (e.g., care pathways or the use of tele-consultations between health-care professionals and clients), or organizational innovations (e.g., staff development programs, reorganization of care teams).

In the Netherlands, many LTC organizations are currently developing and implementing such innovations.[10-13] It is known from practice that these are mostly local initiatives on the part of single organizations. The exchange of knowledge concerning innovations between organizations seems to be scarce. Developing and implementing innovations in care organizations can be a time-consuming and expensive endeavor. If organizations were to share their experiences with regard to the development and implementation of innovations, they could save costs, prevent other organizations from struggling with the same problems and they could profit from each other's experiences.

An overview of potential labor-saving and quality-improving innovations developed and/or are used by LTC organizations could be a valuable basis for knowledge sharing

concerning innovations. Therefore, the aim of this study is to provide an overview of potential labor-saving and quality-improving innovations long-term care organizations are working on and to assess the self-reported extent of effectiveness.

METHODS

Design

A descriptive cross-sectional study was conducted to identify potential labor-saving and quality-improving innovations in home care and institutional LTC organizations for older people.

Research Setting and Subjects

The study was conducted in the region of Limburg in the south of the Netherlands. It is a region with both rural and urban areas, and has approximately 1.1 million inhabitants, of whom some 230,000 are aged 65 or older.[14] Compared to the entire country, the aging of the society in Limburg is advanced in stage, with a shrinking population and an increasing proportion of older people as part of the population.[15]

All LTC non-profit organizations that deliver either home care or institutional LTC for older people within this region were identified and invited to participate in the study.

Data Collection

Data collection took place from September 2013 to January 2014. To identify potential labor-saving and quality-improving innovations, data were collected by means of semi-structured interviews with chief executive officers (CEO), managers and staff members (if recommended by the CEO) of the LTC organizations. A standard topic list was used to guide the interviews, covering the following topics: definition of the concept "innovation" from the perspective of the participating organizations, potential labor-saving and quality-improving innovations that have been developed or have been introduced in the organization (according to their definition of innovation), future plans of the organization concerning innovations, urgent problems in care, and contact details of employees who can deliver specific information about innovations within the organizations.

Procedure

The interviews were conducted by four researchers from the project team (TTL., MB, ML, and NS). The interviews were held by pairs of researchers, one in the role of the main interviewer and one as observer. The interviews lasted approximately one hour. All interviews were audiotaped with the consent of the participants. Based on the information

gathered from these interviews, a standard form was completed by the researchers containing the following topics with regard to the innovations: description of the innovation, goal, setting and target group, status (under development, implemented, regular practice), degree of evidence concerning the effectiveness (obtained within the organization or elsewhere), costs, name of the organization, contact person and contact details. The prefilled forms and a manual describing how to complete the standard form were returned to the chief executive officers or contact persons of the LTC organizations to verify and complete the information about the innovations.

Data Analysis

The innovations were classified by the first author according to a classification from the Organization for Economic Cooperation and Development (OECD) into product innovations, process innovations, marketing innovations, and organizational innovations.[16] The following definitions were used as a guideline to sort the innovations:

- A product innovation is the "introduction of a good or service that is new or significantly improved with respect to its characteristics or intended uses. This includes significant improvements in technical specifications, components and material, incorporated software, user friendliness or other functional characteristics."[16]
- A process innovation is the "implementation of a new or significantly improved production or delivery method. This includes significant changes in techniques, equipment and/or software."[16]
- A Marketing innovations is the "implementation of a new marketing method involving significant changes in product design or packing, product placement, product promotion and pricing."[16]
- An Organizational innovation is the "implementation of a new organizational method in firm's business practices, workplace organization or external relations."[16]

Subsequently, two members of the project team checked the classification made by the first author. In the case of disagreement, they discussed the classification to reach consensus. In addition to the general clusters – product, process, organizational, and marketing –the innovations were classified into subclusters. For organizational innovations, the subclusters business practices, workplace organizations and external relations as defined by the OECD classification were used.[16]. As there were no pre-defined subclusters for product and process innovations, content-related sub clusters were formulated by the first author based on the data. The categorization was discussed with the other authors until consensus was reached on the division of subclusters.

RESULTS

Characteristics of the Participants

Of the 32 LTC organizations invited to participate in the study, 26 organizations actually participated in the interviews. Two organizations declined participation because in their opinion they could not contribute to the goal of the study due to a lack of innovations in their organizations. Four organizations declined to participate without mentioning a reason. Altogether 33 semi-structured interviews (in 22 organizations 1 interview, in 2 organizations 2 interviews, in 1 organization 3 interviews and in 1 organization 4 interviews) have been conducted. In total, 22 of the participating organizations returned completed and verified forms describing the innovations. Four organizations did not return verified descriptions of innovations; three of them gave practical reasons, such as a lack of time to check the data, and one organization did not give a reason. As Figure 1 shows, the majority (n=13) of the participating organizations deliver both institutional LTC and home care to their clients. Seven organizations deliver only home care and two only institutional LTC care.
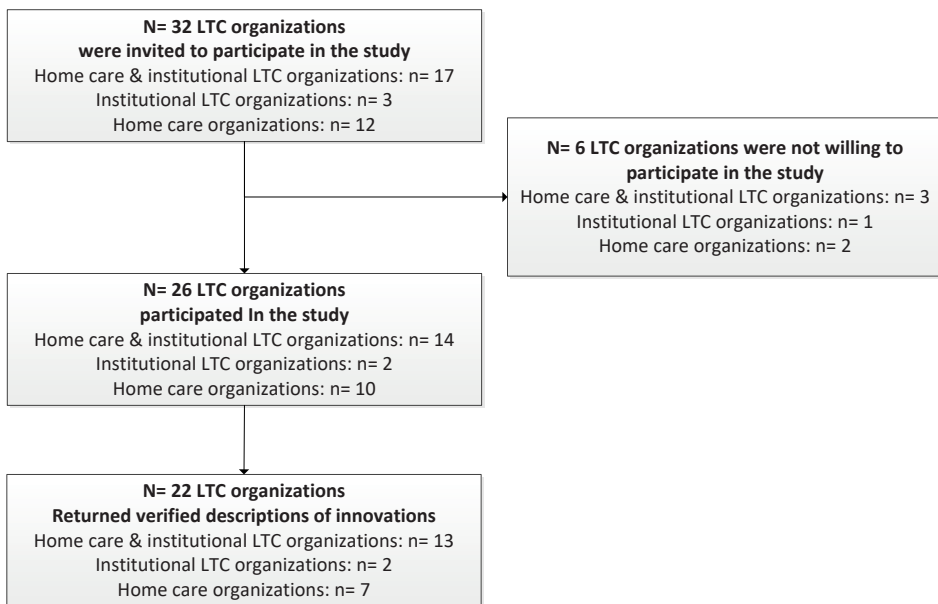
Figure 1. Flowchart of participation of organizations.

The size of the participating organizations varied considerably between 36 clients and 8,619 clients, shown in Figure 2. With regard to the number of employees, the smallest organization has 5.5 full-time equivalent (FTE) employees, while the largest organization has 4,821 FTEs.

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Figure 2. Size of the participating organizations with regard to the number of clients

Data source unless otherwise noted: website https://www.jaarverslagenzorg.nl/ (public accessible annual reports of long-term care organizations)
*Data were obtained from contact persons of participating organization.

A broad range of definitions of innovations were used by the participating organizations. One organization described innovation as "anything which was new to it, irrespective of whether the innovation might be regular practice elsewhere". Another organization considered that innovation is "renewal, change, and improvement with regard to a previous or traditional way of working". This can be small changes, but comprehensive conceptual changes were more important in its view, while another organization interpreted innovation just as small, incremental improvements.

Overview of Potential Labor-Saving and Quality-Improving Innovations

As Table 1 shows, 228 innovations were found overall in the participating organizations. This table contains duplications since some innovations were described by multiple organizations. The overview contains both innovations targeted at institutional LTC or home care only, and others targeted at both institutional LTC and home care. The majority (n=96) were product innovations. In addition, 75 organizational innovations and 42 process innovations were identified, but no marketing innovations. A cluster named "other innovations" was added as there were innovations which had multiple equally important

elements incorporating characteristics of the predefined types of innovations (n=15). Due to the quantity of innovations, it is impossible to describe all of them in detail. Table 2 therefore contains examples of innovations and short descriptions of innovations that were found in at least two organizations.

Table 1 Overview of potential labor-saving and quality-improving innovations in long-term care organizations

Type of innovation	Institutional LTC	Home care	Both	Total
1. Product innovation	N=46	N=35	N=15	N=96 (42, 1%)
1.1. Supportive technology	N=10	N=14	N=3	N=27
1.2. Activity stimulation	N=14	N=4	N =4	N=22
1.3. Therapeutic interventions	N=7	N=0	N=0	N=7
1.4. Improvements in quality of care for certain target groups	N=1	N=3	N=2	N=6
1.5. Residence forms/care services	N=4	N=3	N=1	N=8
1.6. Web services	N=0	N=4	N =1	N=5
1.7. Self-care/self-management stimulation	N=1	N=2	N=0	N=3
1.8. Organization of daily activities	N=5	N=3	N=1	N=9
1.9. Other product innovations	N=4	N=2	N=3	N=9
2. Organizational innovation	N=23	N=22	N=30	N=75 (32, 9%)
2.1 Business practices	N=12	N=9	N=19	N=40
2.2 Workplace organization	N=4	N=9	N=9	N=22
2.3 External relations	N=7	N=4	N=2	N=13
3. Process innovation	N=18	N=19	N=5	N=42 (18, 4%)
3.1 Digitalization of administrative processes	N=5	N=11	N=3	N=19
3.2 Distance care	N=1	N=1	N=1	N=3
3.3 Consistent assignment	N=0	N=2	N=0	N=2
3.4 Rehabilitation process	N=4	N=0	N=0	N=4
3.5 Other process innovations	N=8	N=5	N=1	N=14
4. Other innovations	N=9	N=4	N=2	N=15 (6, 6%)
Total	N=96	N=80	N=52	N =228 (100%)

Table 2 Examples of the different types of innovations

Type of innovation	Examples of different types of innovation described by the organizations
1. Product innovation	
1.1 Supportive technology	Products or services by which technology is used to support the functioning of care-dependent clients or to facilitate the process of care delivery such as: Domotics in institutional LTC: different types of home automation devices, such as movement sensors, fall sensors, camera supervision, night-orientation lights and alarm systems, are used in combination to increase the safety of clients and to enable more self-determination. Screen-to-screen care: video consultation between nurse and client as a new service in addition to an existing care contact. For instance a video call in the morning to check whether the client feels well or has taken the required medication. Lifestyle monitoring: sensor system to assess deviant behavioral patterns to supervise community-dwelling older persons. Electronic drug dispenser: drug dispensers with reminder function. Tool to apply and remove compression stockings: facilitating the process of applying and removing compression stockings by means of a tool. Eventually a patient can manage the process of putting on and removing stockings on their own or the tool is used to facilitate the work of the care provider. Washing without water: washcloths impregnated with specific wash/care lotion and 3% dimethicone are used to do full body wash of bedridden care-dependent patients.
1.2 Activity stimulation	Interventions to increase the level of physical activity of older people such as: Exercise gardens: gardens located closed to institutional LTC organizations that are equipped with various devices to stimulate activity, such as stationary bicycles, balance games, and other exercise equipment. Game console interventions: interventions, for example using a balance board, which are connected to a game console by means of which clients can play virtual games (exergames). Virtual cycling: a stationary bicycle connected to a video screen. When the person steps on the stationary bicycle, a video of a bicycle tour is projected on the screen. This enables the user to cycle a virtual round. Walking groups: services provided for clients of institutional LTC organizations enabling them to join a guided walking tour. Introduction of movement teachers (in institutional LTC): specified movement teachers introduced as a new function in institutional LTC organizations. They can organize group activities or individual interventions for specific clients to stimulate physical activity.
1.3 Therapeutic interventions	Interventions with a therapeutic goal such as: Interventions with the seal robot Paro: the seal robot is used in the care for psychogeriatric patients aiming to reduce behavioral problems, and facilitate daily care tasks and family visits.
1.4 Improvements in quality of care for certain target groups	Interventions to increase the quality of care of certain target groups such as: Introduction of dementia case management: a service for patients with dementia and their informal caregivers. The function of a case manager includes tasks such as support in the diagnostic phase, coordination of care and an advisory function for patients and informal caregivers.
1.5 Residence forms/care services	Introduction of new residence forms or new care services such as: Specific residence forms: residence forms specifically adapted to the needs of certain target groups, for example patients with Parkinson's disease or dementia.

Type of innovation	Examples of different types of innovation described by the organizations
1.6 Web services	Online services/interventions targeted at clients of LTC organizations or older people in general, such as: Virtual communities: online communities that can serve as a market place for services provided by LTC organizations or by volunteers. In addition, these communities provide the opportunity to video call and chat with other users.
1.7 Self-care/self-management stimulation	Interventions to stimulate the self-management ability of care-dependent older people, such as: Introduction of a function called a self-care coach: self-care coaches can be called in, for example by a GP, to support community-dwelling home care clients to optimize their self-care.
1.8 Organization of daily activities	Interventions related to the daily activities of clients of LTC organizations or other community-dwelling older people, such as: Daily activity coaches: a new function called "daily activity coaches" being introduced in institutional care. These coaches support older clients in the planning and execution of daily activities.
1.9 Other product innovations	Other new products and services.
2 Organizational innovation	
2.1 Business practices	Innovations in the field of business practices defined as "the implementation of new methods for organising routines and procedures for the conduct of work".[16] Examples are: E-learning environments: digital portals enabling employees of LTC organizations to access information about learning and development opportunities within the organization. In addition, these environments provide the opportunity to register for and follow e-learning modules provided by their organization. Self-care/self-management training: courses for nursing staff to increase the self-care abilities of clients. During these courses, the importance of the self-reliance of older people is highlighted and the nursing staff members learn how to facilitate their clients in the process of becoming more independent. Centers of expertise: centers that aim to gather, develop and spread knowledge about care for a specific target group (such as psychogeriatric patients or patients in geriatric rehabilitation) within the own organization and outside the organization.
2.2 Workplace organization	Innovations with regard to workplace organization defined as "the implementation of new methods for distributing responsibilities and decision-making among employees for the division of work within and between firm activities (and organisational units), as well as new concepts for the structuring of activities, such as the integration of different business activities"[16] Examples are: Self-managing teams: small teams of 5 to 15 nursing staff members in home care. These teams have the shared responsibility for organizing home care delivery for a certain group of clients and there is no formal leadership role. Scheduling methods: new methods to generate the work schedules for the nursing staff in LTC organizations by which a basic schedule is made centrally for all teams. In addition, the teams gain more control over their schedules, having the opportunity to adapt the basic schedules based on their own preferences in cooperation with the other team members.

Type of innovation	Examples of different types of innovation described by the organizations
2.3 External relations	Innovations with regard to external relations defined as " the implementation of new ways of organizing relations with other firms or public institutions, such as the establishment of new types of collaborations with research organizations or customers, new methods of integration with suppliers, and the outsourcing or subcontracting for the first time of business activities in production, procuring, distribution, recruiting and ancillary services."[16] An example is: Outsourcing of services: organizing the basic medical and paramedic care services in institutional LTC organizations with external GPs and external physiotherapists and occupational therapists.
3 Process innovation	
3.1 Digitalization of administrative processes	Administrative processes are supported by means of computers and computer programs, for example by means of: Electronic patient records (EPR): electronic records replacing handwritten patient dossiers. These records tend only to contain care-related information. Sometimes the EPR is also connected to the registration and invoicing system of the care organization. Digital planning and registration system: equipping home care staff with a mobile phone enabling them to access the digital planning and registration system. By means of this system they can access patient-related information, information about the sequence of patients to be cared for (route planning), and to register the time spent on the actual care delivery. Tablet PC in home care: equipping home care staff with a tablet PC to provide a flexible workplace where they can undertake the following processes digitally: accessing client-related information, reporting in the EPR, filling in required forms, searching care-related information such as protocols or specialist literature, and communicating with clients and colleges via email or video calling.
3.2 Distance care	Providing care services (e.g., consultation or supervision) at a distance, for example by means of: Video communication: enabling clients to contact a nurse or vice versa, by means of video calling on a computer or mobile device. This consultation should replace regular face-to-face consultation.
3.3 Consistent assignment	A principle according to which the same nursing staff members are constantly assigned to the same clients, which can be introduced as follows: Same staff member, same place, same time: a fixed number of nursing staff per patients assigned to deliver home care needed. Efforts are made to schedule the home visits of nurses regularly at the same time.
3.4 Rehabilitation process	Innovations in the organization of rehabilitation care processes, such as: Care pathways: clients in geriatric rehabilitation follow a standardized treatment program that can be adapted to the needs of a specific target group (e.g., trauma care, stroke care).
3.5 Other process innovations	Other changes in care delivery processes.

Type of innovation	Examples of different types of innovation described by the organizations
4 Other innovations	Interventions with multiple, equally important elements incorporating characteristics of different types of innovation, such as: <u>EXBELT program</u>: an intervention to reduce the use of physical restraints in nursing homes. Consisting of four elements: policy change, training for nursing staff, availability of alternative interventions, and the introduction of a specialized nurse as consultant.[17] <u>Hospitality concepts</u>: interventions to increase the hospitality of institutional LTC organizations. Consisting of different elements, such as task differentiation between nursing staff and service staff, changes in work processes, and eventually renovations, hospitality training for staff, and special food and drink related activities for clients. <u>Living and care concepts</u>: newly-built sheltered accommodation in which multiple supportive technology is used, such as inbuilt ceiling hosts, cameras, video call facilities, etc. In addition, new ways of organizing care processes are introduced, such as nurses supervising their clients by means of a camera. These concepts also partly include task differentiation between nursing staff and service staff.

Product Innovations

The majority (n=96) of innovations can be classified as product innovations, which include both goods and services. Table 1 shows that the product innovations can be differentiated into nine subclusters including: supportive technologies, innovations for activity stimulation, therapeutic interventions, improvements in quality of care for certain target groups, residence forms/care services, web services, self-care/self-management stimulation, innovations related to the organization of daily activities of older people, and others not further specified.

Approximately one fourth (n=27) of the product innovations can be summarized as supportive technology. This includes individual products or services, or combinations of products and services, in which technology is used to support the functioning of care-dependent clients or to facilitate the process of care delivery. Innovations clustered as supportive technology are frequently used in home care to support community-dwelling older people with complex care needs. One example of a product innovation mentioned by three organizations is the use of electronic drug dispensers with a reminder function. These drug dispensers are placed in the clients' homes having been prefilled by a pharmacist. At pre-set points in time, the dispensers give a signal indicating that the medication needs to be taken. If the drug is not registered as dispensed, the responsible LTC organization/home care employee will automatically be informed so that further action can be undertaken. An example of a supportive technology frequently mentioned as used in institutional LTC is "washing without water." A full body wash of bedridden care-dependent patients is done by means of special impregnated washcloths. This method is used as substitute for the traditional full body wash with soap and water.

Approximately one fifth (n=22) of the product innovations belong to the subcluster "activity stimulation," which contains interventions to stimulate the physical activity of older people. These interventions are mainly used in institutional LTC organizations. In part, these innovations are based on technological devices, such as virtual cycling systems or

video exergames, used to stimulate physical activity. Others are new services, for example lessons provided by a specified movement trainer in nursing homes. One innovation introduced by multiple organizations is an exercise garden. These gardens are located close to institutional care organizations and are equipped with different devices to stimulate physical activity, such as stationary bicycles and balance games.

Organizational Innovations

A total of 75 innovations can be classified as organizational innovations. Table 1 shows that these innovations are subdivided into three subclusters: innovations with regard to business practices, innovations in workplace organizations, and innovations in external relations of organizations. More than half of the organizational innovations belong to the subcluster of business practices. A considerable number of these innovations aim to stimulate the further development of employees in LTC. For example, three organizations have introduced e-learning environments where employees get information about e-learning modules, and can register for and follow the modules. Three organizations have introduced courses to stimulate the self-management and self-care facilitation skills of the nursing staff.

Process Innovations

Overall, 42 innovations are classified as process innovations. These are divided into five subclusters: digitalization of administrative processes, distance care, consistent assignment, innovations in rehabilitation processes, and others not further specified. Nearly half of the process innovations can be described as the digitalization of administrative processes. Means for digitalizing administrative processes are used both in institutional LTC and home care. In institutional LTC, this has mainly been done through the introduction of electronic patient records, a measure repeatedly found in the participating organizations. The electronic patient record should facilitate the documentation process and gives staff members access to the patient related information digitally. One innovation mentioned by five organizations is the use of digital planning and registration systems in home care. A central database is established that contains information about clients and available staff relevant to planning. Based on these data, the routing is generated for the home care employees. Home care staff can access the routing on their mobile devices. Moreover, the mobile device is used to register the time spent on care delivery for an individual client. By replacing manual registration with digital registration, no time needs to be spent on handing in written forms and entering the data in a computer program to save them.

Other Innovations

Overall, 15 innovations could not be classified as product, process or organizational inno-vation. These innovations contained multiple elements with characteristics of different types of innovations. One such innovation described by three organizations is an inter-vention to reduce the use of physical restraints in nursing homes (Expelling Belts [EXBELT] program). This intervention consists of four elements: policy change, training for nursing staff, availability of alternative interventions, and the introduction of a specialized nurse as consultant.[17] Another example is the introduction of hospitality concepts in institu-tional LTC, consisting of different elements such as task differentiation between nursing staff and service staff, changes in work processes, and in some organizations these con-cepts also include renovations, hospitality training for staff, and the provision of special food- and drink-related activities for clients.

Two organizations have set up new living and care concepts comprising newly built shel-tered accommodation for care-dependent older people. In this sheltered accommoda-tion, multiple supportive technologies are used, for example inbuilt ceiling hoists, cam-eras, video call facilities, etc. In addition, new ways of organizing care processes are being introduced, such as nurses who supervise their clients by means of a camera. Within this new living and care concept, the principle of task differentiation between nursing staff and service staff is used.

Reported Evidence on the Effectiveness of the Innovations

The participating organizations were asked to report on the effectiveness of their inno-vations. For 50 innovations, no information was provided on effectiveness. The organiza-tions stated that 33 innovations were in the development phase and 29 innovations were currently being evaluated internally in pilot studies or externally in larger research pro-jects; consequently, no information on their effectiveness could yet be provided. Organ-izations described their experiences with 50 innovations and for a further 55 innovations the results of internal pilot studies conducted by the organizations were provided. With regard to eight innovations, the organization referred to (national) studies, but did not give further specific details about these studies. Only for the EXBELT program, used by three organizations, were the results of a controlled trial indicating the effectiveness of the innovation reported.[17]

DISCUSSION

The inventory conducted in this study resulted in a large number (n=228) and a wide range of different types of innovation in LTC for older people. Three main types of poten-tial labor-saving and quality-improving innovations were found, namely: product, process

and organizational innovation. In addition we found a category "other innovation" including multiple elements of the three main types of innovations. Most of the innovations were identified in the product category and included supportive technologies and interventions to stimulate the physical activity of older people. This overview contains innovations ranging from relatively small measures (e.g., tools to apply and remove stockings, or special impregnated washcloths) to more extensive developments (e.g., lifestyle monitoring systems or newly built sheltered housing facilities incorporating different types of innovation). With the exception of the EXBELT[17] program, the organizations reported only relatively little (scientific) evidence for the effectiveness of most of the innovations.

Innovations such as digital planning and registration systems and self-managing teams showed promising labor-saving effects according to the experiences of organizations, but their effectiveness has not yet been studied extensively according to the organizations. However, against the background of an "aging society," it is important to know whether the innovations identified provide effective solutions to future challenges in terms of increased demand, decreased availability of workforce, and changes in the expectations of older people, to prevent waste of scare resources, both in terms of time and money. To fill this knowledge gap, further research on the effectiveness of innovations – both in terms of labor savings and quality improvement - is needed. However, it might be neither realistic nor necessary to study every innovation in clinical trials before using them in practice, as is done for example with medical drugs. For example proper and transparent internal evaluations of innovations completed by the organizations themselves could provide important information as well. Nevertheless, organizations need to be alert to the fact that if they implement innovations that are not proven effective, they might be investing in innovations that may not be (cost) effective in the long run. It would be valuable for organizations to share their experiences and the results of internal evaluations and the results of scientific studies, especially of promising innovations. This would provide the opportunity to learn from each other's experiences and might prevent investments in less promising innovations.

The variety of the different types of innovations and the range from relatively small to more extensive measures together show that organizations strive to anticipate and adapt to societal changes in different ways. Hence, it seems there is no "silver bullet" to deal with future challenges. However, it is noticeable that some innovations are introduced by several organizations at the same time. For example, in home care, the introduction of self-managing teams and the use of digital planning and registration systems appear to be very popular; in institutional care, measures such as the "washing without water" method, the EXBELT program, and exercise gardens were implemented by multiple organizations. The fact that innovations are introduced by multiple organizations simultaneously highlights the potential benefits that exchange of knowledge between organizations might bring. Learning from each other's experiences might prevent organizations from struggling with the same problems. The relatively high willingness to participate in

this study indicates that organizations are prepared to share their experiences concerning the innovations they develop and implement.

With regard to the results of this study, several limitations need to be considered. First, a broad definition of the concept innovation was used. As there is no objective measure for innovations, the overview is based on the individual perceptions of the respondents and their personal definitions of innovation. Hence, a measure that is perceived as an innovation by one person is not necessarily an innovation for another person. Second, with regard to the results concerning the level of evidence related to the innovations identified, this study is based on information provided by the participating organizations; no additional literature study has been done to search for studies examining the effectiveness of certain innovations. Third, the interviews were conducted mainly with CEOs, who might not know all innovations used in their organizations. As they were asked during the interviews whether the results of the inventory could be published in the public innovation database, this might have limited their willingness to describe every innovation because they might not want to share all their information with their direct competitors. This might be explained by the fact that innovations are a possible source of competitive advantage[18] and sharing knowledge with competitors could diminish this. Fourth, this inventory was done in a relatively small region in the Netherlands. It can be expected that (inter)nationally more innovations in the LTC for older people do exist. However, from a national perspective, it may be assumed that similar types of innovation would be found because organizations in other regions within one country tend to be dealing with comparable demographic changes and legal requirements, and receive the same information from branch organizations.

The strength of this study is that it resulted in a detailed overview of potential labor-saving and quality-improving innovations. However, this overview is a snapshot of one moment in time, while the introduction of innovations in organizations is a dynamic and ongoing process. Therefore, a public innovation database, which should be updated periodically, is being set up based on this inventory to stimulate a continuous exchange of knowledge.

CONCLUSION AND IMPLICATIONS

The study shows that a large number and wide variety of innovations are currently used or are being developed in LTC for older people. This implies a high potential for innovation in this sector. However, there is insufficient (scientific) evidence concerning the labor-saving and quality-improving effects of many innovations. This overview should serve as a basis for further research on the effectiveness of the proposed innovations to ensure that organizations invest in innovations that are real solutions to future challenges. Be-

sides more scientific research it would be valuable if LTC organizations monitor and evaluate the implementation of innovations more closely, which means that organizations should formulate clear and measurable goals which they aim to achieve by implementing innovations and to monitor whether these goals are achieved. The inventory has shown that different organizations are dealing with the same innovations at the same time; it is recommended that they combine their forces and exchange their experiences of promising innovations. For both professionals in institutional LTC and home care (e.g. healthcare professionals and policy advisors) this overview can provide valuable information on the variety of innovations currently in development or already being used. It might be difficult for them to establish which innovations might be suitable solutions for their particular situations, and it would therefore be valuable to have some kind of guidance or decision support in the selection process of which innovations should be implemented in particular organizations or which are suitable solutions for individual clients.

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Chapter **3**

Facilitating Aging in Place:
A Qualitative Study of Practical Problems
Preventing People with Dementia from Living
at Home

ABSTRACT

Although the majority of people with dementia wish to age in place, they are particularly susceptible to nursing home admission. Nurses can play an important role in detecting practical problems people with dementia and their informal caregivers are facing and in advising them on various ways to manage these problems at home. Six focus group interviews (n=43) with formal and informal caregivers and experts in the field of assistive technology were conducted to gain insight into the most important practical problems preventing people with dementia from living at home. Problems within three domains were consistently described as most important: informal caregiver/social network-related problems (e.g. high load of care responsibility), safety-related problems (e.g. fall risk, wandering), and decreased self-reliance (e.g. problems regarding self-care, lack of day structure). To facilitate aging in place and/or to delay institutionalization, nurses in community-based dementia care should focus on assessing problems within those three domains and offer potential solutions.

INTRODUCTION

Background

The number of people suffering from dementia is increasing worldwide.[1,2] Currently, about 260,000 people with dementia live in the Netherlands,[3] and about 70% of them are living at home supported by informal and formal caregivers.[4] Formal community-based dementia care in the Netherlands basically consists of care providers such as general practitioners, home care organizations, day-care centers, and care coordinators (e.g. dementia case managers).[5] Since dementia is a progressive disease characterized by cognitive and functional decline, it makes people increasingly dependent on support[2] and particularly susceptible to nursing home admission.[6] At the same time, the expected preference of the majority of people with dementia is to live at home as long as possible,[1,7] which is also a common policy aim of many Western countries.[1,8]

During the last years the policy concerning the eligibility for publicly funded professional long-term care in the Netherlands has changed significantly.[9,10] Where in the past people were widely supported by publicly funded professional care either at home or in long-term care facilities, people now need to live as long as possible in their own home environment. Moreover, the social network of a care dependent person is expected to fulfill as much care tasks as possible before publicly funded care can be requested.[10] [9] These changes put new responsibilities on informal caregivers and ask for new solutions to delay or even prevent nursing home admission.

To delay nursing home admission of people with dementia it is necessary to have insight into the factors which prevent people with dementia from living at home. General predictors of nursing home admission of people with dementia have already been extensively studied, and the results are, to a large extent, summarized in two systematic reviews by Gaugler, et al. [11] and Luppa, et al. [12] According to Luppa et al.[12] the predictors can be categorized into predisposing variables (sociodemographic and relationship characteristics of patients and caregivers), needs variables (primary stressors such as severity of dementia, functional impairment and caregiving hours and secondary stressors such as caregiver burden or life satisfaction) and enabling variables (personal and social resources and community-based care). A recent European study[13] showed that caregiver burden and dependency in activities of daily life, are the most consistent factors predicting a nursing home admission for people with dementia. In order to support people with dementia and to delay or even prevent institutionalization it is necessary to focus on potentially modifiable predicators such as caregiver burden or ADL dependencies. Consequently, this theoretical knowledge needs to be operationalized into concrete solutions to delay or even prevent institutionalization of people with dementia. To tailor (innovative) solutions first deeper insight into the underlying practical problems (daily struggles)

people with dementia and their caregivers are experiencing in the daily life which prevent them from living at home is needed.

Professionals can play an important role in advising people with dementia and their informal caregivers on possible solutions and care options[14] as people with dementia and their informal caregivers might not be aware of available and quickly evolving (technological) solutions.[15] In community-based dementia care nurses in the function of district nurse or and case manager often fulfill this advisory role. Hence, nurses need to have insight into most important the practical problems people with dementia and their informal caregivers are experiencing, that prevent them from living at home. Those problems should be addressed first in an attempt to delay or prevent nursing home admission.

Aim

Therefore, the aim of this study was to gain deeper insight into the most important practical problems preventing people with dementia from living at home. These insights may inform nurses in community-based dementia care how to target their assessments as well as their advice on possible solutions to delay or prevent institutionalization.

MATERIAL AND METHODS

Design

A qualitative study using six focus group interviews was conducted to gain insight into the most important practical problems in daily life preventing people with dementia from living at home.

Sample/participants

A purposive sampling method was applied so that participants were selected who are regarded as particularly knowledgeable about the topic under consideration and can provide relevant information.[16] Therefore, we chose important stakeholders involved in different phases of community-based dementia care. Those stakeholders were divided into three types of focus groups (A, B and C). A total of six focus group interviews were conducted. The size of the individual groups was planned to be between 6 and 11 participants. The first three focus group interviews (type A) consisted of professionals who had a direct role in care coordination for community-dwelling people with dementia (case managers, home care nurses, general practitioners, client advisors of long-term care organizations) (n=23). Those professionals work with community-dwelling people with dementia on a daily basis and have experienced numerous transitions from home to a nursing home. Two focus group interviews (type B) were planned with occupational therapists, experts in the field of assistive technology, suppliers of assistive technology, and a

consultant working for a non-profit organization that advises informal caregivers about their caregiving tasks (n=14). The participants in this group were included because they were expected to have insight into specific practical problems in the daily life of community-dwelling people with dementia, as they are often involved in the process of solving such problems. Finally, one focus group (type C) was composed of informal caregivers of people with dementia and representatives from dementia support groups (who were also informal caregivers) (n=6), as they are the ones actually "co-experiencing" the practical problems in daily life. Informal caregivers were included because they provide, to a large extent, the care for community-dwelling people with dementia. Moreover, evidence shows that they can be considered a reliable source of information on reasons for nursing home admission of people with dementia.[17] All participants were recruited via the Living Lab in Aging and Long-Term Care South Limburg and via a network organization for innovative care and technology located in the south of the Netherlands.

Data collection

The six focus group interviews were held in September and October 2014. The interviews took place in a meeting room at the university and were planned to last for about two hours. All interviews were audio recorded with verbal consent of all participants. The interviews were led by experienced moderators (two authors M.B., M.L. and one other researcher) who are doctorally-prepared researchers in gerontology, assisted by one or two observers (one author T.T.L. and one other researcher). A topic list with two main open-ended questions (1. "What are the most important problems preventing community-dwelling patients with dementia from living at home?" If no informal caregiver-related problems were described initially, the moderator asked the following question: 2. "What are problems informal caregivers experience that threaten the ability of people with dementia to live at home?") was used to structure the interviews. Prior to the interviews, the participants received information about the aim of the interview as well as the first main question of the topic list via email or mail. To ensure that all participants had an equal chance of expressing their opinion, the focus groups were conducted based on elements of the Metaplan method.[18] According to this method, to visualize and lead group discussions, participants are asked to write down their arguments on cards, which are subsequently jointly clustered. At the start of each focus group interview, all participants were asked to write down on sticky notes what, according to them, were the three most important problems preventing people with dementia from living independently at home. To start the discussion, each member was asked to name the three most important problems. All notes were collected and jointly clustered into categories to get an overview of the problems mentioned and to verify whether important problems were missing. When no new categories emerged, it was assumed that saturation was reached. During the interviews, the observers took field notes. At the end of each interview, the

participants were asked to voluntarily complete a socio-demographic questionnaire containing questions about age, gender, and their role in caring for community-dwelling people with dementia.

Data analysis

The data analysis started with collecting the sticky notes containing the most important problems according to the respondents after each focus group interview. After all interviews were conducted, the sticky notes from all six focus groups were clustered by two pairs of project team members (three authors T.T.L., M.B., M.L. and one other researcher) into themes indicating the problem domains, keeping in mind the clusters made during the focus group interviews. They discussed the clusters to reach consensus about the themes (subsequently described as problem domains). Based on the audio files, literal transcripts were made for each focus group session. The interview texts were analyzed according to the principles of qualitative content analysis.[19] The first author T.T.L. read the entire interview text several times and highlighted passages where the interviewees expressed their opinion about the problem domains, as previously defined. All information provided about one problem domain was first summarized using condensation, which means shortening the text but preserving the essence[19] for each individual interview. Subsequently, the condensed descriptions of the problem domains of all interviews were combined into one overall MS Word document. The information about the problem domains was reviewed, and content-related categories were formulated by the first author and discussed amongst the co-authors to reach consensus.

To strengthen the trustworthiness of the study, different measures were taken to meet the criteria of credibility, dependability, confirmability, and transferability, based on the framework of Lincoln and Lubba.[20] Since choosing participants with various experiences can lead to a richer description of the topic under consideration and therefore increase the credibility of the results,[19] a purposive sampling method was used to include various perspectives of stakeholders playing a central role in community-based dementia care. Moreover, the main problem domains were derived from the sticky notes and clustered by two pairs of researchers, who subsequently reached consensus about the problem domains. This procedure was followed by a member check where the main results were presented and discussed with a sample of former participants of focus group type A (N=5) to further improve the credibility and dependability of the results.[20] To enhance dependability, the procedures followed in this study were meticulously described, and the same topic list was used for all focus group interviews. To increase the confirmability, which means ensuring the objectivity of the data,[21] the moderator summarized the main results at the end of each focus group interview and encouraged the participants to critically reflect on the results and correct or add information where necessary. Detailed descriptions of the findings backed with literal quotes from all six focus groups are provided in

order to increase the transferability[19] all results presented in this article were substantiated with literal quotes from all six focus groups in this article.

Ethical considerations

The study protocol was approved by the medical ethics committee of Atrium-Orbis-Zuyd (14-N-95). Information about the aim of the study and the expected burden of the focus group session was provided to all participants in advance, either by email or post. Participation in the interviews was strictly voluntary for all participants. Before the start of each interview, oral consent to contribute to the study was given by all participants. Additional written informed consent was obtained from representatives from interest groups and informal caregivers.

RESULTS

A total of 43 participants took part in the six focus group interviews. Table 1 provides information about the composition of the focus groups and socio-demographic characteristics of the participants.

Table 1: Participant characteristics (n=43)

Type A (N=23) – 3 groups		N (%)
Role	Dementia case manager	11 (48)
	Home care nurse	5 (22)
	Client advisor of long-term care organizations	5 (22)
	General practitioner (physician)	2 (9)
Sex	Male	4 (17)
	Female	19 (83)
Mean age		43,7 years (SD 11.7)
Type B (N=14) – 2 groups		
Role	Occupational therapist	4 (29)
	Assistive technology expert	4 (29)
	Assistive technology provider	5 (36)
	Informal care consultant	1 (7)
Sex	Male	3 (21)
	Female	11 (78)
Mean age		41,0 years (SD 9.9)
Type C (N=6) – 1 group		
Role	Informal caregiver	4 (67)
	Patient representative	2 (33)
Sex	Male	2 (33)
	Female	4 (67)
Mean age		68,0 years (SD 4.3)

Practical problems in daily life preventing people with dementia from living at home

The participants came up with a variety of practical problems in daily life, such as problems due to insufficient food and fluid intake, wandering, or absence of a person who can detect risks and intervene in case of emergency. The participants initially reported that defining the three most important problems was challenging. In their opinion, the problems in daily life are highly determined by the individual situation, and a combination of problems may lead to a situation in which living at home may become impossible. However, when asking them to write down what first came to their minds, comparable problems within all groups were described, which could be categorized into common "problem domains": problems due to decreased self-reliance, safety-related problems, informal care/social network-related problems, behavioral problems, formal care-related problems, and cognitive decline. Those problem domains were also confirmed during the member check.

In the following paragraphs, the practical problems mentioned by the participants are described for each problem domain, starting with the most often described problem domains, followed by the less frequently mentioned problems. Table 2 provides an overview of the practical problems described within the problem domains, supported by quotations from the participants. The codes assigned to the quotes stand for FG (focus group), followed by two numbers, with the first indicating the number of the focus group (1–6) and the second indicating the number assigned to the individual participant.

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Table 2: Overview of problem domains preventing people with dementia from living at home

Problem domain	Categories	Practical problem	Quote*
Decreased self-reliance	Lack of ability to conduct activities of daily living (ADL)/ instrumental activities of daily living (IADL)	Person with dementia forgets to eat and drink	"What we see a lot in daily care is that people often forget to eat and forget to drink. Consequently, they become malnourished and dehydrated (…)." (FG12)
		Inability to move inside the house	"I also wrote down decreased mobility (as a problem), thus people face problems going up and down the stairs, or when they use a walker and have difficulties with barriers." (FG66)
		Person with dementia cannot or does not go to toilet	"First, I wrote down self-care, actually, the whole range of caring for oneself, from eating and drinking, going to the toilet, and washing, to housekeeping." (FG16)
		Person with dementia cannot or does not wash oneself	
		Person with dementia cannot or does not keep their house	
		Person with dementia cannot judge whether food is still edible	"Not being able to take responsibility, not knowing that things (food) are moldy or at the expiration date. Not knowing when you need to clean up (the house) and also not knowing how to perform certain actions." (FG35)
		Person with dementia does not know when he or she needs to clean up the house	
		Person with dementia cannot use Meals on Wheels because he or she is not able to use a microwave to prepare the meal or person with dementia cannot open the door to receive 'meals on wheels'	"This (the inability to do grocery shopping) is compensated for by Meals on Wheels, or something comparable, but the fact that people cannot open the door to receive these meals and cannot warm up the meal because of having to use a microwave becomes more and more challenging, (makes this solution insufficient)." (FG13)
		Person with dementia does not do grocery shopping	"And often, there is nothing to eat and drink at home because people don't go grocery shopping." (FG11)
		Person with dementia cannot manage his or her own medication	"Medication use is also a huge problem related to self-management (…)." (FG31) "To take them at the right time?" (Moderator) "Yes, to swallow it. Besides, everything is mixed up and medication packages are scattered everywhere. To give up this self-management is very difficult for people." (FG31)

Problem domain	Categories	Practical problem	Quote*
		Person with dementia cannot find things at home	"She got more and more chaotic in her head and in daily life; she continued to wash (clothes) and to iron, but storing things went wrong. You would find different things in the wrong places, for example, she stored the cutlery in the wrong place after washing, or she lost the keys, those kinds of things." (FG46)
		Person with dementia stores things in unusual places at home	
		Person with dementia cannot handle financial administration	"The IBAN number, which you need to use for bank transfers, leads to huge problems. In the past, one could go to the bank counter, but nowadays you need to be happy with one ATM in the village." (FG33)
	Lack of structure	Person with dementia has no daily structure and does not know what to do at a particular moment during the day	"In the first instance, I wrote down scheduling and daily structure. That is very difficult when people don't know what time it is and what it is that they need to do at a particular moment in time. That is very uncomfortable for them, but maybe also for the family. Family is frequently called, or people need a lot of attention. This leads to a lot of insecurity and agitation." (FG51)
	Lack of meaningful activities	Person with dementia has no meaningful content during the day	"(...) In addition to what he *(another participant)* said regarding a lack of structure, they *(people with dementia)* don't spend their day in a meaningful way. *(One example is)* a person who sits apathically in a chair the whole day long and who doesn't know what to do." (FG27)
	Disrupted day/night rhythm	Person with dementia loses a normal day/night rhythm	"The third *(problem)*, and for me the most important one, is that people lose their day and night rhythm. They lose their feeling for time; consequently, they don't know when they need to eat and their normal feeling of being hungry is also gone. They don't drink enough, causing dehydration and-related problems." (FG210)
Safety-related problems	Inability to make own decision and to judge risks	Person with dementia lacks the ability to make own decisions and to judge risks	"(...) The loss of self-reliance and independence, (...), the ability to make your own decisions when it is necessary. Additionally, the ability to identify risks. That is gone. When a person has partially or completely lost this ability, another person needs to detect the risk." (FG57)
	Hazardous situations	Person with dementia forgets to switch off the gas, which leads to fire hazard	"Once, I (an informal caregiver) noticed fire inside my house because the gas was not switched off." (FG42)
		Person with dementia cannot safely use electronic devices	"In addition (to other problems), I have dangerous behavior; for example when a person uses scissors to cut the wire of a lamp because he/she doesn't know how to switch off the light anymore." (FG12)
		Person with dementia has a high risk of fall incidents	"(...) Fall incidents or the risk of fall incidents. Often people have an unstable balance, but when the person falls and breaks his/her hip, then this is finally the decisive reason for (nursing home) admission." (FG12)

3

Problem domain	Categories	Practical problem	Quote*
		Strangers entering the house of the person with dementia	"As the third one (*problem*), I have dangerous situations – fall risk, fire hazard – but also clients (People with dementia) who live alone in rural areas where strangers try to enter; we had that several times. We wanted to admit the person *(to a nursing home)*, because it became too risky, especially in the winter time." (FG28)
		Person with dementia takes too much or too little medication	"Medication, and particularly the medication errors that can occur when the medication is managed by the person *(with dementia)* themselves or when the medication is stored in a place where the person has access to it. What you see is that people forget that they have already taken their medication. They take the medication several times, or they forgot to take it, which also leads to serious health risks." (FG12)
		Person with dementia who wanders on the motorway during the night, leading to unsafe situations in traffic	"Hazard for the person him/herself or for the environment. If a person searches for ice cream on the motorway during the night, I think we *(as professionals)* are too late." (FG33)
		Person with dementia who wanders and gets lost	"I wrote down *(the following problems)* wandering and getting lost. Thus, people go outside, wearing too little clothing and can't find their way back." (FG61)
		Person with dementia wears clothes that are not appropriate for the temperature	
		Unsafe handling of finances	"Safety also includes *(the following situation)* a person with dementia going to the bakery to buy bread for 50 euros and does this 60 times a day. (...) We have had this situation once where a person went to the florist 10 times a day to buy flowers for 20 euro. (...) This is not a risk in itself, because he knows his way back, but it costs a lot of money and the person doesn't know it." (FG35)
	Lack of supervision	Lack of a person who identifies risks and undertakes actions to compensate for the deficiency of the person with dementia to judge risks	"Lack of a signaling function at home, thus there is nobody who intervenes when a situations is about to go wrong. (...) To identify risks on time, for example when the gas is switched on." (FG13)

Problem domain	Categories	Practical problem	Quote*
Informal care/ social network-related problems	High load of care responsibilities for informal caregivers	Load of the care responsibilities placed up on the informal caregiver exceeds the capabilities of the caregiver	"For me, the primary problem was the burden for the informal caregiver. As long as the informal caregiver can manage it well, then it usually still works. (…) The informal caregiver doesn't only get the tasks he/she already had to do, but he/she also gets additional tasks that the person with dementia can no longer conduct by himself or herself. But also because the person with dementia requires a lot of attention, which causes less available time for the caregiver to complete all of the tasks. This leads to overburdening the informal carer." (FG67)
		Insufficient recovery time of the informal caregiver leads to higher burden	"If you have time to sleep at night then you *(the informal caregivers)* are able to handle it, but when it becomes 24 h care, when you need to be alert continuously during the night and you wake up all the time because your partner who is lying next to you starts wandering and wants to leave the house, (…) that is when things get out of hand (…)." *(FG46)*
	Inability to handle the person	Informal caregiver does not know how to deal with the person with dementia	"And also *(in addition to other problems mentioned earlier)* the high burden to informal caregivers, which is sometimes combined with an inability to deal with dementia and everything related to dementia (…)." (FG13)
	Lack of availability of informal caregivers	No or too little availability of informal caregivers to compensate for deficiencies of the person with dementia and to provide social and emotional support	"As the third *(problem)*, I wrote down none or too little informal care. Because you see that people, who have several informal caregivers around them, get by *(living at home)* for a longer period of time, because they get more practical things done and also get more social and emotional support, on all domains actually. And thus they run a smaller risk, for example, with regard to too little eating and drinking." (FG14)
		No or few informal caregivers are available	"The first *(problem)* concerns little or no informal care. Sometimes there is no informal caregiver and sometimes the informal caregiver is no longer able to care and these are often points in time when the situation escalates. Then you see, especially when the person is in a more advance stage of the dementia process and when there is only (professional) home care to support the person, that it gets out of hand." (FG34)
		Informal caregiver is no longer able to care	"Lack of a safety net regarding informal care. Children are, due to their responsibilities at work, often unable to keep an eye on mom and dad 24 h a day (…) or married couples from which the healthy partner suddenly becomes ill or unable to perform the same tasks as before, then literally the whole world collapses, and we have a huge problem." (FG35)
		Sudden loss of an informal caregiver for example due to illness of the informal caregiver	*Another participant said:* "I *(an informal caregiver)* need to undergo two knee joint replacements, but that is impossible *(due to informal care responsibilities)*." (FG42)

Problem domain	Categories	Practical problem	Quote*
	Loss of social contacts	Loss of social contacts	"Aggressive behavior against other people, which causes those people to visit them less frequently and for that reason, probably are also unable to provide support (for the person with dementia)." (FG62) *Additional statement by another participant:* "Loss of social contacts, this is very important. I think that it is not necessarily caused by behavioral problems. If, during a birthday party, a person asks "when are we going home" 20 times, this is not aggressive behavior, but perhaps this is a reason for the informal caregiver to decide to no longer go there (*to visit friends or attend a party*)." (FG67)
Behavioral problems	Refusal of care	Person with dementia neglects that he/she needs help/support, which can lead to hazardous situations	"Lack of insight in the disease, which causes resistance and unwillingness to accept care. Those people don't want the involvement of others; this quickly leads to hazardous situations and risks for the persons themselves and for others." (FG14) *Another participant said:* "What I also want to indicate is acceptance of help and resistance against care. (...) Often this goes hand in hand with dementia; that one doesn't want to accept and doesn't want to see what is going on." (FG24)
	Behavioral problems	Specific behavior (e.g. aggression, anxiety) is difficult to handle for the informal care giver	"I think that when a person with dementia exhibits certain behavior, especially when there is a partner, and the person with dementia is difficult to handle, difficult to manage, querulant, maybe aggressive, verbally or physically, that this can lead to a situation in which the partner is not able to deal with the situation any longer." (FG34) "Anxiety and suspiciousness of the person with dementia. In the beginning it is a problem because the suspiciousness is caused by memory problems, forgetfulness; this means that people ask the same question five, six, seven times within two minutes. That drives you crazy." (FG45)
Formal care-related problems	Lack of suitable care services	Lack of suitable day care facilities	"And suitable day care is not available. (...) There is day care but it is not suitable in the sense that it doesn't fit to the specific phases of dementia; there are not enough skilled professionals, there is not enough staff, and the activities are not suitable for a variety of different people with dementia. Therefore, I think, or we think, that it is not suitable enough." (FG25)
		Lack of availability of respite care facilities	"What I (*an informal caregiver*) really miss are easily accessible places for people with dementia to stay overnight (...) to give me (*the informal caregiver*) the possibility to recover, to catch my breath, which would enable me to continue (*the informal care*) for a while." (FG44)

Problem domain	Categories	Practical problem	Quote*
	Bad coordination of care services	Formal care for a person with dementia at home is not well coordinated, leading to agitation and stress for informal caregivers	"Often we *(professional care givers)* don't know from each other whether we are involved with a client." (FG16) *Reaction of another participant:* "And this is very bad; it causes a lot of agitation and often also causes extra burden (stress overload) for informal caregivers." (FG11)
Cognitive decline	Cognition	Person with dementia's loss of ability to recognize things	"The ability to recognize certain things, loss of recognition." (FG55)

* The words written in italics have been added by the author to make the quotation more easily understandable.

Decreased self-reliance of the person with dementia

The first problem domain consistently described during all six focus group interviews was problems regarding decreased self-reliance of the person with dementia, meaning that people with dementia lost their ability to conduct, plan, and decide about normal activities of daily living (ADL) during the course of a day. A frequently described problem preventing people with dementia from living at home was decreased ability to conduct basic ADL (especially eating, drinking, washing, mobility and transfers).

Respondents frequently stressed that a lack of ability to conduct the most basic activities, such as eating and drinking, can lead to serious consequences as the following quote shows:

> "What we see a lot in daily care is that people often forget to eat and forget to drink. Consequently, they become malnourished and dehydrated (…)." (FG12)

Moreover, an inability to conduct higher-order activities/instrumental activities of daily living (IADL), such as housekeeping and medication management, and difficulties regarding financial administration are also considered problems preventing people with dementia from continuing to live at home. Additionally, the participants emphasized that a lack of ability to structure the sequence of daily activities, a lack of meaningful activities, and a disrupted day/night rhythm also threaten the ability of people with dementia to live at home as the following quote indicates:

> "The third (problem), and for me the most important one, is that people lose their day and night rhythm. They lose their feeling for time; consequently, they don't know when they need to eat and their normal feeling of being hungry is also gone. They don't drink enough, causing dehydration and-related problems." (FG210)

Safety-related problems

The second major problem domain consistently described during all focus group interviews was safety-related problems. These problems include an inability to judge risk and make independent decisions, dangerous situations for people with dementia or their environment, and a lack of safety measures to prevent dangerous situations. One participant (an informal caregiver of a person with dementia) described a dangerous situation as follows:

> "Once, I noticed fire inside my house because the gas was not switched off." (FG42)

The participants described additionally various other safety hazards such as improper use of electronic devices, the risk of being mistreated or robbed by strangers entering the house, the risk of falling incidents, unsafe behaviours in traffic, unsafe handling of finances, and the risk of getting lost outside the house and not being able to find the way

back home. Moreover, the risks of health-related problems due to improper medication use, insufficient intake of food and liquids, or wearing clothes that are not appropriate for the temperature were discussed. Another frequently reported problem was the absence of a "supervision function" to detect possible risks for the person with dementia as the following quote shows:

> "Lack of a signaling function at home, thus there is nobody who intervenes when a situations is about to go wrong. (…) To identify risks on time, for example when the gas is switched on." (FG13)

As described earlier, people with dementia can lose their ability to judge risks and to act in a reasonable way to prevent safety hazards. Therefore, they need to be supported in the judgment of risks and regarding interventions in case of emergency. If this "supervisor" is lacking, this might hinder the ability to live at home.

Informal care/social network-related problems

The third problem domain described during all six focus group interviews are informal care/network-related problems. This domain includes problems concerning excessive informal caregiver's responsibility, the inability of the informal caregiver to properly handle the person with dementia, a lack of availability of informal caregivers, and the loss of social contacts of the person with dementia. Informal caregivers can compensate, to a certain extent, for their deficits in functional abilities and safety judgment. This can be very burdensome for the informal caregivers, especially when the person with dementia requires attention and support 24 hours a day as illustrated by the following quote:

> "If you have time to sleep at night then you (the informal caregivers) are able to handle it, but when it becomes 24 h care, when you need to be alert continuously during the night and you wake up all the time because your partner who is lying next to you starts wandering and wants to leave the house, (…) that is when things get out of hand (…)." (FG46).

In cases in which the burden exceeds the personal limit of the informal caregiver, the ability of the person with dementia to stay at home can be threatened. Another problem mentioned was that informal caregivers misinterpret the behaviors of the person with dementia. Problems with dealing with difficult behavior may occur when a caregiver lacks the ability to empathize with the perceptions of the person with dementia. When people know that certain behaviors are a consequence of the disease, it might be easier for them to accept those behaviors. Another frequently described problem is the lack of available informal caregivers as the following quote illustrates:

> "Lack of a safety net regarding informal care. Children are, due to their responsibilities at work, often unable to keep an eye on mom and dad 24 h a day (…) or married couples from which the healthy partner suddenly becomes ill or unable

to perform the same tasks as before, then literally the whole world collapses, and we have a huge problem." (FG35)

It seems that people who have no informal caregivers at all or who have a small social network, such as when they have no children or the family members live too far away, are less likely to remain living at home. A situation in which an informal caregiver is suddenly unable to provide care due to various reasons (e.g. hospital stay) can also seriously threaten the ability of people with dementia to live at home. Finally, the loss of social contacts was described as a problem hindering the ability of people with dementia to live at home. Loneliness may ensue from a loss of social contacts, the inability to build new social relationships or challenging behavior of the person with dementia.

Behavioral problems

The fourth problem domain put forward during five focus group interviews is related to the specific behaviors of people with dementia. First, a person with dementia may not be willing to accept care because the person does not see the necessity of help, which can lead to safety hazards. Second, the person with dementia can show certain behaviors, such as aggression, wandering, anxiety which are very burdensome for the person with dementia as well as the informal caregivers to deal with as the following quote indicates:

> "I think that when a person with dementia exhibits certain behavior, especially when there is a partner, and the person with dementia is difficult to handle, difficult to manage, querulant, maybe aggressive, verbally or physically, that this can lead to a situation in which the partner is not able to deal with the situation any longer." (FG34)

These examples indicate that it is not the behavior itself that hinders the ability of people with dementia to live at home, but rather the consequences (e.g. safety hazard or increased burden of informal care) of these behaviors.

Formal care-related problems

In five of the six focus groups interviews, formal care-related problems were discussed. The problems regarding formal care can be summarized as a lack of availability of care services adapted to the needs of people with dementia/the informal caregivers and inappropriate coordination of care services With regard to the lack of suitable care services, one respondent mentioned:

> "What I (an informal caregiver) really miss are easily accessible places for people with dementia to stay overnight (…) to give me (the informal caregiver) the possibility to recover, to catch my breath, which would enable me to continue (the informal care) for a while." (FG44)

Besides a lack of respite care a lack of day-care facilities that meet the needs of the individual person with dementia who is not interested in mainstream activities (e.g. bingo or singing) was described. With regard to inappropriate coordination of care services, the respondents mentioned that, frequently, several formal care providers are involved in the care of community-dwelling people with dementia and that they are often unaware of each other's work. Moreover, it was described that sometimes too many caregivers are involved, which can have negative consequences on the behavior of people with dementia.

Cognitive decline

Cognitive decline was described less frequently during the focus group interviews (twice in one interview). The respondents described forgetfulness and a lack of ability to recognize things as hindering the ability to live at home.

DISCUSSION

Important problem domains preventing people with dementia from living at home

In the present study, problems within three domains threatening the ability of people with dementia to live at home were described most frequently during all six focus group interviews and can therefore be regarded as the most important ones, namely problems involving decreased self-reliance, safety-related problems, and informal caregiver/social network-related problems. In addition, behavioral problems, formal care-related problems, anxiety, and decreased mobility and cognition were described, but less frequently. Our results of the identified problem domains are supported by the results of other studies describing problems regarding ADL activities and behavioral difficulties[22] as well as decreased abilities to perform IADL activities.[23] A recent study on causes of crisis situations, defined as situations in which immediate psychiatric interventions are needed by community-dwelling people with dementia, described problems relating to risks and hazards at home, family carer-related problems, problems involving memory and behavior, community services-related problems, physical health problems, and social and environmental changes.[24] Social and environmental changes were not explicitly mentioned as problems that hinder the ability to live at home in the present study; possibly, these factors are more specifically related to a crisis, instead of the ability to live at home.

Our study adds knowledge by identifying that problems in the three domains, decreased self-reliance, safety-related problems, and informal caregiver/social network-related problems, seem to be the most important barriers for aging in place that nurses in com-

munity-based dementia care should pay attention to. These problem domains are inter-related since the underlying problem of decreased self-reliance underscores the need for willing and able informal caregivers that can compensate for functional deficits and a lack of meaningful activities, provide structure and prevent risky behavior. Otherwise the person with dementia will experience decreased autonomy, quality of life, and dignity as well as increased risk of h hospitalization and institutionalization.[25] The data might indicate that an optimal amount of support exists to enable persons with dementia to prolong living at home. It was described that too many professionals being involved in care can cause coordination problems. While too few informal caregivers being available, may cause a lack of practical and emotional support. In both situations the ability of the person with dementia to live at home might be threatened. Moreover, it needs to be recognized that proving informal care can be very burdensome and can lead to a situation in which the burden exceeds the personal capabilities of the caregivers. Therefore, it is essential to tackle not only problems that people with dementia are experiencing directly but also those problems related to informal caregivers and their social network in order to delay or prevent nursing home admission.

Implications for practice and research

Knowledge of the most important problem domains facilitate nurses to target their efforts in early detection so that they can intervene as soon with (innovative) solutions to prevent transfer to nursing homes. To support self-reliance, technological solutions may be employed such as medication dispensers with a reminder function, tools to apply and remove compression stockings,[26] audible or visual prompts for other ADL activities such as eating or drinking, or specific clocks or agendas for people with dementia to facilitate a daily structure.[27] For safety-related problems, of the caregiver can consider GPS tracking devices for people who tend to wander, fall sensors, systems to shut of the gas or water to prevent injuries at home,[27] or lifestyle monitoring to assess deviant behavioral patterns from a distance.[26] Solutions to support informal caregivers are also currently available. Examples of solutions to reduce caregiver burden or to increase caregivers well-being are: adult day care, respite care,[28] educational programs for informal caregivers[29] or internet-based support interventions for informal caregivers.[30]

People with dementia and their informal caregivers are often unaware of the available treatment options for their practical problems.[14] Hence, professionals (e.g. district nurses and case managers) can play an important role in detecting those problems, introducing possible solutions and coordinating these solutions. As one person with dementia is not like the other, each individual might face different combinations of practical problems. Since they might have different resources to compensate for their deficiencies, an individualized approach would be advisable when it comes to assessment of problems and a search for possible solutions. What is considered an optimal solution for one person might not be suitable for another. Moreover, new (technological) solutions are constantly

developed and become available for implementation in practice. Thus, it can be challenging for nurses to keep up to date on the available solutions and to choose the right solution for the individual person. In addition, it must be considered that a certain infrastructure is needed to implement more complex technological solutions, such as telecare systems. Therefore, to fulfill their advisory role, nurses need to have detailed information on the solutions and their requirements for implementation. To obtain this information is to access general databases for assistive technology such as EASTIN [31] and AbleData.[32] However, those general databases might not contain all dementia-specific solutions and solutions beyond the scope of assistive technology. An area for further research might be the development and evaluation of a (computerized) decision support tool specifically developed for nurses in community-based dementia care. This might be helpful to facilitate nurses in their advisory role. Such a tool could match possible solutions for specific identified problems.

The aim to detect problems early and to introduce solutions is in line with an international attempt to facilitate people to live well with dementia, which was one of the main themes of the first international WHO Ministerial Conference on Global Action against Dementia held in 2015. The conference stressed that it is essential to empower people with dementia to participate in society as much as possible.[33] Any effort to empower people with dementia assumes that people have abilities to cope with deficiencies caused by their disease. This is also one of the underlying assumptions of the new definition of health "as the ability to adapt and to self-manage."[34p.2] One dimension within this definition is social health, which is described as a "dynamic balance between opportunities and limitations, shifting through life and affected by external conditions such as social and environmental challenges."[34p.2] This underpins the importance of detecting practical problems that people with dementia and their informal caregivers experience, which threaten this balance in daily life, and finding suitable solutions to recover the balance between opportunities and limitations.

Considerations and limitations

First, we included mainly professionals, and we conducted the member check with a selective sample of professionals. However, this was a conscious choice, because professionals with a coordinating function (such as home care nurses and case managers) in community-based dementia care were expected to be a good and reliable source of information about frequently occurring practical problems in daily life. They have experienced many transitions of people with dementia from the home to a nursing home, whereas people with dementia and informal caregivers can only report about their own case. We deliberately included a small group of informal caregivers and patient representatives to validate whether the problems described by them differ considerably from those put forward by the professionals; as this was not the case, we decided to include only this limited number. People with dementia were not included in this study those

who had experienced problems threatening their ability to live at home are expected to be in an advanced stage of the disease, in which they could not meaningfully participate in such an interview. Second, the focus of this study was to explore the most important practical problems in daily life by using sticky notes to gather information. This, on the one hand, ensured that every participant got an equal chance to share his/her view during the interview. On the other hand, it might have limited the richness of descriptions of the practical problems because people were forced to write down their ideas in a few words. However, during the interviews, the moderators tried to stimulate the participants to express their opinions in more detail by providing examples where possible. Finally, the participants were asked to indicate what were, according to them, the most important problems preventing people with dementia from living at home. What is seen as important may be a rather subjective interpretation. However, since certain problems were described consistently throughout the focus groups, it seems that those problems occurred frequently and therefore were regarded as important barriers for living at home. Nevertheless, to validate whether those problems can be generalized to a larger population, a longitudinal cohort study is recommended.

CONCLUSION

To facilitate aging in place and/or delay institutionalization of people with dementia, nurses in community-based dementia care should focus on detecting problems in the domains of decreased self-reliance, safety-related problems, and informal care/social network-related problems . Moreover, they should be able to advise people with dementia and their informal caregivers on possible solutions to deal with the daily struggles they encounter within these three domains

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3

Chapter 4

Development and Usability of a Decision Support App for Nurses to Facilitate Aging in Place of People with Dementia

ABSTRACT

Aim: The aim of this study was to develop a decision support tool for nurses to facilitate aging in place of people with dementia and to test its usability.

Background: Nurses play an important role in detecting practical problems preventing persons with dementia (PwD) from aging in place and advising them on possible solutions. These are complex and challenging tasks for nurses.

Methods: A mixed methods study was conducted. The content development of the App comprised a literature and internet search, and individual and group interviews with professionals (n=8) and researchers (n=5). The technical development was an iterative process in which usability was tested by the project team (n=4), experts (n=6), and end-users (n=9), using heuristic evaluation, a think-aloud approach, and a questionnaire (PSSUQ).

Results: The App contains a structured problem assessment for three problem domains—self-reliance, safety, and informal care—based on validated questionnaires and self-formulated questions. The problem assessment is linked to an overview of possible solutions for the problems detected. Three prototypes have been developed. The users of the third prototype were overall satisfied with the App as they scored on average 1.7 on the PSSUQ (range 1-7 and lower scores indicating higher satisfaction).

Conclusions: A user-friendly prototype of the decision support App is now available. Users indicated to be very willing to use to App in daily practice. However, besides further technical development, implementation of the App into practice requires evidence supporting its efficacy, feasibility and effectiveness.

INTRODUCTION

The incidence and prevalence of dementia worldwide is rapidly increasing as a result of the aging population.[1] Currently, about 270,000 persons with dementia (PwD) live in the Netherlands, of whom around 70% are living at home supported by family members and professional care providers.[2] During the course of their disease, PwD become increasingly dependent on support from their network and over time often become susceptible to nursing home admission.[3,4] However, PwD often prefer to continue to live a normal life in their own home for as long as possible.[5] In many Western countries, facilitating aging in place and delaying or even preventing nursing home admission is a common policy aim.[6] This is also the case in the Netherlands where, since long-term care reform in 2015, only people who need 24-hour supervision are eligible for residential care.[7]

Despite both the wishes of the older persons themselves and policies focusing on aging in place, living at home can become extremely difficult for PwD. Dementia is characterized by ongoing cognitive and functional decline as well as behavioral changes, causing increased problems in daily functioning and dependency.[8] As the dementia process proceeds, people often experience problems in performing instrumental activities of daily living (IADL) (e.g. handling finances or preparing hot drinks)[9] or more basic activities of daily living (ADL) (e.g. going to the toilet or eating).[10] A recent study of practical problems preventing PwD from living at home has shown that problems in three particular domains seem to be the most striking. These domains are decreased self-reliance (e.g. inability to conduct ADL activities or to plan and structure a day), safety-related problems (e.g. improper use of electronic devices, wandering, or fall injuries), and informal care/network-related problems (e.g. high burden or absence of informal caregivers).[11]

To facilitate aging in place of PwD the focus should be on the early detection of practical problems and the introduction of possible solutions. Various technological solutions (e.g. lifestyle monitoring, screen-to-screen care, GPS systems, and internet-based interventions) as well as social solutions (e.g. respite care facilities, day care at green-care farms, and case management) to support PwD and their informal caregivers are currently available.[12-15] Nevertheless, PwD and their informal caregivers might not be aware of all these options.[16,17]

Professionals in community-based dementia care play an important role in assessing practical problems and searching for possible care and treatment options for PwD and their caregiver(s) in order to deal with the problems that PwD experience in daily life [17]. In the Netherlands, district nurses and case managers often fulfill this coaching and coordinating role.[8,18] Professionals are expected to have insight into the needs, problems, and preferences of their clients and their informal caregivers, which may change over time. They should be able to advise them continually on possible solutions (e.g. professional care options, assistive technology, information sources, or informal caregiver support) to

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deal with the practical problems identified and to develop an individual action and intervention plan to facilitate aging in place.[19,20] District nurses and case managers are thus faced with complex diagnostic and advisory tasks, as these professionals need to have detailed insight into the constantly changing individual situation of a client and be aware of possible and evolving solutions.

There are various tools (e.g. questionnaires, checklists, and assessment forms) that professionals can use to gain insight into the different aspects of problems that PwD and their informal caregivers might experience. In the Dutch guidelines for community-based dementia care it is stated that individual need for care should be assessed according to the 'state of the art'.[20] However, the guidelines provide freedom for professionals to choose between various tools. From research it is known that besides the explicit use of tools, nurses also rely on their intuition and experience when making judgments and decisions.[21] Consequently, problem assessment and advice on possible solutions to these problems may depend on the knowledge and experience of the individual professional.

A decision support tool that combines a structured problem assessment with an overview of possible solutions could assist case managers and district nurses in their coaching and coordinating role. In these times of electronic client files and the use of tablet-computers by nurses and case managers, a computerized decision support tool for these professionals could be easily integrated into their work process. Computerized decision support for nurses is defined broadly by Dunn Lopez, et al. [22,p.441] as "providing clinicians (nurses) with computer-generated clinical knowledge and patient-related information which is intelligently filtered and presented at appropriate times to enhance patient care."

As facilitating aging in place is the central aim of community-based dementia care in the Netherlands, a decision support tool for district nurses and case managers should focus on the three most important practical problems preventing PwD from living at home, as described above (decreased self-reliance, safety-related problems, and informal care/network-related problems), and provide solutions to these problems. To develop a successful tool that will be used in daily practice, it is essential to involve end-users from the start of the process to make sure that the tool is adapted to their needs.[23] Therefore, a stepwise, user-centered development process was considered the most appropriate method for designing a decision support tool for professionals with a coaching and coordinating role in community-based dementia care.

The aim of this study was to develop a decision support tool for district nurses and case managers to facilitate aging in place of people with dementia and to test its usability. The tool aims to support the process of problem assessment and provide solutions for problems within the domains of decreased self-reliance, safety-related problems, and informal care/social network-related problems.

MATERIALS AND METHODS

A mixed-methods study was conducted to develop, in close collaboration with potential end-users (district nurses and case managers), a decision support tool in the form of an application (App) to be installed on a tablet PC. Figure 1 shows that the stepwise, user-centered development process was divided into two phases: content development and technical development. For the content development a literature and internet search, and individual and group interviews, were conducted. The technical development took the form of an iterative process of prototype development and usability testing using a think-aloud approach, heuristic evaluation, and a questionnaire to assess level of usability.

Research setting and subjects

The study was conducted in the region of Limburg in the south of the Netherlands. Participants were recruited from four, long-term care organizations that provide home care and participate in the Living-Lab in Ageing and Long-Term Care, South Limburg[24], the Centre of Excellence for Innovative Care and Technology [25], or the regional care network for dementia care.[26]

The tool was developed for professionals with a coordinating and coaching function in community-based dementia care (e.g. case managers and district nurses). In the Netherlands a case management program has been introduced into community-based dementia care over the past decades.[27] Case management is defined as "a collaborative process which: assesses, plans, implements, co-ordinates, monitors and evaluates the options and services required to meet an individual's health, social care, educational and employment needs, using communication and available resources to promote quality cost effective outcomes".[28] District nursing can be described as follows: "Home nursing care (*wijkverpleging*) is provided by district nurses (*wijkverpleegkundigen*). District nurses assess the needs of their clients and coordinate the care between client, informal carers, GPs, other healthcare professionals and social care professionals involved in the care for the client. They provide nursing care and personal care, such as dressing and bathing".[29]

We purposely selected three groups of participants for the content and technical development of the App. These groups were: first, experienced professionals (district nurses or case managers) working in community-based care, as potential end-users; second, researchers with particular knowledge in the field of gerontology or assistive technology; and third, experts in the field of application development in health care. Table 1 provides an overview of the distribution of participants in both development phases.

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Development process of decision support app

The app focusses on three problem domains based on the results of a prior study:

- Self-reliance
- Safety-related problems
- Informal care/network-related problems

Content development

1. Problem assessment part

Searching and selecting assessment tools and development of additional questions to detect problems within the three domains.
Methods used:
Literature and internet search, prior focus group study, interviews (individual and group)

2. Overview of solutions part

Searching and selecting possible solutions within three domains

Methods used:
Internet search and interviews

3. Combining problem assessment part with the overview of possible solutions part into an overall flowchart

Technical development

Paper-based prototype

Usability evaluation
by end-users: interviews

First tablet-based prototype

Usability evaluation
by project team: check for major technical or content related problems

Second tablet-based prototype

Usability evaluation
by experts: heuristic evaluation

Third tablet-based prototype

Usability evaluation
by end-users: think aloud method and questionnaire

Eventually further tablet-based prototypes and usability testing
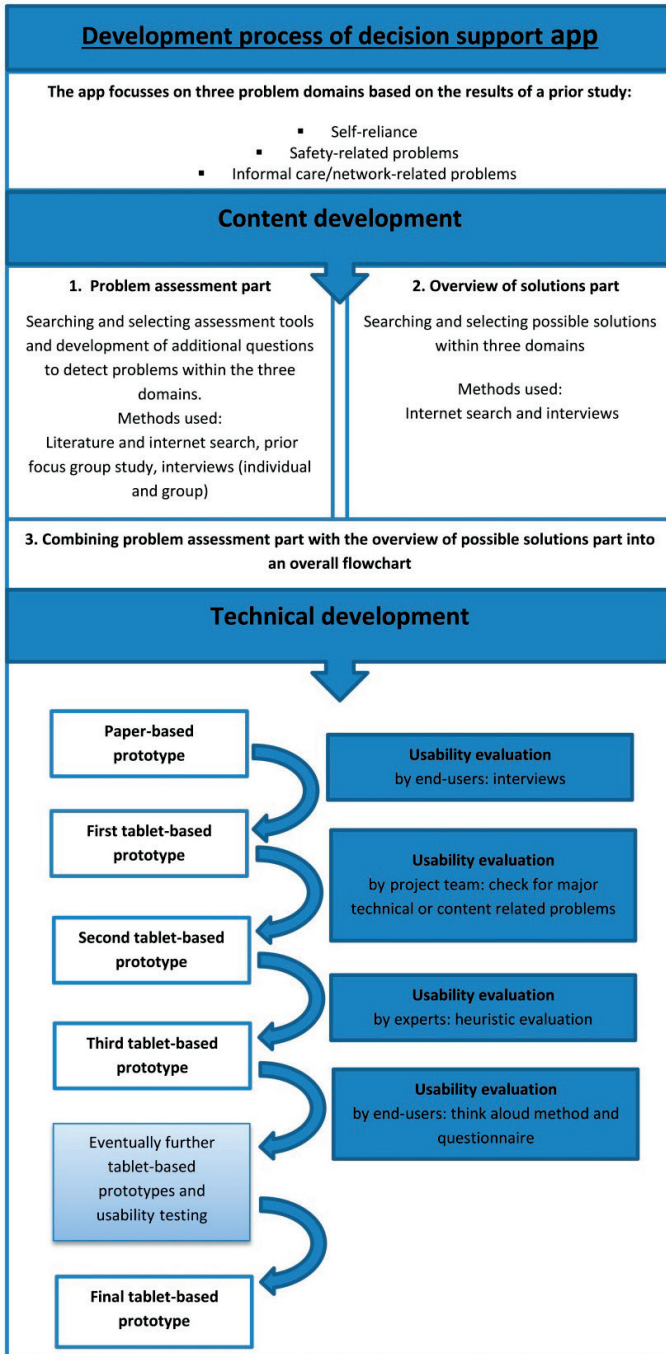
Final tablet-based prototype

Figure 1: Development process of the decision support App

Table 1 Overview of participants in the development process

Phase	Type participants	N
1. Content development	Case managers	6
	District nurses	2
	Researchers	5
2. Technical development and usability evaluation	Case managers	5
	District nurses	4
	App development experts	5
	Project team (researchers)	4

Data collection and procedure

Content development

The content development consisted of three steps. In the first, the problem assessment part of the tool was developed. To select suitable and widely used assessment tools in the domains of decreased self-reliance, safety-related problems, and informal care related problems we asked professionals working in community-based dementia care (n=16), during focus group interviews in a prior study[11], to give an overview of the tools they use in daily practice to assess the problems faced by their clients that could prevent them from living at home. In addition, an internet search to identify current guidelines for community-based dementia care in the Netherlands was conducted, in order to ascertain whether those guidelines gave suggestions for assessment tools. A literature search was also conducted, in PubMed, Google Scholar and Google, to identify available (evidence-based) tools for problem assessment in at least one of the three problem domains. The search terms used were related to the problem domains of self-reliance (ADL, IADL, daily activities, day structure, day/night rhythm), safety (safety, risk assessment), and informal care/network (informal care, network, burden). From the resulting overview of possible instruments, the project team made an initial selection of instruments to be included in the App. For this selection, the following criteria for the tool were kept in mind: it is currently used by professionals; it is feasible to use in daily practice (e.g. with regard to time needed to complete the assessment, availability of the tool in the Dutch language); and, it has been validated. Additional questions were developed by the project team for problems that had been identified as being important in preventing PwD from living at home in a prior study[11], but were not covered by existing tools. The project team also developed questions to gain deeper insight into the problems and to assess whether new solutions were needed or suitable solutions were already in place. To develop an algorithm for the App, the questionnaires and self-developed questions were integrated into flowcharts describing the process from problem assessment to problem statement. The initial flowcharts were evaluated in two group interviews (first n=5, second n=2) and one individual interview (n=1) with case managers and district nurses. The flowcharts were then adapted according to the feedback from the interviews. The updated versions of the flowcharts were then evaluated in individual interviews with district nurses and

case managers (n=3). In addition, the flowcharts were discussed with researchers who are experts in gerontology (n=3). The aim of these interviews was to evaluate the selected questionnaires and to assess the face-validity of the newly developed questions. Based on the feedback of professionals and researchers, the flowcharts were again adapted.

In the second step, an overview was compiled of possible technological and non-technological solutions for each problem that could be detected through the problem assessment in the domains of decreased self-reliance, safety-related problems, and informal care and network-related problems. For this purpose, an internet search was conducted on guidelines for community-based dementia care in the Netherlands, national and international databases for assistive technology, and dementia-related websites of, e.g. national patient organizations, national research institutes, and centers of excellence). Moreover, two experts in assistive technology and one expert in dementia interventions were interviewed.

Finally, in the third step both parts, the problem assessment and the overview of possible solutions, were combined in one final flowchart. This final flowchart served as the basis for the development of a paper-based prototype of the App.

Technical development and usability evaluation

To eliminate major usability issues from the start, the technical development started with a paper-based prototype. This graphical representation of the actual App was evaluated in interviews with district nurses and case managers (n=6) on its usability in terms of intuitive use, structure, and layout. The feedback provided by the participants was used to develop the first prototype of the App. Subsequent prototypes of the actual App were developed iteratively in conjunction with an engineering team. Each prototype was evaluated with regard to its usability. The feedback from each usability evaluation served as input for the improvement of the next prototype.

The first prototype was evaluated by researchers from the project team (n=4). They checked whether the flowcharts were correctly translated into the digital version of the App and whether the App was technically stable.

The second prototype was evaluated by experts in the field of App development in health care (n=5), using heuristic evaluation based on the 10 Usability Heuristics of Nielsen.[30] Individual interviews with the experts were organized. First, the experts got a few minutes to explore the App on their own. Then, they were asked to conduct thirteen predefined tasks with the App (e.g. logging on, conducting a problem assessment in one of the three domains, consulting the overview of possible solutions). While completing these tasks they were asked to provide suggestions for further improving the App's usability. Their comments were summarized on screen shots. After completion of the tasks the experts were asked to fill in a questionnaire in which they were requested to judge the App against the 10 Usability Heuristics of Nielsen[30] (e.g. visibility of system status, language

use, error prevention, esthetic, and minimalistic design), with scores ranging from 1 (bad) to 7 (good). For each item mean scores were calculated in order to detect major usability flaws. A mean score of 4 or lower was regarded as a violation of the heuristic[31]. In addition, the participants were asked to rate the importance of each individual principle on a scale of 1 (not important) to 7 (very important). Finally, the researcher who conducted the interviews discussed the feedback and the scores from the heuristic evaluation with the experts.

The third prototype was evaluated by potential end-users (case managers and district nurses) (n=9), using a think-aloud approach[23] and a Dutch version of the Post-Study System Usability Questionnaire (PSSUQ). The PSSUQ is a 19-item questionnaire rated on a 7-point Likert scale (answers ranging from strongly disagree to strongly agree), which is used to assess users' perceived satisfaction with computer systems.[31,32] The PSSUQ consists of one overall satisfaction scale (OVERALL: Items 1 through 19) and three subscales: system usefulness (SYSUSE: Items 1 through 8), information quality (INFOQUAL: Items 9 through 15), and interface quality (INTERQUAL: Items 16 through 18) [32]. For all scales the rating range was between 1 and 7; the lower the score, the higher the satisfaction. After the usability evaluation of the third prototype, the feedback was adopted. On the basis of positive feedback from the users, the project team decided that no further prototypes were needed and that the efficacy of the latest version could be tested in a next phase.

For all participants data on age, gender, profession and educational level were gathered.

Data analysis

Content development

The feedback provided during the interviews was summarized and clustered by topic, e.g. self-reliance, safety, informal care, overall feedback. The feedback was then discussed by the project team in order to evaluate whether the suggested improvements required immediate adoption in order to achieve the actual goal: i.e. to develop an App, focusing on three major problem domains that could be tested in a laboratory setting before possible implementation in practice. Hence, the feedback was categorized according to whether it should be adopted immediately, kept for possible adoption at a later stage, or not adopted at all.

Technical development

Feedback regarding the usability of the different prototypes was written on screen shots. At the end of the process, the feedback on each screen was summarized and subsequently discussed by the project team. Again, the team evaluated whether the improvements required immediate adoption in order to achieve the goal of developing an App that could be tested in a laboratory setting. Another aspect the team considered was

whether the suggested technical adjustments were possible within the financial con-straints of the project. On this basis the feedback was then categorized according to whether it should be adopted immediately, kept for possible adaptations at a later stage, or not adopted at all.

The quantitative data from the heuristic evaluation and the PSSUQ were analyzed through descriptive analyses (means and standard deviations) using SPSS software (IBM SPSS statistics 23).

Ethical considerations

No ethics approval was needed for this study according to Dutch Law.[33] The participation was strictly voluntary for all participants. Furthermore, the CEO's of the participating or-ganizations gave consent to recruit employees form their organizations.

RESULTS

Content development

Overall, eight different professionals working in community-based dementia care either as case managers or district nurses participated in the content development phase. The majority were female (n=7). The mean age of participants was 41 years, ranging from 23 and 53 years. In addition, five different researchers participated in interviews, three with a background in gerontology and two in assistive technology. The researchers' mean age was 45, ranging from 32 and 58 years. The majority were female (n=4), and all had at least a Master's (n=2) or PhD (n=3) degree.

Assessment tools

Different tools were identified that could be used by professionals to assess specific ele-ments of the situation of people with dementia and their informal caregivers. Appendix 1 provides an overview of the identified tool in the three problem domains decreased self-reliance, safety-related problems and informal care/ network-related problems.

Content of the decision support tool

The final App consists of two parts: a stepwise problem assessment and an overview of possible solutions in three problem domains—decreased self-reliance, safety-related problems, and informal care/network-related problems. Both parts are interrelated in the sense that the App provides tailored suggestions for possible solutions to the problems detected during assessment.
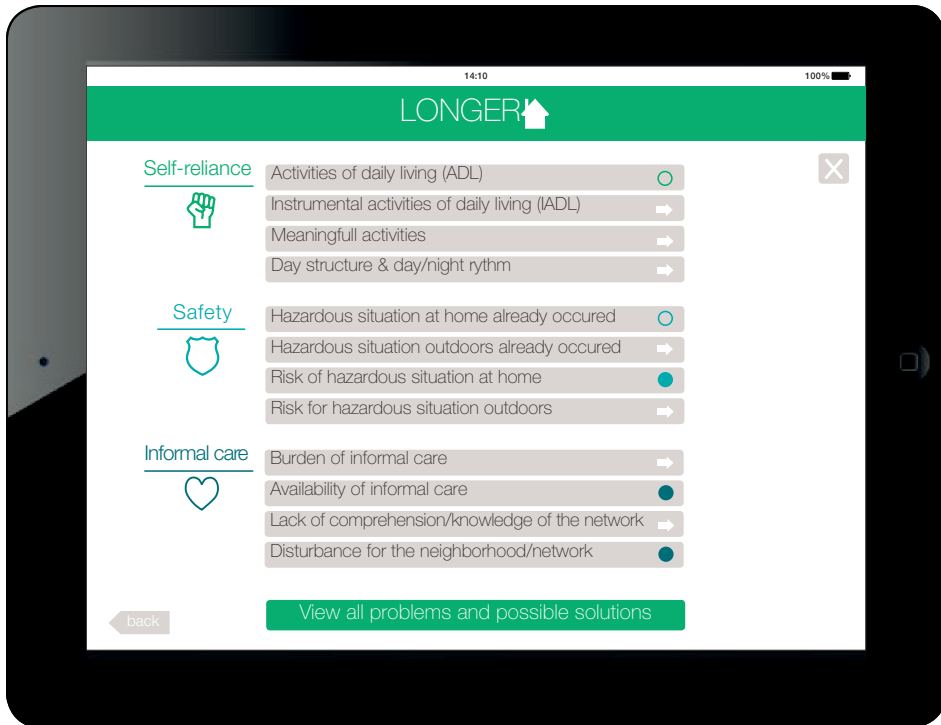
Figure 2 The Longer at home App

Based on the results of a prior study[11] and the feedback provided by participants in the current study, all three problem domains were dived into four subcategories. Decreased self-reliance was subdivided into: Activities of Daily Living (ADL), Instrumental Activities of Daily Living (IADL), meaningful activities (leisure time and work), and day structure & day/night rhythm. Safety-related problems were subdivided into: hazardous situations at home that have already occurred, hazardous situations outdoors that have already occurred, the risk of hazardous situations at home, and the risk of hazardous situations outdoors. Informal care/network-related problems were subdivided into: burden of informal care, availability of informal care, lack of comprehension/knowledge of the network, and disruption of the neighborhood and/or the person's network.
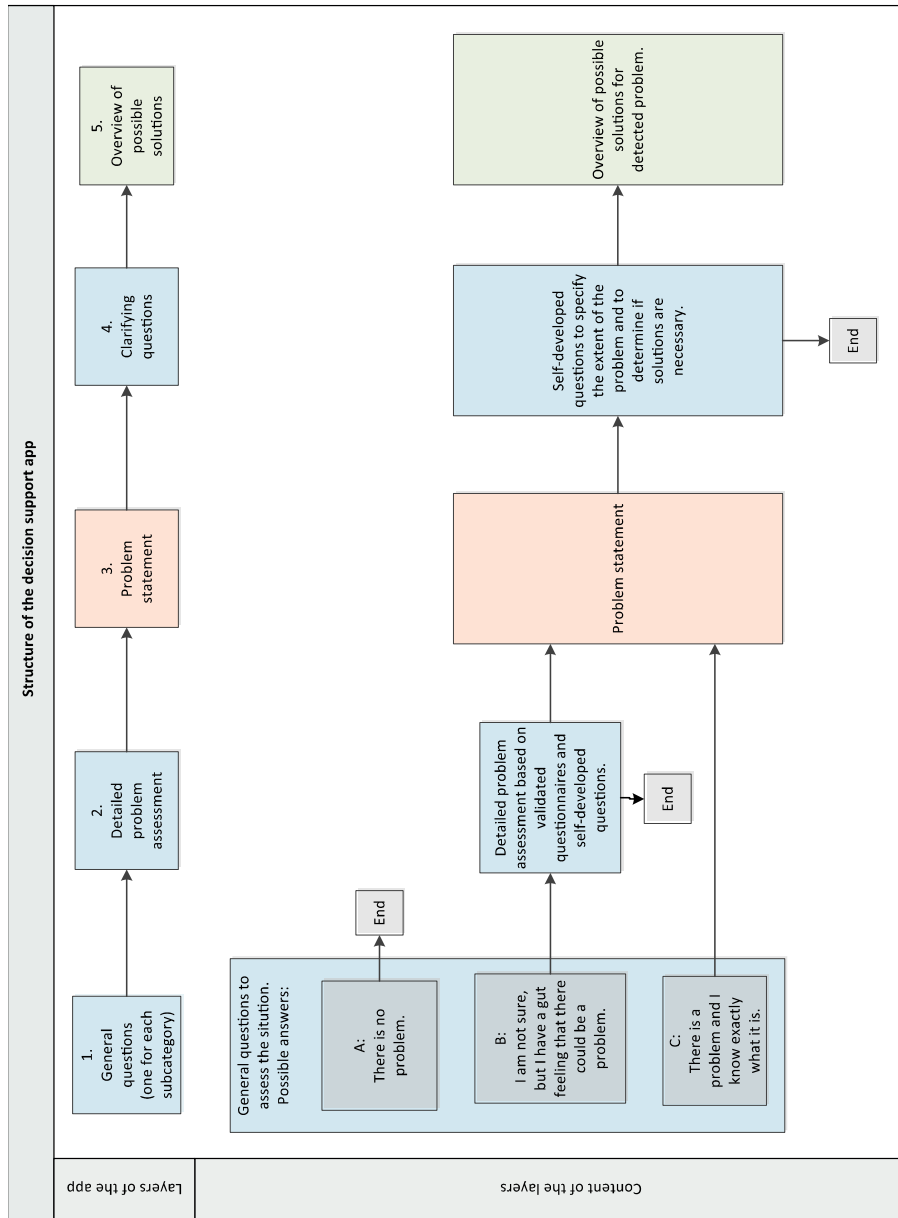
Figure 3 Layers of the App

The final App contains five different layers (figure 3): three different layers of questions, a problem statement, and an overview of possible solutions. The problem assessment for the three domains contains three layers of questions. The first layer contains g*eneral questions*, one for each of the four subcategories to assess whether there is a problem in

that subcategory. For example, for the subcategory activities of daily living (ADL) the general question is as follows: "Is the person with dementia able to conduct all basic ADL activities with the support he/she receives at the moment?" A sample question for the subcategory caregiver burden is: "Are there any signs that the caregiver perceives a high burden of care responsibility?" The general questions have three possible answers: A: There is no problem; B: I'm not sure, but I have a gut feeling that there could be a problem; and, C: There is a problem and I know exactly what it is. If option A is chosen, the problem assessment for that specific category ends and one may decide to assess another category. If option B is chosen, the user is directed to the second layer of questions. This layer contains questions to assess the situation in more detail *(questions to conduct a detailed problem assessment).* These questions are posed in case the 'I'm not sure' option was chosen for one or more of the general questions, in order to guide the professional through a structured problem assessment. The detailed problem assessment was partly based on validated questionnaires. Based on the criteria of current use in practice, feasibility and psychometric properties the following tools were selected: the Dutch version of the Barthel index for ADL[34]; a Dutch translation of the Lawton and Brody IADL questionnaire for IADL[35]; the Dutch version of the Self-perceived Pressure from Informal Care (SPPIC) to assess caregiver burden[36]; a translation of the items of the Home Safety Inventory to assess hazardous situations[37] and partly on self-formulated questions in case no validated questionnaires were available. Based on the results of the detailed problem assessment, a problem statement is generated automatically including an overview of the detected problems. In case no problem is detected, the assessment of the subcategory ends. If the user chooses option C in the first layer, indicating that they know exactly what the problem(s) is or are, they are immediately directed to the problem statement. In this case, the professional defines the problem based on prior knowledge by selecting a problem from a pre-defined list. The problem statement is followed by the third layer of questions. This layer contains questions intended to gain more insight into the problems (c*larifying questions):* These questions can be used to assess whether possible problems are already being sufficiently tackled or if new solutions are needed. For example, when a problem with a basic ADL activity such as going to the toilet is detected, a clarifying question would be: "Does the inability to go to the toilet hinder the daily functioning of the person?" If the answer is yes, the next question is "Does the person receive any support with toileting or is there any other compensatory solution in use?" If the answer is yes, the last question asks: "Is/are the delivered care or support/solutions sufficient?" If the answer is no, the user will be guided to an overview of possible solutions to this specific problem. Finally, the problem assessment results in a list of detected problems in the three problem domains. All the problems are linked to an overview of possible solutions to deal with them. The solutions are based on guidelines for community-based dementia care in the Netherlands, national and international databases for assistive technology, and dementia-related websites of, e.g. national patient organizations, national research institutes, centers of excellence, and information provided by researchers as

experts in the field. The solutions vary between relatively simple suggestions/tips for information (e.g. information websites, guidelines) and supportive aids and devices (e.g. drug dispensers with a reminder function, walking frames), to more complex, technological solutions, such as GPS devices, lifestyle monitoring systems, or screen-to-screen care. The overview contains a broad spectrum of solutions and it is up to the user to decide which might be suitable and might then be discussed with, and/or recommended to, the client, or his/her family or social network.

Technical development and usability evaluation

Paper-based prototype

The paper-based prototype of the App was evaluated by six potential end-users (five case managers, one district nurse). All were women, with a mean age of 39 years (range 23 and 52 years). Overall, the participants were positive about the intuitive use, readability, and layout of the paper-based prototype. They appreciated the clear and minimalistic design, and indicated that they were keen to use the App in daily practice. Examples of suggestions for improvement, which were subsequently adopted, included: 1.) adding an overview page showing all three problem domains and sub-themes at a glance, including an opportunity to request more information on the exact content of the problem domains; 2.) adding the opportunity to temporarily skip questions when answers are not immediately available; 3.) adding more information on individual items and sum scores of validated questionnaires, to be better able to interpret the results of the assessment; and, 4.) changing the layout of the App from portrait to landscape, as the professionals were used to using a tablet PC in landscape format.

Evaluation by the project team of the first tablet-based prototype of the App

The first prototype is an application that runs on an iPad2 with internet connection. Four project team members evaluated the first tablet-based prototype of the App to detect any major usability issues that needed to be eliminated immediately. This evaluation led to the detection of errors in the sequence of questions, missing functions (e.g. the ability to search for more information, links to external websites), and the technical stability of the App. All identified problems were forwarded to the engineering team, who resolved the problems where possible.

Evaluation by experts of the second tablet-based prototype of the App

Five experts in the field of App development in health care participated in a heuristic evaluation. Two experts were men and three women, with a mean age of 33 years (ranging from 28 to 46 years). The experts had different educational backgrounds (e.g. health sciences, occupational therapy, informatics, and psychology). The evaluation of Nielsen's

heuristics [30] indicated no major flaws (defined as scores of 4 or lower) in the system, as all items scored on average 4.8 or higher (Table 2). The experts indicated that they would have liked information showing their progress during the problem assessment process. This issue was resolved by adding icons to the main screen that visually depicted the status of the problem assessment. With regard to the flexibility and efficiency of using the App, the experts said that the App lacked a page giving an overview of all the problems and solutions. This option was added to the third and final prototype.

Table 2: Results of the heuristic evaluation

Heuristic principles	Mean scores (SD) Rating (range 1-7); 1 (bad) – 7 (good)	Mean scores (SD) Importance of the principle (range 1-7) 1(not important) – 7 (very important)
1. Visibility of system status	4.8 (1.6) (N=5)	5.2 (0.8) (N=5)
2. Match between system and the real world	6.0 (1.0) (N=5)	6.6 (0.9) (N=5)
3. User control and freedom	5.6 (1.7) (N=5)	6.2 (0.4) (N=5)
4. Consistency and standards	6.0 (1.2) (N=5)	6.4 (0.5) (N=5)
5. Error prevention	6.7 (0.6) (N=3[a])	6.4 (0.5) (N=5)
6. Recognition rather than recall	6.4 (0.9) (N=5)	6.0 (1.4) (N=5)
7. Flexibility and efficiency of use	5.4 (1.5) (N=5)	5.8 (0.8) (N=5)
8. Aesthetic and minimalist design	6.0 (1.0) (N=5)	5.4 (0.5) (N=5)
9. Help users recognize, diagnose, and recover from errors	6.0 (0.0) (N=2[a])	6.4 (0.5) (N=5)
10. Help and documentation	5.8 (1.0) (N=4*)	5.2 (1.3) (N=5)

[a]missings: participants scored not applicable

Evaluation by end-users of the third tablet-based prototype of the App

Nine potential end-users participated in the evaluation sessions (five case managers and four district nurses). All the participants were women, mean age 41 years (ranging from 23 to 60 years). The results of the PSSUQ showed that the participants were satisfied with the usability of the App (Table 3). Problems that were detected mainly related to the technical stability of the App, which was subsequently adapted in the final version.

Table 3. Results of the Post Study System Usability Questionnaire

Scores on PSSUQ	Mean scores (SD); Range 1-7 Lower scores indicate better usability
Overall satisfaction	1.7 (0.5)
System Usefulness	1.8 (0.7)
Information quality	1.6 (0.4)
Interface quality	1.9 (0.9)

DISCUSSION

This mixed-methods study resulted in the development of a usable decision support App. The App contains both a structured problem assessment and an overview of possible solutions for problems in the domains of decreased self-reliance, safety-related problems, and informal care/network-related problems. The problem assessment contains three layers of questions, culminating in a problem statement that is linked to an overview of possible solutions for each problem detected. The usability of all the prototypes was evaluated positively, with the feedback from each round serving as input for the development of the next prototype.

A strength of this study is that throughout the development process the principles of user-centered design were respected.[38] The involvement of nurses and case managers in each phase of the development process should increase the chance of the decision support App's implementation in practice being successful, given that involvement of users in the development of an innovation is a facilitating factor for implementation.[39] Other facilitating factors for successful implementation of innovations are compatibility, which means that the innovation fits existing norms and values, and adaptably, which means that the innovation can be adapted to the needs of the target group.[39] By involving users in all phases of the development, it can be assumed that the final App is in line with the norms and values of nurses and case managers and is adapted to their needs. A review by Kawamoto, et al. [40] concluded that four features of decision support tools for professionals can increase the change of improvements in clinical practice. These are: integrating decision support in the workflow, providing both assessment and recommendations, providing support at the time when the decision is taken, and computer-based decision support. This decision support App for case managers and district nurses meets all these requirements. It has been developed in close collaboration with end-users, which means that it is adapted to their needs and fits into their workflow.[41] Professionals indicated that the tool could be used in various ways: for example, in direct contact with the client or informal caregiver in order to assess the situation or discuss possible solutions, or prior to a home visit for preparation purposes or afterwards as a checkup.

Limitations and challenges

To identify available tools for problem assessment in the three domains, decreased self-reliance, safety-related problems, and informal care and network-related problems, a literature search was conducted. It was beyond the scope of this study to conduct various systematic reviews over several databases with a comprehensive set of search terms and strict selection criteria. Consequently, there is a chance that not all available tools were screened. However, the App is designed to be sufficiently flexible that where new, more suitable tools are identified they can be integrated at a later stage.

With regard to the overview of possible solutions, while the App does not provide information about the scientific evidence behind the individual solutions it is based on clinical knowledge and expert opinion. However, information about the scientific underpinning of solutions might be valuable information for professionals who are expected to make evidence-based decisions. Adding information concerning the effectiveness and suitability of the interventions, and keeping the overview of possible solutions up to date could be the greatest challenge when it comes to implementing the App in practice. Further research would be needed to screen, evaluate, and summarize available (scientific) literature on possible solutions.

To evaluate the usability of the App, the Dutch version of the PSSUQ was used. No information on its psychometric properties is available as yet. However, the main goal was to detect usability flaws in order to further improve the App rather than to compare its scores with norms; the latter is also not recommended by the developers of the PSSUQ.[42]

Implications for practice and directions for further research

The App aims to help professionals to deal with complex diagnostic and advisory tasks. It may also increase their awareness of problems that prevent PwD from living at home and aims to support them in exploring possible solutions to those problems. However, in its current version the App is only to be used for research purposes. To actually implement the App in daily practice, additional development steps need to be taken. For example, to ensure the security of client data the App needs to be adapted according to current guidelines. Moreover, the overview of possible solutions should be updated constantly as new solutions become available. An example of an adaptation that was considered desirable by the participating professionals was the option of extraction of data from the App and linkage to the electronic patient file. Moreover, participants felt that it would be valuable if the App contained additional to general solutions also local solutions available in the specific area in which they worked. Due to available time and financial constraints it was not possible to carry out all the suggested improvements of the App immediately.

Besides further technical development, implementation of the App into practice also requires evidence supporting its efficacy, feasibility and effectiveness.

CONCLUSIONS

A usable decision support App for nurses and case managers working in community-based dementia care, which guides the user though a stepwise problem assessment and provides an overview of possible solutions for the problems detected, is available now. However, additional development and research is needed before actual implementation in practice should be considered.

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APPENDIX 1: OVERVIEW OF ASSESSMENT TOOLS

Decreased self-reliance	Safety-related problems	Informal care/network-related problems
Barthel index (Dutch translation) [1]	Home Safety Inventory [2]	Self-perceived Pressure from Informal Care (SPPIC) [3]
Katz ADL [4]	Safety Assessment Scale for people with dementia living at home [5]	Caregiver Reaction Assessment (CRA) [6]
GARS [7]	HEAP Home Environmental Assessment Protocol [8]	Caregiver Strain index (CSI) [9]
Lawton and Brody IADL [10]	Cougar Home Safety Assessment [11]	Zarit Burden Scale [12]
Self-Sufficiency Matrix (SSM-D) [13]	Home Falls and Accidents Screening tool [14]	BSFC (Burden Scale for Family Caregivers) [15].
A Dutch instrument called "ZelfredzaamheidRadar" [16]	Safety Assessment of Function and the Environment for Rehabilitation (SAFER) tool [17]	
A Dutch instrument called "Zelfredzaamheidsmeter" [18]	Dutch checklists, developed in part by the organizations for which the participants worked.	
Elements of the EDOMAH assessment [19] (a community-based occupational therapy program)		
Self-developed checklists of the organizations for which the participants worked		

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Chapter 5

Evaluation of a Decision Support App for Nurses and Case Managers to Facilitate Aging in Place of People with Dementia. A Randomized Controlled Laboratory Experiment

ABSTRACT

Detecting practical problems of persons with dementia (PwD) experience at home, and advising them on solutions to facilitate aging in place are complex and challenging tasks for nurses and case managers. In this two group randomized, controlled laboratory experiment, the efficacy of a decision support application (App) aiming to increase nurses' and case managers' confidence in clinical judgment and decision-making was tested. The participants (N=67) assessed a case of a PwD within the problem domains: self-reliance, safety and informal care, and provided suggestions for possible solutions. Participants used either their regular procedure with (intervention group) or without the App (control group) to conduct these tasks. No statistically significant difference was found on the primary outcome measure, the overall level of confidence. However, nurses and case managers highly recommended use of the App in practice. To explain these results, more research on the potential added value of the App is needed.

INTRODUCTION

Worldwide, about 46.8 million people live with dementia and this number is expected to rapidly increase in the near future.1 People with dementia (PwD) often wish to live at home as long as possible2,3; however, they are especially susceptible to nursing home admission because of their increasing care and support needs.4,5 Facilitating aging in place and preventing nursing home admission of PwD is a common policy aim of many western countries nowadays, including the Netherlands.2,6,7 Hence, the complexity of community-based dementia care is increasing as PwD live longer in the community. A variety of solutions, such as different care and welfare services, and assistive technology are available with new interventions constantly evolving to support aging in place of PwD.8,9 However, finding the best suitable solution can be extremely challenging for PwD and their informal caregivers as they might not be aware of all possibilities.10,11 In addition, recent research has shown that informal caregivers of PwD have a substantial need for additional professional support and advice, e.g. on how to deal with behavioral problems or how to cope with emotional problems.11

In the Netherlands, professionals with a coordinating role in community-based dementia care support PwD to live at home as long as possible.[12] This role is often fulfilled by district nurses and case managers (of whom the most have a nursing background). It is their task to detect important practical problems PwD and their informal caregiver's experience. In a previous study, it was found that practical problems within the domains of decreased self-reliance, safety-related problems and informal care and network-related problems are the most threating ones with regard to the ability of PwD to live at home.[13] Those problems may not always be easy to detect as PwD themselves, and sometimes also the informal caregiver, might not be aware of them. Examples are, informal caregivers who tried to keep up caregiving while they felt overburdened or PwD who lack awareness of their disease and therefore refuse support. Moreover, due to the progressive nature of the disease, the problems change over time and may become even more complex. In addition, nurses and case managers are expected to advise them on possible solutions to deal with these problems. These tasks require conscious clinical judgments about the expected consequences of the detected problems. Moreover, advice on possible solutions often results from complex decisions about the best suitable and available solution. To fulfill these diagnostic and advisory tasks, nurses and case managers need to have detailed insight into the living situation of the individual PwD, including their needs and enabling resources (e.g. informal support or financial resources) to fulfill these needs.[14] Moreover, they need to be up to date with regard to possible solutions and should be able to make decisions about the added value of possible suitable solutions for the individual PwD.

Judgments and decisions made by nurses are characterized by uncertainty because the information available is sometimes unclear or incomplete, and the outcomes that result

are often not directly predictable.[15] Hence, nurses can lack confidence as to whether they have detected all problems and advised suitable solutions. Especially nurses who are new in a coordinating role might feel less confident, because knowledge and experience are known as important factors influencing decision-making.[16] Research has shown that even when nurses have the same information they can make different judgments and decisions.[15] For PwD and informal caregivers, this would mean that the detection of certain problems, and advice on possible solutions, highly depends on the specific nurse they encounter. This variability is not desirable, as ideally it should not matter whether they encounter a recently graduated nurse with less experience or a highly experienced nurse working in community-based dementia care for years. From a theoretical perspective, this variation could be explained by the use of different (combinations of) reasoning strategies for clinical judgment and decision- making. Two reasoning strategies nurses might use are: first, a fast, intuitive, relatively automatic form of reasoning which is based on expertise, and second, is the slower rational deliberative type of reasoning. When nurses use a more intuition-based reasoning strategy instead of rational-analytic reasoning, without having the requisite expertise, it can cause variation in judgment and decisions. Moreover, in some situations nurses might not be aware of other decision options which remain beyond the scope their knowledge.[15] As new solutions are constantly developed, it is very difficult for nurses to continuously be up to date with regards to the latest developments. A possibility to reduce this variation is to support nurses in the usage of more rational and deliberative reasoning strategies by means of education, guidelines or computerized decision support,[15,17,18] and provide them easy access to recent information about possible solutions. Research has shown that computerized decision support systems may be valuable tools to support nurses to make judgments and decisions under uncertainty; however, not much high quality evidence is available yet supporting these tools.[15,17]

To the best of our knowledge, no decision support tool specifically for nurses and case managers in community-based dementia, guiding them through a problem assessment and providing them an overview of possible solutions, is currently available. Therefore, a decision support tool in the form of an application (App) on a tablet PC has been developed in a user-centered development process.[19] The App consists of two parts: first a stepwise problem assessment focusing on the detection of problems within the three most important problem domains, i.e. decreased self-reliance, safety-related problems and informal care and network-related problems.[13] The problem assessment is partly based on validated questionnaires such as the Barthel index[20] and the Self-perceived Pressure from Informal Care (SPPIC)[21] and partly based on self-developed questions. The second part contains an overview of possible solutions to deal with the detected problems, such as care and support services, information sources and assistive technology. This overview is based on information retrieved from e.g. clinical guidelines, databases for assistive technology and expert interviews. In a previous study one low-fidelity (paper-

based prototype) and three high-fidelity prototypes have been tested with regards its usability by end-users, experts and researchers. We used a combination of different methods including heuristic evaluation, a think-aloud method and a questionnaire to assess the overall satisfaction with the usage of the tool.[22] This led to the conclusion that the decision support App is usable tool which in a next step needs to be tested with regard to its efficacy in a laboratory experiment.

Aim

The aim of this study was to evaluate the efficacy, potential added value and usability of a decision support App for nurses and case managers with a coordinating role in community-based dementia care, with the intention to improve problem assessment and provision of advice on possible solutions to deal with problems which may prevent PwD from living at home.

To evaluate the efficacy of the decision support App, the following questions were formulated:

1. Does use of the decision support App increase the nurses' and case managers' confidence in the correct outcome of their problem assessment and their ability to provide good advice on possible solutions? (primary outcome measure)

2. Does use of the decision support App increase uniformity between nurses and case managers with regard to the detection of problems preventing people with dementia from living at home?

3. Do the nurses and case managers who use the decision support App in addition to their usual procedure advise more possible solutions than nurses and case managers who only use their usual procedure?

To evaluate the potential added value and the usability of the decision support App, the following questions were formulated:

4. Do nurses and case managers regard the App as being of added value and what is, according to them, the added value of the App compared to their usual procedure?

5. To what extent is the decision support App a usable tool according to nurses and case managers and what are suggestions and recommendations for further improvement of usability?

MATERIALS AND METHODS

Design

A two group, randomized, controlled laboratory experiment was conducted to evaluate the efficacy of the decision support App for nurses and case managers with a coordinating role in community-based dementia care. The allocation ratio was equal between both groups.

Participants

Eligibility criteria

R Professionals with a (future) coordinating role in community-based dementia care, including case managers, district nurses and nursing students being potential (prospective) users of the App, were eligible for participation. Dementia case managers and nurses were eligible if they were currently working in community-based care in the Netherlands. Nursing students were eligible when they were in their last two years of their bachelor studies. They were included as they might become a district nurse or case manager after graduation and, therefore, can represent the user group which is less experienced (the novices).

Recruitment and setting of data collection

Nurses and case managers were recruited via the network organizations Living Lab in Aging and Long-Term Care South Limburg,23 the Centre of Expertise on Innovative Care and Technology,24 local network organization for dementia case management25 and three other long-term care organizations which were not affiliated with one of the network organizations. The students were recruited via the Zuyd University of Applied Sciences. Recruitment took place via various channels (e.g. via contact persons of long-term care organizations/network organizations, lectures and email invitations).

With all nurses/case managers/students who were willing to participate in the study, an individual meeting of a maximum of two hours was scheduled with a researcher or student assistant, who conducted the data collection. The meetings took place in a meeting room either at the participants' workplace or at the university. The participants were asked to bring along all materials they usually use to conduct a problem assessment and to provide community-dwelling persons with dementia and their informal caregivers advice on possible solutions (e.g. own registration forms, questionnaires, tablet/laptop).

Intervention group

The intervention to be tested within this study was an App which was installed on an Apple iPad 2 (Figure 1). The App guides the user through a problem assessment, focusing on three problem domains: decreased self-reliance, safety-related problems and informal care and social network-related problems, which were found to be most challenging with regard to the ability to live at home.[13] The problem assessment results in an overview of problems (problem statement) which is linked to an overview of possible solutions to deal with the detected problems. In the 'overview of possible solutions' part, the App directs the user to external websites and documents where more information on certain solutions can be found. The participants in the intervention group were asked to conduct a problem assessment within three problem domains (self-reliance, safety and informal care/social network) and to write down their advice on possible solutions to deal with the detected problems for one specific case of a community-dwelling PwD. The participants needed to use the App for conducting a problem assessment and or the provision of advice for possible solutions. They could use it in addition or in place of their regular procedure for these activities. Besides the App, the users received a short user manual which outlined the goal of the App, its content, its relationship with their regular procedure and general advice on how to select suitable solutions.

Control group

Participants in the control group were asked to conduct a problem assessment within three problem domains (self-reliance, safety and informal care/social network) and to write down their advice on possible solutions to deal with the detected problems for one specific case of a community-dwelling PwD according to their usual procedure.

Randomization

A random allocation sequence was generated by the principal researcher (TTL) using a random numbers generator to determine the group and the case for participants 1–40. From 40 onwards, block randomization was used with a block size of four to make sure that the groups were equally allocated, even if the expected number of participants was not reached. After participants were recruited, and had indicated that they were willing to participate in the study, the principal researcher assigned them randomly to either the intervention or the control group and subsequently to either case A or B.
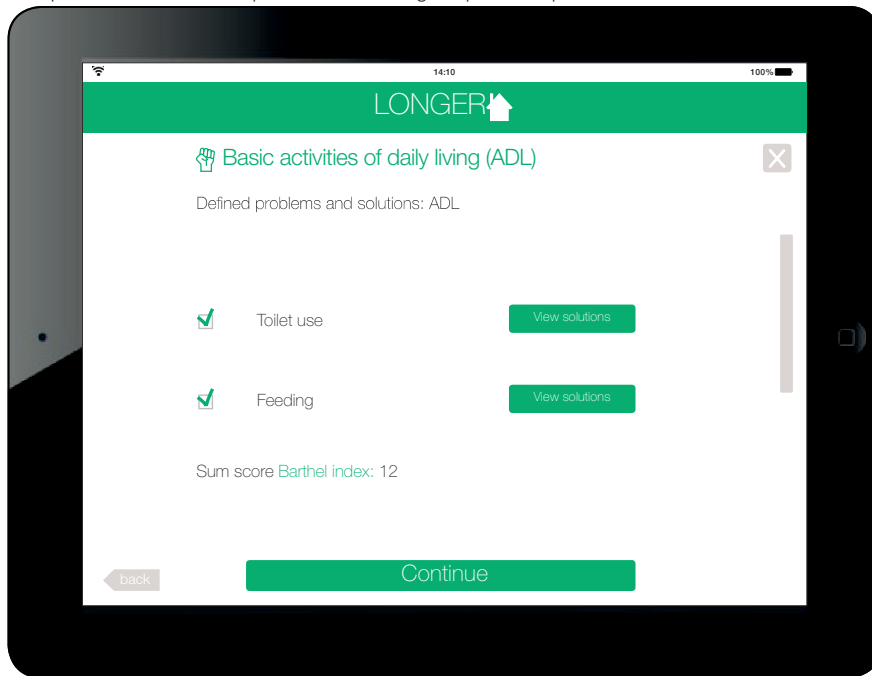
Overview page with three problem domains with each having four subdomains which could be assessed
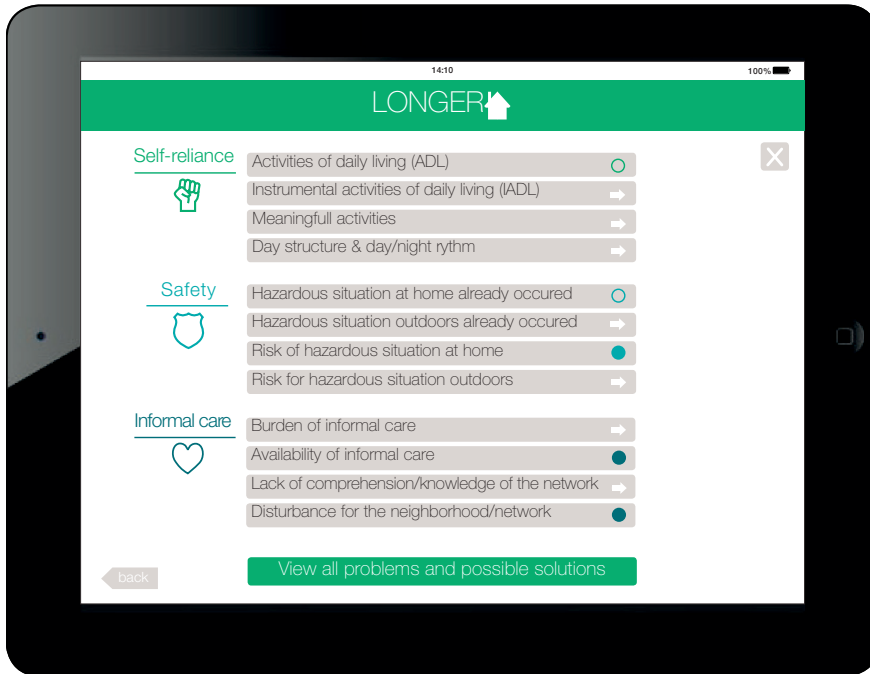
First main questions of subdomain ADL
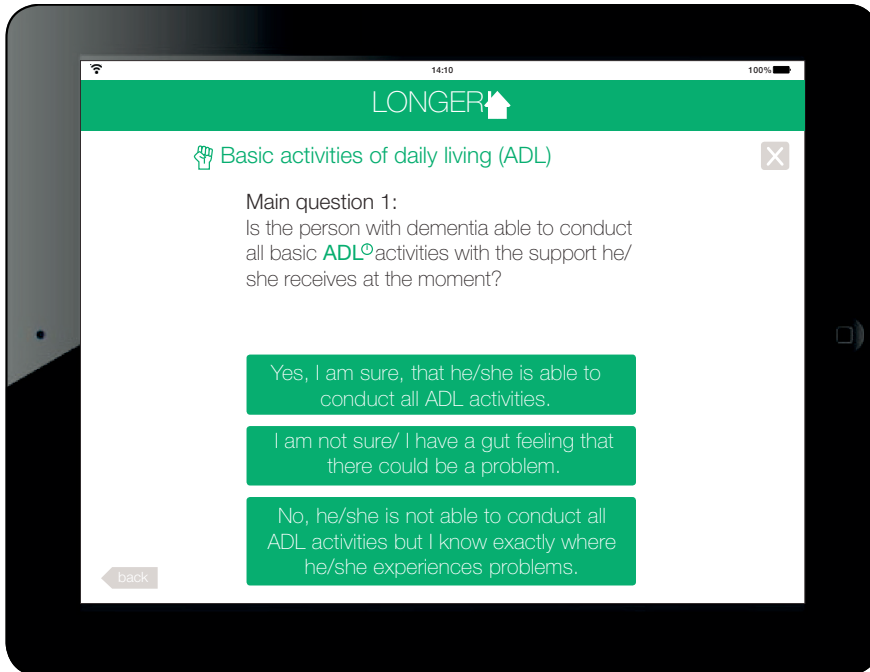
Example overview of detected problems after having completed the problem assessment within the subdomain ADL

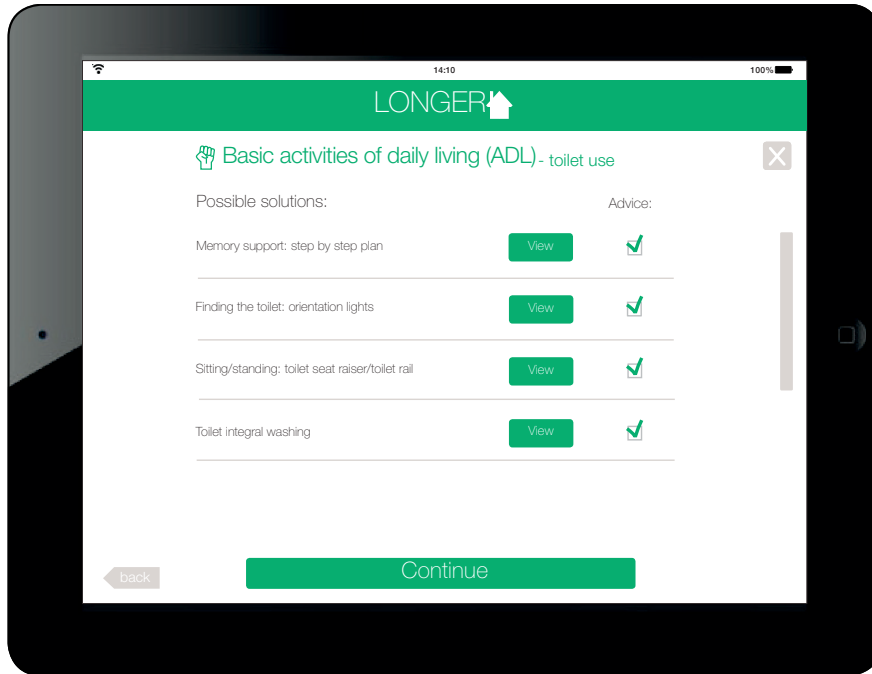Example overview of possible solutions for the problem 'incontinence'

Figure 1: The Decision support App

Procedure

Figure 2 provides an overview of the procedure followed during the study. All participants received a general introduction about the aim and the procedure of the study by one of the researchers or student assistants who conducted the data collection. The participants of the intervention group got a short verbal introduction to the App, time to read the user manual and the possibility to try working with the App for a maximum of 10 min. Next, all participants got the assignment to analyze the case describing the situation of a community-dwelling PwD and his/her primary informal caregiver. Two different cases (A and B) were used to prevent case effects. The cases consisted of a written vignette (in the form of an email from a general practitioner) and a conversation with 'simulated' informal caregivers providing more information on the case based on a script (consisting of background information about the case and a set of standard answers). The cases were based on data retrieved form the RightTimePlaceCare study, a large European study investigating patterns of transition from home care towards institutional dementia care.26 The case descriptions were extended based on feedback from two experienced case managers and based on the experiences from a pilot study which was conducted with four participants (nurses and case managers) to test the proposed procedure. An example of a background description of a case can be found in Appendix 1.

During the study, participants in both groups were asked to conduct a problem assessment within three problem domains (self-reliance, safety and informal care/social network) and to write down their advice on possible solutions to deal with the detected problems on an answer sheet within one meeting. The participants in the control group were asked to conduct the problem assessment and give advice on possible solutions according to their usual procedure without the App. Participants in the intervention group were also asked to conduct the problem assessment and give advice on possible solutions according to their usual procedure; in addition, they needed to use the App.

All participants got 45 min to analyze the case (reading the vignette and talking to the simulated informal caregiver), to determine the problems and to write down their advice on possible solutions on the answer sheet. This time frame was chosen as it is known from practice that nurses and case managers often schedule about an hour for a first encounter. In this study however, we stated that nurses and case managers did not need to spent time introducing themselves and getting in touch with the informal caregiver; therefore, it was regarded as reasonable to set a time limit of 45 minutes.

The informal caregivers were simulated by a researcher from the project team or by a student assistant who had at least a bachelor's degree in health sciences or a related discipline. Simulation means that the researcher was equipped with a script (including the same background information about their case (A or B) and a set of standard answers to all questions which are incorporated in the App). With that background information at

hand, they try to engage in an as natural possible conversation. They answered all questions the participants posed as far as they were within the scope their script; otherwise they rejected the question by stating that they do not have that information at the moment. Subsequently, the participants were asked to fill in questionnaires. Figure 2 provides an overview of the procedure. Due to practical reasons, blinding of participants, simulated caregivers and outcome assessors was not possible
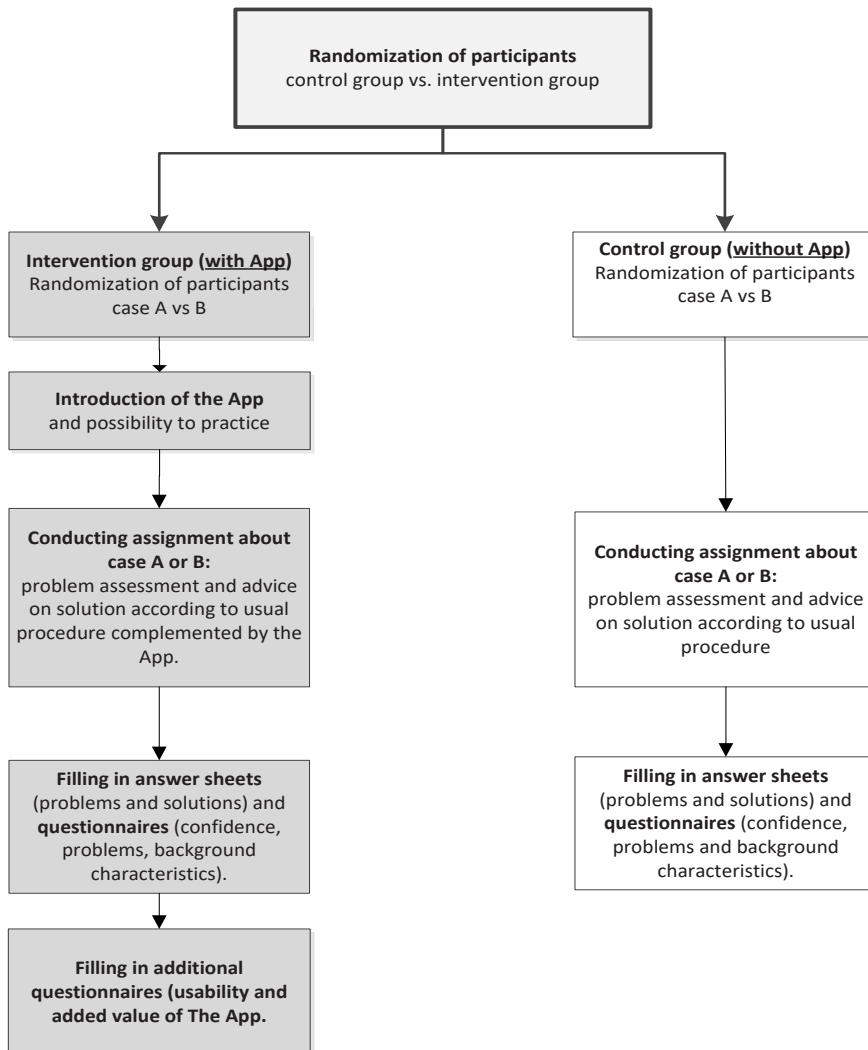

Figure 2: Flowchart of procedure

Outcomes

Primary outcome measure

The primary outcome measure was the overall level of confidence with regard to problem assessment and the ability to provide advice on possible solutions, which was assessed by means of three items scored on a 10 cm horizontal VAS.

Secondary outcome measures and background characteristics

The secondary outcome measures include uniformity of decision -making, number of solutions provided, perceived added value and usability of the App. In addition, background characteristics of the participants were assessed (e.g. gender, age, educational level). Table 1 provides a detailed overview of the outcome measures that were assessed. All outcome measures and the background characteristics were assessed once after the participants had completed the assignment.

Sample size calculation

We calculated the sample size based on the primary outcome (level of confidence) measured on a 10 cm visual analogue scale (VAS). Assuming an alpha of 0.05 (two-tailed testing), and beta of 0.10 and an expected mean difference of two cm, the required sample size was n = 33 per group (n = 66 in total).

Data-analysis

All statistical analyses were conducted using IBM SPSS 23.0.

Analysis of primary outcome measure

To analyze the overall level of confidence, we first calculated the mean score of all three items measured on a VAS. Then the means from both groups were compared to means of an independent sample t-test.

Analysis of secondary outcome measures and background characteristics

The secondary outcome uniformity was measured in two different ways. First by means of three items on a VAS scale, which were analyzed using Levene's test of equality of variances. Second, by means of comparing the problems detected (as written on the answers sheets) between both groups. To do so, the problems described by the participants on the answer sheet were clustered around the three problem domains (self-reliance, safety and informal care/social network and others) by the project team. In a next step, sub-clusters describing specific problems were formed based on the data. Finally, it was counted how many participants detected the specific problems. The number of problems

detected per group was analyzed by means of Pearson's Chi square tests. The average number of solutions provided per problem for the secondary outcome measure was analyzed by means of an independent sample t-test to compare the difference between means. Descriptive techniques were used to analyze background characteristics.

Table 1: Overview of outcome measures and analysis

Concept	Operationalization	Control/ intervention group
Level of confidence (primary outcome measure)	Combined measure: mean of three items measured on 10 cm visual analog scales, a 10 cm horizontal line (0 = not confident at all; 10 = very confident) 1. 'How sure are you that you have conducted a good problem assessment?' 2. 'How sure are you that you have a good overview of possible solutions for the detected problems?' 3. 'How sure are you that you provided good advice on possible solutions for the detected problems?'	Both
Uniformity in problem assessment	Three items measured on 10 cm visual analog scales, a 10 cm horizontal line (0 = low extent of problems; 10 = high extent of problems) 1. 'To what extent do you think this case contains problems with regard to decreased self-reliance?' 2. 'To what extent do you think this case contains problems with regard to safety?' 3. 'To what extent do you think this case contains problems with regard to informal care/social network?'	Both
	Answer sheet describing the detected problems.	Both
Advice on possible solutions	Answer sheet describing the advice for possible solutions for the detected problems	Both
Perceived added value	Three open-ended questions 1. 'Would you like to use this application in practice? If yes, why? If no, why not?' 2. 'What is, according to you, the added value of this application for daily practice?' 3. 'Would you like to recommend this application to your colleagues? If yes, why? If no, why not?'	Intervention group only
Usability	Dutch version of the post study system usability questionnaire (19 items)[27,28] and calculating the scale scores for; • Overall satisfaction (item 1–19) • System usefulness (item 1–8) • Information quality (item 9–15) • Interface quality (item, 16–18) One additional open-ended question: 'Do you have any further suggestions for improvement of the App?'	Intervention group only
Background characteristics	Age, gender, educational level For nurses/case managers only: primary function (case manager/district nurse)	Both

The scores on the PSSUQ were analyzed through descriptive analyses (means and standard deviations) and subsequently calculating scale scores (means and standard deviations) for: Overall satisfaction (item 1–19), System usefulness (item 1–8), Information quality (item 9–15), and Interface quality (item, 16–18). Background characteristics were analyzed through descriptive analyses (frequencies, means and standard deviations).

Qualitative data-analysis

The secondary outcome measure, perceived added value of the App, was analyzed according to the principles of conventional content analysis.29 To ensure the trustworthiness of the qualitative data several measures have been taken: To ensure credibility data triangulation was used. The participants were explicitly asked to describe their perceptions about the added value of the App. In addition they were also asked if they would like to use the App in practice and if they would recommend its usage to a colleague and why. The information provided on all three questions was used to get insight into the perceived added value. Moreover, the quantitative data about the willingness to use the App can be regarded as verification of the perceived added value. To ensure the confirmability of the findings, which means reducing potential personal bias by the researcher, the analysis was conducted by two researchers (TTL and ML) independently. They individually coded the statements of the participants. In case of discrepancies in coding, the researchers discussed the theme to reach consensus.

Ethics

The study protocol was reviewed by the medical ethics committee of Zuyderland-Zuyd (16-N-222), they indicated that this research did not fall under the scope of the Medical Research Involving Human Subjects Act (WMO) and that it does not need to undergo further review. Participation was strictly voluntary and all participants gave their written informed consent to participate in the study.

RESULTS

The study was conducted in the period between January and May 2017.

Participants

In total 71 persons gave verbal consent to participate. One of them was not eligible because he/she was neither a district nurse or case manager nor a student. Three participants retracted their verbal consent. All three mentioned personal time constraints as reason to refuse participation. Finally, 67 participants entered the study and gave written informed consent. There was no drop out during the study, all participants who started

the meeting, finished it. The mean age was 41 years and the majority of participants were female (n = 60). In total, 29 case managers, 27 district nurses and 11 students participated. The majority of participants were educated at the bachelor's level.

Table 2: Background characteristics of the participants

Characteristics	Intervention (n = 34)		Control (n = 33)	
Case (A or B)	A (n = 17)	B (n = 17)	A (n = 17)	B (n = 16)
Mean age in years (SD*)	41.4 (13.1)		40.9 (13.1)	
Sex				
Male	n = 2 (6%)		n = 5 (15%)	
Female	n = 32(94%)		n = 28 (85%)	
Function				
District nurse	n = 14 (41%)		n = 13 (40%)	
Case manager	n = 13 (38%)		n = 16 (48%)	
Nursing student	n = 7 (21%)		n = 4 (12%)	
Educational level				
Academic education	n = 1 (3%)		n = 0 (0%)	
Bachelor educated	n = 21 (62%)		n = 23 (70%)	
Vocationally trained	n = 4 (12%)		n = 5 (12%)	
Bachelor students	n = 8 (24%)		n = 5 (12%)	

*SD: Standard deviation

Primary outcome: Level of Confidence

There was no statistically significant difference in the overall level of confidence (with regard to problem assessment, overview of solutions and advice on possible solutions) between both groups (Table 3). Also, with regard to the individual items (problem assessment, overview of solutions and advice on possible solutions), no statistically significant differences between both groups were found.

Table 3: Comparison of the mean level of confidence between both groups

	Intervention (n = 34)	Control (n = 33)	Comparison of differences in mean **: p-value***
Overall level of confidence Mean (SD*)	6.93 (0.97)	6.66 (1.25)	0.324
Individual items:			
Level of confidence: problem assessment Mean (SD*)	6.63 (1.22)	6.33 (1.39)	0.354
Level of confidence: overview of possible solutions Mean (SD*)	6.88 (1.16)	6.68 (1.34)	0.531
Level of confidence: advice on possible solutions Mean (SD*)	7.29 (0.97)	6.96 (1.34)	0.260

*SD: Standard deviation
** Independent sample t-test
***alpha 0.05

Secondary outcomes

Uniformity

Overall, there was no statistically significant difference in uniformity of problem assessment between both groups. When comparing the variances of scores on the three items measuring the extent of a problem in the three problem domains self-reliance, safety and informal care/ social network, both groups did not significantly differ (Table 4).

Table 4: Comparison of the variance in judgment of the extent of a problem between both groups

	Intervention (n = 34)	Control (n = 33)	Comparison of the variances in scores** on VAS indicating the extent of a problem: p-value***
Problem self-reliance: Mean (SD*)	7.35 (2.28)	7.62 (1.43)	0.091
Problem safety: Mean (SD*)	6.29 (2.16)	6.46 (1.89)	0.324
Problem informal care/network: Mean (SD*)	7.68 (2.21)	8.06 (1.68)	0.156

*SD: Standard deviation
** Levene's test of homogeneity of variances
*** alpha 0.05

When comparing the number of participants who detected at least one problem within the three domains, also no statistically significant difference was found. In the intervention group, 88% of the participants detected a problem with regard to decreased self-reliance vs 94% in the control group (p-value 0.414); the same is true for safety-related problems 74% in the intervention group vs. 85% in the control group (p-value 0.225), and informal care and network-related problems 94% intervention group vs 85% control group (p-value 0.215). When looking at the problems which were detected by the participants more in detail, a variety of different problems with in the three domains were detected. Frequently detected problems in both groups included lack of meaningful activities, problems with ADL activities, safety problems with regard to nutritional status and high burden of informal caregiver. Participants also described a variety of problems which could not be summarized under one of the three domains, such as mood or behavioral problems. It was not the case that the intervention group detected more of the same problems compared to the participants in the control group, as we had expected beforehand.

Advice on possible solutions

There was no statistically significant difference in the mean number of solutions provided by the participants in the intervention and control groups for the three most detected problems within each problem in each problem domain (decreased self-reliance, safety and informal care), as Table 5 shows.

Table 5: Comparison of the average number of solutions provided per problem

Average number of solutions provided for the detected problems	Intervention (n = 34) mean (SD*)	Control (n = 33) mean (SD*)	Comparison of differences in mean **: p-value***
(Meaningful) daily activities	2.2 (1.1)	1.8 (0.8)	0.253
Safety (eating)	2.3 (1.4)	2.0 (1.1)	0.561
High burden of informal care	2.8 (1.4)	2.9 (1.4)	0.833

* SD: Standard deviation
** Independent sample t-test
***alpha 0.05

Added value

Among the 34 participants in the intervention group, 30 indicated that they would like to use the App during their daily work. Four participants said they were neutral, they provided arguments for and against use of the App in practice. No participant indicated that he/she was not willing to use the tool in practice. From all users, 33 stated that they would recommend the App to a colleague and one participant indicated they were undecided about recommending the App. When asking the participants what, according to them, is the potential added value of the App and to provide arguments for the usage of the tool in practice, they came up with two major themes: first, they described that the App can help them to obtain better insight in the situation of the PwD and the App can be viewed as a control measure to check whether one has detected the major problems. Second, they indicated that they value the overview of solutions as it contained besides familiar solutions, also new/unknown ones. In addition, they indicated that that they regard it as an user-friendly tool which might help them to work more efficiently. Moreover, they also stated that they see the App as complementary to their usual procedure.

Usability

With regard to usability of the App, the results of the PSSUQ indicate that the participants were overall satisfied with the usability of the App, as the mean score of 1.91 of the PSSUQ indicates (Table 6).

Table 6: Usability of the decision support App

Scores on PSSUQ	Mean scores (SD*); Range 1–7**
Overall satisfaction	1.91 (0.61)
System Usefulness	1.96 (0.62)
Information quality	1.83 (0.76)
Interface quality	1.94 (0.67)

*SD: Standard deviation
** Lower scores indicate better usability

DISCUSSION

This study has provided no evidence that the decision support App improved nurses' and case managers' confidence in problem assessment or the provision of advice for possible solutions. With regard to the secondary outcome measures, no statistically significant differences were found in uniformity of the problems detected or the number of solutions provided for the detected problems between the intervention and control group. However, among participants there was a high willingness to use the App in practice and they valued the App as user-friendly. Participants indicated that the App could help them get better insight into the problems experienced by the person with dementia and their informal caregivers and to find new or unknown solutions for the detected problems.

Explanation of the results and implications

The study has shown contradictory results, as no effects on confidence, uniformity or quantity of solutions were found, but participants were very willing to use the App and appreciated its added value. One possible explanation is that the App is indeed not of added value and that the willingness to use the App is based on socially desirable answers. However, there are other arguments which might explain the lack of efficacy in contrast to the high willingness to use the App in practice. During the study, the participants in the intervention group had limited time to explore the features of the App and to get accustomed to it. Often participants had insufficient time to use all problem assessment elements, to run through all possible solutions provided and to view additional information. Therefore, participants in the intervention group may have felt more time pressure compared to those in the control group. From research, it is known that time pressure has a negative influence on decision accuracy and the choices for interventions, even in experienced nurses.30 The aspect of time pressure might have also caused the participants in the intervention group to rely mainly on solutions they already knew and with which they had good experiences.

Moreover, participants were expected to immediately use a new technology and to combine it with their usual procedure. Even though the App was regarded as very user-friendly, it remains challenging to immediately integrate a new technology in an existing routine. Another factor which might have influenced the results in favor of the control group is the assignment to assess the problems within three domains, this might have caused participants in the control group, who wouldn't pay specific attention to those problems, to investigate all three in detail. Moreover, the chosen procedure in the laboratory experiment, which according to several participants felt like an exam, could have triggered the participants to assess the situation as explicitly as possible and to automatically use a more rational and deliberative reasoning strategy. Using real-life cases was impossible; as it would have been unethical ask different nurses/case managers and stu-

dents to assess the same case. Practically, this would have meant that an informal care-giver had to undergo about 30 conversations with different participants about exactly the same topic. Using different cases would have meant that a comparison of the assessments and advice of different participants for the same cases would not be possible. However, it remains unclear to what extent these simulations represent reality. Even though the cases were based on information from real-life cases and the simulated informal caregivers tried to engage in a natural conversation, another drawback of using cases and simulations is that the participants were not able to see the PwD and his/her real living environment. As a result, parts of the regular procedure could not be applied, e.g. checking for unsafe furniture or observing the behavior or emotions of the PwD. However, pre-implementation evaluations, using simulations, to test the efficacy of decision support tools for professionals is recommended as this can save costs by preventing the implementation of poorly evaluated tools in practice. In addition, it is possibility to discover problems to be refined before actual implementation of the tool in practice.[31]

It remains unclear why the participants were so eager to use the App in daily practice. More research is needed to unfold their underlying perceptions regarding the potential added value of the App. Depending on the results, it needs to be defined how the added value can be operationalized to study the effectiveness of the App in practice. In addition, more research is needed to study the long-term effects of the applications within the App when participants had more time to get used to it and to integrate the App in their daily working routine. This could be done in a field study comparing two groups, an intervention group (with App) and control group (without App) of similar professional caregivers with similar client populations over a longer period of time with regard to their confidence in problem assessment and providing advice on possible solutions. In such a study it might be worthwhile to also investigate whether the App increases nurses' and case managers' efficiency in finding suitable solutions, as they described this as a potential added value. A field study would also allow for measuring the effect of the App at the level of the PwD in addition to the outcomes on a nurse level.

Strengths and limitations of the study

Strengths of this study were: first, the rigorous study design in the form of an RCT, which allows conclusions to be drawn on causal relationships. Second, contamination, which is often a problem in real-life studies testing decision support systems,[17] was prevented by conducting the assessment and all related measurements in just one meeting. At the end of each meeting all participants were requested to handle all information confidentially and not to share any information about the cases, the procedure or the App with their colleagues until the end of the study.

This study is not without limitations. First, due to feasibility reasons blinding was not possible. The principal researcher (TTL) was responsible for the recruitment of participants,

the randomization, the planning of the meetings and also involved in data collection as one of the 'simulated' informal caregivers. Also, the other researchers who acted as simulated caregivers were not blinded as they also needed to introduce the App and hand out the additional questionnaire to the participant of the intervention group. Second, the chosen recruitment method, via various channels (e.g. via contact persons of organizations or lectures) and the dependence on volunteers to participate in a two hours sessions might have led to selection bias. The sample might include more motivated and research-minded nurses, case managers and students than average in that population. Third, to measure the level of uniformity, inter-judge comparisons were used as method, as there was no gold standard to compare the results. The disadvantage of this method is the risk of systematic measurement errors. Expert-panel consensus could have been used as an alternative method.[32] Fourth, although participants were randomly allocated to either intervention or control group, there is a chance that the groups were different with regard to their confidence levels at baseline due to the relatively small sample size. As the primary outcome measure could not be assessed beforehand without having conducted the assignment, a baseline measurement of the primary outcome was not possible. Consequentially, we are not able to check and eventually correct for baseline differences. Fifth, in the evaluation of computerized decisions support systems, it is desirable to also test a paper-based counterpart to evaluate the added value of the technology.[17] However, due to the large quantity of information which is included in the App testing a paper based version was not feasible.

CONCLUSION

This randomized, controlled laboratory experiment did not show promising results with regard to efficacy of the App in terms of increased nurse confidence, increased uniformity in problem assessment and increased quantity of solutions advised per problem. However, the study did show a high willingness of nurses and case managers to use the App in practice and to recommend usage of the App to colleagues. More research is needed to explain these contradictory results and to explore the potential added value of using the App more in detail.

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Chapter 6

Perceived Added value of a Decision Support App for Formal Caregivers in Community-Based Dementia Care

ABSTRACT

Aims and objectives: The aim is to gain insight into the perceived added value of this decision support App for district nurses and case managers and to investigate how they would implement the App in daily practice.

Background: District nurses and case managers play an important role in facilitating aging in place of persons with dementia (PwD). Detecting practical problems preventing PwD from living at home and advising on possible solutions are complex and challenging tasks for nurses and case managers. To support them with these tasks a decisions support App was developed.

Methods: A qualitative study using semi-structured groups interviews was conducted A photo- elicitation method and an interview guide was used to structure the interviews. The data were analyzed according to the principles of content analysis.

Results: In five interviews with seven district nurses and case managers the added value was described in terms of five themes: 1. Providing a broader/better overview of possible solutions; 2. supporting an in-depth problem assessment; 3. providing a guideline/checklist for problem assessment and advice on solutions; 4. being a support tool for unexperienced case managers/district nurses; 5. providing up-to-date information. The participants regarded the App as complementary to their current work procedure, which they would use in a flexible manner at different stages in the care continuum.

Conclusions: The participants valued both parts, the problem assessment and the overview of possible solutions. An important requisite for the usage would be that the content is continuously up-dated. Before implementation of the App can be recommended, an evaluation of its effectiveness regrading decision making should be conducted.

Relevance to clinical practice: This study underpins the importance of listing to users experience and their perceived added value of decision support tools besides of judging the value of a tool merely based on quantitative outcome measures.

Chapter **7**

General Discussion

The first aim of this dissertation was to get an overview of the potential labor-saving and quality-improving innovations that are currently developed and/or used in long-term care (LTC) organizations providing care for older people in the region of Limburg in the Netherlands, and to gain insight into the level of evidence of effectiveness of these innovations. The innovation inventory resulted in a broad variety of different types of innovations, which makes it difficult for formal caregivers to be well informed about available innovations they could use or recommend to their clients. Therefore, it was decided to develop a decision support tool for formal caregivers, helping them to make better use of the available innovations. This led to the second and major aim of this dissertation, namely to provide insight into the development and evaluation of a decision support App for district nurses and case managers to facilitate aging in place of persons with dementia (PwD). The development and evaluation of the App was conducted in a stepwise user-centered process in which first the scope of the App was determined by an explorative study on the most important practical problems preventing PwD from living at home. In the next step the content and technical development took place which was conducted in an iterative process of prototype development and usability evaluations. This was followed by an evaluation of the efficacy and potential added value of the decision support App in a randomized-controlled laboratory experiment and a subsequent interview study. This chapter outlines the main findings of this dissertation followed by methodological and theoretical considerations. Finally, recommendations for both future research and practice are described.

MAIN FINDINGS

A broad variety of different types of potential labor-saving and quality-improving innovations that are being developed and/or used in Dutch LTC organizations was found. However, there is relatively little reported evidence supporting the effectiveness of these innovations.

The stepwise user-centered development process has led to a usable decision support App for district nurses and case managers. The App contains an assessment and an overview of possible solutions for the most important practical problems preventing people with dementia from living at home. These problems were found to be within the domains of decreased self-reliance (e.g. inability to conduct activities of daily living), safety-related problems (e.g. safety-hazards at home or outdoors) and informal care and network-related problems (e.g. lack of availability or high burden of informal caregivers). Inconsistent evidence was found for the ability of the developed decision support App to support district nurses' and case managers' clinical judgment and decision-making. Nurses and case managers evaluated the App a usable tool, which they were willing to use in daily practice. The App was described as being of added value to their daily work in terms

of support to gain detailed insight into practical problems preventing PwD from living at home and to be up to date with regard to possible solutions for those problems. However, no statistical significant effects were found on nurses' and case managers' level of confidence in problem assessment and providing advice on solutions, uniformity in problem assessment and number of possible solutions provided for each detected problem.

METHODOLOGICAL CONSIDERATIONS

In this section some methodological considerations regarding the study designs and measurements used within the studies combined within this dissertation will be outlined.

Study designs

Development of the decision support App

User-centered design is an iterative process of prototype development and usability evaluation in which the end-user plays a prominent role. It is a preferred methodology for the development of health-care applications as this can increase the usability of the technological innovation and the chance of successful adoption by the target population.[1] Ideally, the usability of a health-care application is tested using a combination of different usability methods such as heuristic evaluation, cognitive walkthrough or a think-aloud method.[2] Preferably a combination of usability evaluations in a laboratory setting as well as in field studies are conducted to increase the chance of developing usable products.[2] In line with the literature the development process of the decision support App described in this dissertation was conducted in an iterative process of prototype development and usability evaluation. Different methods (e.g. heuristic evaluation and a think-aloud approach) including researchers, experts as well as end-users (district nurses and case managers), were involved which resulted in a usable decision support App. However, the usability of the App has not been tested yet in a field study. The choice to initially develop an App that is suitable for a test in a laboratory setting was a deliberate decision, based on practical and economic considerations. An App that could have been immediately used in clinical practice would have required more features e.g. safeguards to fulfill all data-safety requirements to protect personal and sensitive data, a back office for user support and offline availability of the App. These requirements need not be met for a laboratory experiment as no real patient data was used and Wi-Fi availability could be ensured at all times. Hence, a fully developed App would have caused more development and implementation costs compared to a version to be tested in a laboratory setting. Testing a high-fidelity prototype of the App in a laboratory experiment had the advantage of gaining insight into the usability, efficacy and perceived added value before full invest-

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ment in technical development. Moreover, this procedure leads to only promising interventions being implemented in practice, which is desirable in terms of dealing with scarce resources both in terms of financial as well as labor resources.

Evaluation of the decision support tool

The Medical Research Council (MRC) framework is a widely used guidance for the development and evaluation of complex health-care interventions. According to this framework the gold standard to evaluate the effects of complex health-care interventions is a randomized controlled trial (RCT).[3] The major strengths of RCTs' are their ability to test causal relationships between an intervention and outcomes. Randomization, manipulation and control, the three main characteristics of RCTs, increase the certainty with which conclusions about causality can be drawn.[4] Experiments can be conducted in "real" clinical practice (the context for which the intervention is intended for, i.e.to study the effectiveness) or in a laboratory setting (aiming to imitate "real" practice as well as possible, i.e. to study the efficacy). Laboratory experiments are often criticized for being artificial and underestimating the complexity of clinical practice[5] and therefore having lower external validity.[6] Consequently, conclusions concerning the generalizability of the results could only be cautiously drawn. In the laboratory experiment described in this dissertation several measures were taken to imitate the practice as well as possible. The vignettes used were based on information from real-life cases; the scripts for the simulated informal caregivers were tested in a pilot study and discussed with experienced case managers before the start of the laboratory experiment. This procedure ensured that the artificiality of the vignettes is reduced. Moreover, the researchers/student assistants who acted as simulated caregivers strived to engage in a natural conversation with the participants to reduce the artificiality of the simulation. More measures could have been taken to reduce the artificiality, such as using VR-glasses and videos to show a real-life case; use of professional actors as simulated caregivers; conducting the sessions in a home-like environment. Those measures would add visual cues, which in practice might also play a role in problem assessment and the advice on possible solutions. However, the additional measures are much more expensive than those used in the laboratory experiment described in this dissertation. It is debatable whether the extra investment is justified without knowing exactly the added value of these measures. Due to the abovementioned practical and economic considerations it was decided to first test the decision support App in a laboratory experiment. If the efficacy study yielded promising results it was planned to invest in further development of the App and to study its effectiveness. This choice was based on the assumption that it would have been impossible to find effects in practice if no effects were found under ideal circumstances.[5]

Measurements

To study whether an intervention contributes to its intended outcomes it is important to deliberately choose outcome measures reflecting the aim(s) of the intervention.[7] Hence, to measure whether the decision support App contributes to the goal of improved clinical judgment and decision-making we would have ideally used standardized and validated measures to operationalize the concept of improved judgment and decision-making. This was impossible as there is no gold standard to measure whether the users of the App conducted a better problem assessment and provided better advice on possible solutions, as there is no clearly defined way on how to conduct a problem assessment and how to advise solutions. Based on information from formal caregivers working in community-based dementia care it is known that formal caregivers often use different strategies to acquire insight into the practical problems of the PwD and their informal caregivers and use different sources of information concerning possible solutions. They might use questionnaires, checklists, and assessment forms but from practice and prior research it is known that this process is often conducted without using an explicit tool but based on their knowledge and experience of the individual caregiver.[8] Moreover, the care standard for community-based dementia in the Netherland provides no detailed recommendations on how to conduct a problem assessment and provide advice on solutions.[9] In fact there is no gold standard to assess the situation and provide advice on solutions. Therefore, we chose to use a combination of different self-developed quantitative and qualitative outcome measures to estimate the efficacy in terms of improved clinical judgment and decision-making, the willingness to use the App and its potential added value. We measured quantitatively the level of confidence, uniformity and number of solutions per problem detected to measure the outcome as closely as possible in relation to the aim of the App. In addition, we assessed subjective perceptions of the willingness to use the App and qualitatively measured the perceived added value to gain more insight into the users perceptions of the App and its potential added value for their daily work.

Regarding the contradictory results of the laboratory experiment it remains debatable whether the quantitative outcome measures of confidence in problem assessment and providing advice on solutions, uniformity and number of solutions provided per problem detected adequately reflect the added value as described by the participants. Moreover, previous research has shown that nurses' level of confidence does not always adequately reflects the accuracy of their clinical judgment and decision-making. Nurses could be both over- and underconfident both of which can have negative consequences on the quality of care they provide.[10] Given the chosen design and its outcome measures, it is not possible to check whether the confidence level adequately reflects the quality of the problem assessment and the advice provided. Another aspect is that the chosen design and outcome measures did not allow for a baseline comparison of confidence levels between both groups. Even though randomization was used to ensure comparable groups, there is always a chance that characteristics between groups differ at baseline, especially in the

case of relatively small sample sizes. In addition, the participants had very limited time to familiarize with the App which could have decreased their confidence level. They were expected to be able to immediately integrate a new technology into their work procedures while time to familiarize themselves with it was described as prerequisite for optimal usage in the subsequent interview study. In future studies it might be better to use objective criteria to evaluate whether the clinical judgment and decision-making has improved. This can be done by for example comparing the judgments and decisions made by the participants with the results of expert panel consensus.[11] Moreover, time to familiarize themselves with a new technology is recommended before the start of an evaluation study in the future.

In an ideal situation it would also be desirable to study whether the App contributes to its ultimate goal to facilitate aging in place for PwD. Studying the relationship between the App and the ability to age in place is, however, quite complicated as the App might only indirectly influence the ability of PwD to live longer at home. The underlying assumption was that by supporting professional caregivers to better detect practical problems and better advise on possible solutions to deal with these problems, PwD would make better use of the available solutions and could ultimately live longer in their own home. An evaluation of this line of reasoning is, however, hardly possible as many influencing factors (e.g. progression of the disease, level of evidence of the proposed solutions, actual uptake and usage of proposed solutions) need to be controlled in order to draw conclusion about the effect on the ability to age in place. Thus, an evaluation of the effectiveness of the App in terms of improved clinical judgment and decision-making might be the only measurable and reliable outcome.

THEORETICAL CONSIDERATIONS

In this section a critical reflection on the results of this dissertation is provided.

Computerized decision support

In this dissertation contradictory evidence has been found for the efficacy and perceived added value of a decision support App for district nurses and case managers. Computerized decision support tools have several theoretical advantages, such as providing tailored information right at the point of care and presenting tailored information based on large amounts of information.[12] Moreover, a recent literature review about the usability, process and patient-related outcomes of decision support systems for registered nurses working in hospitals showed promising results regarding their ability to improve quality of care. However, diverse decision support tools with different purposes such as support in diagnostic decision-making or medication management were included in this review. In addition a variety of different outcomes were used: for example, subjective satisfaction

and usefulness, to measure usability, nurses' accuracy and workload as process measures and mortality or length of stay as patient related outcomes. Of the studies included in this review only about half performed statistical analyses to detect changes, and only one of the studies was an RCT.[13] This implies that caution is needed when drawing conclusions about the (overall) effectiveness of decision support tools for nursing practice. Another systematic review from 2007 about the effects of computerized decision support for clinical nurses concluded that computerized decision support does not necessarily lead to measurable positive outcomes on professional and/or patient level and recommends further research to find out in which contexts the use of computerized decision support is most effective.[14] The results of the randomized controlled laboratory experiment presented in chapter 5 of this dissertation showed no significant improvements in clinical judgment and decision-making of district nurses and case managers, whilst participants did rated it as usable tool and highlighted its added value for daily practice. This discrepancy shows the difficulty in proving statistically significant effects of computerized decision support tools while they are perceived as useful by the users.

The lack of evidence supporting the efficacy of the decisions support App presented in this dissertation as opposed to the positive perceptions concerning the added value and usability of the App may be partly explained by methodological drawbacks of the efficacy study. For example, a lack of time for participants to familiarize themselves with the App before the start of the study and the diversity in the use of the decisions support App during the study could have influenced the results. However, from a theoretical perspective it is recommended that decisions support tools allow the combined use of decision support and own clinical experience. Previous research by Dowding et al.[15] showed that if nurses feel that they can combine the use of decision support technology with their own clinical experience, this increases their perceived usefulness and has a positive impact on their work. Moreover, they found decision support tools (providing binding recommendations for a certain course of action) were often used in an unanticipated way and recommendations were routinely neglected. This can result in negative consequences instead of improved practice. It was therefore a deliberate decision to develop a decision support App as an aid instead of a protocol, to support clinical reasoning instead of making it redundant. The App was not intended to be a cookbook, providing caregivers with a clear recipe of what to do in which situation, because clinical knowledge and experience in a caregiver/patient encounter cannot be fully substituted by technology.

However, it is debatable if the goal of improving clinical judgment and decision-making can be reached when the users themselves decide when and how to use the tool. Research shows that nurses' level of confidence does not always adequately reflect their level of accuracy in clinical judgment and that nurses can be both over- and underconfident.[10] With freedom of choice in how to use the App, under-confident nurses might be more prone to use a tool and to seek additional information than overconfident nurses,

although the latter's' accuracy of clinical judgment is not per definition better. Another aspect that can influence the usage of the App in practice is that nurses often use peers as a major source of information to reduce uncertainty surrounding decisions.[16] In practice, this could lead to a situation in which nurses and case managers only use the App if their peers could not help them. Thus if nurses and case managers would only use the App optionally, when they perceive a need for additional information, the App's ability to improve uniformity in clinical judgment and to broaden the scope of solutions to be considered, may be diminished. In psychology, human thinking is often described in terms of two systems, A and B. Whereas system A represents the fast and intuitive way of thinking, system B is the slower and conscious way of reasoning.[17] Intuitive thinking is likely to be biased by false trust in heuristics.[17] Thus, if nurses and case managers intuitively think that they judged a problem correctly and that they have enough information about possible solutions, they will not be eager to use the App. Hence, to increase accuracy and uniformity in problem assessment and the provision of advice on possible solutions, more guidance in the usage of a decision support tool may be recommended. In such a user guideline it should be defined when and how to use the App in the care continuum. The guidance should be presented in such a way that it encourages nurses to actively use the tool but to also critically reflect on the recommendations provided by the tool. According to the cognitive continuum theory, decision-making is based on two continua, the cognitive continuum (ranging from intuition-based to analysis-based decisions) and the structure of the judgment task (from ill structured to well structured). In theory, the more structured the tasks, the more analysis-based is the decision and the less structured the tasks, the more likely is the decision intuition-based.[18] Guidance in the use of the tool should focus on helping professionals in structuring the tasks of problem assessment and providing advice on solutions to support a more analytic line of reasoning. However, a more intuition-based line of reasoning should not be restricted at all, but should be used in situations in which a more analytical line of reasoning is not possible.

Evidence-based innovation management - a contradiction in terms?

Due to aging of the population and its consequences in terms of increased demand and decreased availability of workforce in LTC, as well as changing expectations of older people with regard to LTC services, innovating LTC for older people is necessary to ensure its sustainability and quality in the future. The findings from this dissertation show that Dutch LTC organizations are busy developing and implementing a broad variety of innovations. It was found that personnel, responsible for the implementation and/or management of innovations within organizations, often had limited insight into the evidence supporting the effectiveness of such innovations. Thus on the one hand it can be argued that there is a large innovation potential in the LTC for older people, but on the other hand there is little insight if these innovations indeed contribute to labor-savings and quality-improvement. Based on these results it cannot be concluded whether these innovations

are indeed the solutions to deal with future challenges of LTC in terms of increased demand, decreased availability of workforce and changing expectations of LTC recipients.

From a research perspective implementation of an intervention in health care comes typically after its effectiveness has been proven, ideally in an RCT including information about cost-effectiveness, as this is recommended by the MRC framework.[3] Thus, only if an intervention is evidence-based will an implementation on broad scale be recommended. This is also partly in line with the Implementation of Change Model described by Grol and Wensing in which the implementation of innovations in health care is described as a planned and systematic process.[19] According to Grol and Wensing's model, the implementation of an innovation is either initiated by the availability of new evidence about effective innovations or by best practices being developed to deal with problems in health care. This implies that people who are responsible for the management and implementation of change in LTC organizations are expected to have insight into the evidence or the theoretical rationale supporting the innovations to be implemented. From a business perspective, innovation management concerns the organization and control of the innovation process. According to the Innovation Pentathlon Framework, this process consists of different phases, starting with idea generation, selection, implementation, finally leading to the market launch of an innovation. This process is linked to the firm's strategic aims and the elements of the people, culture and organization of the firm.[20] Whether an idea reaches the last stage depends on complex considerations and decisions. However, the level of evidence supporting the effectiveness of an innovation might only be one aspect that is considered by a commercial company in the decision to further develop or launch an innovation. Other relevant aspects might be market size for an innovation, the expected profits and the fit with the firm's strategy.[20]

LTC organizations in the Netherlands are often not-for-profit organizations and need to pursue a public goal of delivering a high quality of care and dealing responsibly with scarce public resources. These organizations act as the intersection of commercial companies and scientific research. On the one hand they need to buy innovations from commercial companies or develop their own innovations based on best practices to improve the quality of care and to deal with scarce resources. On the other hand they are expected to take evidence- based decisions due to their public responsibility. However, the innovation inventory presented within this dissertation has shown that the evidence supporting the effectiveness of innovations is often not explicitly known by personnel responsible for the management/implementation of innovations in LTC organizations. This might lead to the conclusion that that the majority of innovations are initiated as best practices to deal with specific problems in care or that innovations are bought from commercial companies based on a trust their information about the effectiveness of an innovation. An alternative explanation is that information about the evidence is simply lacking and that decisions are often not evidence-based.

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Another aspect that is important to consider in the context of evidence-based innovation management is that generating a high level of evidence for health-care interventions can be a long-lasting process.[21] To build a robust evidence base, interventions should ideally run through the following stages subsequently: discovery, proof of concept, feasibility, safety, and efficacy and effectiveness evaluation. Those are followed by three additional phases—translation, implementation, maintenance and sustainability of an intervention in clinical practice.[21]

An example of such a long journey of developing and testing an innovation is the decision support App described within this dissertation. The chosen process of running successively through the stages of content-development, technical development, usability testing and efficacy evaluation, has advantages and disadvantages. Extensive pre-implementation evaluations of high-fidelity prototypes can prevent costly investments in ineffective interventions. Moreover, major usability drawbacks can be detected and adapted before an intervention is implemented in practice. A major disadvantage of pre-implementation testing is that the content of an innovation (such as an App) is already outdated before the actual implementation of an "innovation" in practice can be recommended.[22] Therefore, it is debatable whether all innovations in LTC need to be extensively tested in efficacy studies, and subsequently in larger RCTs before implementation, or whether evidence can be generated during implementation.

Alternative methods of research such as hybrid designs combining effectiveness evaluation and implementation research[22] might be an option to speed up the process from development to implementation. Hybrid designs focus on both assessing the clinical effectiveness of interventions as well as implementing. They can for example combine testing for effectiveness with assessing implementation interventions and/or strategies.[22] In particular, these designs could be considered for innovations with relatively low risks of harm.[22]

In a recent report of the Dutch Council for Health and Society, the concept of learning organizations was proposed instead of evidence-based innovation management. They proposed that organizations should constantly critically reflect on their work and use the lessons learned (e.g. from the implementation of an innovation) to initiate the next step.[23] However, to be critical and to learn from experiences and decisions, organizations need some form of evaluation of the effectiveness of the interventions they decide to implement. Otherwise, it is impossible to judge whether a decision was successful or not. Therefore, it is important to clearly determine the aim of an intervention and to monitor whether this aim is fulfilled or not. An option could be to implement innovations on a small scale and to evaluate whether they are successful or if adaptation is needed in a cyclic process of change, using a method such as the Plan, Do, Study, Act (PDSA) cycle if they are successful or if adaption is needed.[19] Such methods will not allow conclusions on

causal relationship to be drawn but would speed up the time from development to up-take. Moreover, in practice it is often the case that the innovation developers are commercial for-profit companies who want to sell their products to LTC organizations for whom the Innovation Pentathlon Framework might be more applicable than the MRC framework or the Implementation of Change Model. More rapid cycles of prototype development and evaluation might be more in line with the work procedures of commercial companies and could therefore facilitate the cooperation between development companies, LTC organizations and research institutes.

In conclusion, evidence-based innovation management is not per definition a contradiction in terms. Innovations do not always need to be entirely new, as they could also already be an established intervention in one context and be newly introduced to another context. In this case, it is very possible that an innovation already has a strong evidence base before implementation. It is recommended to foster that process of knowledge exchange about innovations between different organizations and different settings. However, not all innovations are already well established and often an innovation begins with a new idea and the development of a first prototype. In this case, it is important to carefully ponder the advantages and disadvantages of different research methods to on the one hand gain the best possible level of evidence and on the other hand shorten the process from invention to implementation.

7

FUTURE DIRECTIONS FOR PRACTICE AND RESEARCH

Implications for practice

First, the findings of this dissertation have shown that LTC organizations have a large innovation potential. However, there is often little knowledge about the evidence backing the effectiveness of an innovation. To ensure that only effective innovations are used in practice it is important to determine when an innovation is regarded successful a priori and to carefully monitor whether an innovation contributes to its goals. If the goals are not reached there are two options: One is to adapt the innovation and to monitor whether goals are reached after adaption and the other is to stop using the innovation. Moreover, LTC organizations might profit from more knowledge exchange about (un)successful innovations, to avoid the same mistakes being repeated and to make more efficient use of valuable resources.

Second, the findings of this dissertation have shown that PwD and their informal caregivers experience a variety of practical problems in daily life that prevent them from living at home. Problems within the domains of decreased self-reliance, safety-related problems and informal care/network-related problems were found to be the most crucial ones for the ability to age in place. Formal caregivers in community-based dementia care

should focus on the detection of these problems and should support PwD and their informal caregivers in finding the right solutions to fulfill their needs. A tool that might help them assess the problems in detail and to access an overview of possible solutions could be the developed decision support App.

Third, even though the results of the efficacy study of the decision support were contradictory, decision support tools for formal caregivers in community-based dementia care might be of added value if they provide up-to-date and easily accessible information on possible solutions to facilitate aging in place. Before implementing decision support tools in practice it is therefore a crucial step to determine how the information provided by the tool can be constantly updated. If the information is up to date, and ideally also contains information about the level of evidence of the provided solutions, this might facilitate formal caregivers in their attempt to provide evidence-based care.

Fourth, in the implementation of decision support tools in practice it is recommended to also consider a guideline for usage of the tool in practice. Such a guideline can ensure that the tool is used as intended, but should also stimulate the users to critically reflect on the recommendations made by the decision support tool.

Recommendations for further research

Based on the experiences made in the studies presented in this dissertation several recommendations for further research can be formulated.

First, in the attempt to provide an overview of innovations used within one region and to facilitate knowledge exchange about promising innovations, it is recommended to conduct more research about the effectiveness of innovations. In this study the level of evidence as reported by the organizations was presented, while overall there might be more information about the effectiveness of innovations which was probably beyond the scope of their knowledge. This could for example be done by means of systematic or scoping reviews supported with expert interviews. This would facilitate organizations in taking more evidence-based decisions about innovations to be implemented.

Second, in the development, evaluation and implementation of innovations with a low risk of being harmful one might consider using research designs combining effectiveness evaluation and implementation research. This could be done by implementing innovations on a small scale while monitoring whether the goals of the innovation are reached e.g. by means of the PDSA cycle. This might speed up the process from development to uptake while still preserving careful evaluation and might be more suitable for the cooperation between commercial companies, LTC organizations and research institutes.

Third, until now there is relatively little evidence supporting the effectiveness of computerized decision support tools in terms of improved clinical judgment and decision-making.[12] Because of the theoretical advantages of these tools such as providing information

at the point of care and hiding complex information behind user-friendly screens it is recommended to conduct more research in that area.[12] The studies conducted in this dissertation have shown that choices about the design and outcome measures to test the effectiveness of a decision support App are very challenging. Before setting up a study it is important to carefully determine the aim of the decision support tool and to operationalize the measurements based on that aim. A combination of qualitative and quantitative measures is recommended to enable triangulation.

Fourth, in studies testing the efficacy or effectiveness of a new technology, it is important to provide participants sufficient time to familiarize themselves with the technology before the start of the study. Even though the technology is easy and intuitive in use people need time to get used to it and to integrate it into their work. Only if these requirements are fulfilled is it possible to measure the effects of the technology.

To conclude, even though the development and evaluation of innovations in LTC for older people are complex and challenging, they are crucial to ensure the sustainability and quality of LTC for older people in the future. Careful evaluations of innovations using suitable study designs are necessary to avoid ineffective innovations remaining in usage and to make more efficient use of valuable resources.

7

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Samenvatting

De doelstelling van dit proefschrift was tweeledig. Het eerste deel was gericht op het verkrijgen van een overzicht te geven van potentieel arbeidsbesparende en kwaliteitsverbeterende innovaties die ontwikkeld en/of toegepast worden binnen de Limburgse verplegings-/verzorgings- en thuiszorg (VVT) organisaties. Het tweede (hoofd)doel van dit proefschrift was het ontwikkelen en evalueren van een beslissingsondersteunende applicatie (App) voor professionals werkzaam in de zorg voor thuiswonende ouderen met dementie.

Hoofdstuk 1 beschrijft de algemene introductie van het proefschrift. Hierin worden innovaties gepositioneerd als belangrijke middelen in de omgang met een stijgende zorgbehoefte, afnemende beschikbaarheid van personeel en de veranderende verwachtingen van de ontvangers ten aanzien van langdurige ouderenzorg. Daarnaast worden de overwegingen die geleid hebben tot de ontwikkeling van een beslissingsondersteunende App voor professionals met een coördinerende rol in de zorg voor mensen met dementie thuis (zoals wijkverpleegkundigen en case managers dementie) beschreven.

In **hoofdstuk 2** worden de resultaten van een crosssectionele inventarisatie van innovaties in de ouderenzorg beschreven. Doel van deze studie was inzicht te krijgen in de potentieel arbeidsbesparende en kwaliteitsbevorderende innovaties die op het moment van onderzoek binnen de Limburgse VVT organisaties ontwikkeld en/of toegepast werden. Door middel van semigestructureerde interviews met bestuurders, beleidsmedewerkers en eventueel andere medewerkers, die met een bepaalde zorginnovatie bezig waren, werden de innovaties in kaart gebracht en werd voor elke innovatie informatie verzameld over: de inhoud; het doel; de doelgroep; de status van de innovaties (in ontwikkeling of geïmplementeerd); bewijs van effectiviteit; kosten en contactgegevens van de betreffende zorgorganisatie. De inventarisatie heeft geleid tot een breed palet aan verschillende type innovaties. In totaal werden er 228 innovaties beschreven, waarvan 96 geclassificeerd kunnen worden als productinnovaties (bijv. ondersteunende technologie zoals leefstijl monitoring systemen of interventies om fysieke activiteit te stimuleren bijvoorbeeld een beweegtuin). Het overzicht bevatte 75 organisatorische innovaties. Hierbij kan gedacht worden aan bijvoorbeeld het inrichten van e-learning modules voor deskundigheidsbevordering van medewerkers of de introductie van zelfsturende teams in de thuiszorg. Daarnaast werden 42 procesinnovaties beschreven. Bijvoorbeeld het digitaliseren van administratieve processen door gebruik te maken van digitale planning- en registratiesystemen voor thuiszorgmedewerkers of vormen van zorg op afstand (bijvoorbeeld video-communicatie tussen zorgverleners en cliënten). Daarnaast werden 13 innovaties beschreven die geclassificeerd werden als overige innovaties omdat hierin elementen van de andere type innovaties gecombineerd werden. Voor alle innovaties werd door de 22 deelnemende organisaties relatief weinig gerapporteerd over de mate van (wetenschappelijk) bewijs voor de effectiviteit van de innovaties.

De inventarisatie van innovaties heeft geleid tot de conclusie dat de oplossingen voor de toekomstige uitdagingen in de ouderenzorg niet liggen op het gebied van het toepassen van enkel slimme innovaties, maar juist in het beter gebruik maken van de reeds beschikbare innovaties. Professionele zorgverleners spelen hierin een belangrijke rol, ze adviseren cliënten en mantelzorgers over mogelijke oplossingen voor hun praktische problemen in het dagelijkse leven en daarmee ook over de mogelijke inzet van innovaties. Omdat het detecteren van praktische problemen en het adviseren van oplossingen complexe en ingewikkelde taken kunnen zijn voor zorgverleners werd ervoor gekozen om een beslissingsondersteunend instrument voor hen te ontwikkelen. Het feit dat steeds meer mensen geconfronteerd worden met een diagnose dementie, de grote zorgbehoefte in deze doelgroep, een hoog risico op verpleeghuisopname bij mensen met dementie en een grote behoefte aan ondersteuning binnen de doelgroep, hebben geleid tot de keuze voor de ontwikkeling van een beslissingsondersteunend instrument voor de formele zorgverleners van mensen met dementie.

Om te bepalen waar een beslissingsondersteunend instrument voor formele zorgverleners in de zorg voor mensen met dementie thuis zich op zou moeten richten werd een kwalitatieve studie uitgevoerd. In **hoofdstuk 3** worden de resultaten van 6 focusgroep interviews met zorgverleners (o.a. wijkverpleegkundigen en case managers), mantelzorgers en cliënt vertegenwoordigers en experts op het gebied van ondersteunende technologie (o.a. ergotherapeuten, onderzoekers en leveranciers van hulpmiddelen) beschreven, waarbij het doel was om de belangrijkste problemen die het thuis wonen van mensen met dementie in de weg staan in kaart te brengen. Uit deze studie kwam naar voren dat praktische problemen binnen drie gebieden, namelijk eigen regie/zelfredzaamheid, veiligheid en mantelzorg/sociaal netwerk het meest bepalend zijn voor het al dan niet thuis kunnen blijven wonen van mensen met dementie. Bij problemen op het gebied van eigen regie kan gedacht worden aan het niet meer kunnen uitvoeren van dagelijkse activiteiten of een verstoord dag/nacht ritme. Veiligheid gerelateerde problemen bevatten onder andere dwalen of het onveilig gebruik van elektrische apparatuur. Binnen het gebied mantelzorg/sociaal netwerk gerelateerde problemen kan gedacht worden aan problemen zoals overbelasting van de mantelzorg, afwezigheid of onbegrip of onkunde van mantelzorgers. Gebaseerd op de resultaten van deze studie werd bepaald dat een beslissingsondersteunend instrument, in de vorm van een App, voor formele zorgverleners in de zorg voor mensen met dementie thuis (wijkverpleegkundigen en casemanagers dementie) zich zou moeten richten op de drie meest belangrijke probleemgebieden namelijk verlies van eigen regie/zelfredzaamheid, veiligheid gerelateerde problemen, mantelzorg/sociaal netwerk gerelateerde problemen.

In **hoofdstuk 4** wordt het ontwikkelproces van een beslissingsondersteunende App voor wijkverpleegkundigen en case managers dementie beschreven. Bij de ontwikkeling van de App stonden de toekomstige gebruikers centraal hetgeen ook wel 'user-centered development' wordt genoemd. Tijdens de ontwikkeling is in een iteratief proces gewerkt

aan de totstandkoming van de App. De App is bedoeld om wijkverpleegkundigen en casemanagers te ondersteunen bij het opsporen van praktische problemen die mensen met dementie belemmeren thuis te kunnen blijven wonen en hen te informeren over mogelijke oplossingen voor de gedetecteerde problemen. In totaal werden er vier prototypes van de App (een papieren-prototype en drie digitale prototypes) ontwikkeld. In vier opeenvolgende rondes werden de prototypes door eindgebruikers, experts en onderzoekers geëvalueerd op hun gebruiksvriendelijkheid. Hierbij werd gebruik gemaakt van verschillende methodes zoals een 'think aloud' methode en 'heuristic evaluation'. Dit proces heeft uiteindelijk geleid tot een gebruiksvriendelijk beslissingsondersteunende App die geschikt was voor nader onderzoek. The App bestaat globaal uit twee onderdelen. Het eerste gedeelte bevat een gedetailleerd probleemassessment op de gebieden eigen regie/zelfredzaamheid, veiligheid en mantelzorg/sociaal netwerk dat deels gebaseerd is op gevalideerde vragenlijsten, zoals de Barthel-index of Ervaren Druk Informele Zorg (EDIZ) vragenlijst. Het tweede gedeelte bevat een overzicht van mogelijke oplossingen (bijv. in de vorm van informatie, zorg of (technologische) ondersteuningsmogelijkheden).

In **hoofdstuk 5** worden de resultaten van een gerandomiseerd laboratorium experiment weergegeven. In deze studie werd de beslissingsondersteunende App op zijn werkzaamheid getest met 67 wijkverpleegkundigen, casemanagers en studenten verpleegkunde. Tijdens het experiment werden de deelnemers gevraagd om een casus (A of B) van een thuiswonende persoon met dementie in kaart te brengen. Over de casus ontvingen de deelnemers beknopte informatie op schrift. Daarnaast konden ze een gesprek voeren met een gesimuleerde mantelzorger. Alle deelnemers kregen de opdracht de praktische problemen op de gebieden eigen regie/zelfredzaamheid, veiligheid en mantelzorg/sociaal netwerk in hun casus in kaart te brengen en adviezen te geven voor mogelijke oplossingen m.b.t. de gedetecteerde problemen. De deelnemers werden verdeeld over twee groepen, waarbij de deelnemers in de controle groep geacht werden de casus in kaart te brengen middels hun gebruikelijke werkwijze terwijl de deelnemers in de interventiegroep aanvullend de App moesten gebruiken. Als primaire uitkomstmaat is het gevoel van zekerheid over het in kaart brengen van de problemen en het geven van adviezen voor oplossingen bij de deelnemers gemeten. Daarnaast is de mate van uniformiteit bij het opsporen van problemen, het aantal oplossingen per probleem dat ze aangaven, de waargenomen toegevoegde waarde en de gebruiksvriendelijkheid van de App in kaart gebracht. De studie liet zien dat de deelnemers in de interventie groep met betrekking tot hun gevoel van zekerheid niet significant verschilden van de deelnemers in de controle groep. Ook was er tussen beide groepen geen verschil met betrekking tot de uniformiteit of het aantal oplossingen dat geadviseerd werd per probleem. De studie liet wel zien dat de deelnemers in de interventiegroep de App graag zouden willen gebruiken in de praktijk en dat zij de toegevoegde waarde van de App voor hun dagelijks werk benadrukten.

Om de tegenstrijdige resultaten van het laboratorium experiment beter te kunnen ver-klaren werd een vervolgstudie uitgevoerd. In deze studie werd door middel van semige-structureerde (groeps-) interviews met 7 voormalige deelnemers van het laboratorium experiment de toegevoegde waarde van de App en de toepasbaarheid van de App in de dagelijkse praktijk nader in kaart gebracht (**hoofdstuk 6**). De toegevoegde waarde, zoals beschreven door de deelnemers, werd samengevat in 5 thema's, namelijk: 1) het bieden van een breder/beter overzicht van mogelijke oplossingen; 2) het ondersteunen van een gedetailleerd probleemassessment; 3) het bieden van richtlijn/checklist voor het pro-bleem assessment en het geven van adviezen voor mogelijke oplossingen; 4) ondersteu-ning van onervaren medewerkers; en 5) het bieden van recente informatie over moge-lijke oplossingen. Wijkverpleegkundigen en case managers beschreven de App als een nuttig instrument en als waardevolle aanvulling op hun gebruikelijke werkwijze. Ze gaven aan dat ze de App op verschillende momenten in het zorgproces (voor, tijdens of na een huisbezoek) zouden gebruiken als ze zelf de behoefte hebben aan meer ondersteuning. Wijkverpleegkundigen en case managers gaven aan dat een belangrijke voorwaarde voor het gebruik van de App is dat de inhoud steeds actueel is.

Hoofdstuk 7 bevat een samenvatting van de hoofdbevindingen van dit proefschrift. Daar-naast wordt kritisch gereflecteerd op de gekozen onderzoeksdesigns en worden de ge-kozen uitkomstmaten voor het evalueren van de werkzaamheid van de beslissingsonder-steunende App bediscussieerd. Daarna volgen theoretische overwegingen met betrek-king tot de toegevoegde waarde van beslissingsondersteunende middelen en de rol van wetenschappelijk bewijs in innovatie management. Ten slotte worden aanbevelingen ge-geven voor verder onderzoek en voor de praktijk. Hierbij ligt de nadruk op het onder-zoeken van de effectiviteit van innovaties, gebruikmakend van passende studie designs om een verantwoorde inzet van schaarse middelen te garanderen. Daarnaast wordt ge-concludeerd dat beslissingsondersteunende instrumenten veelbelovende middelen zijn, die zorgverleners kunnen ondersteunen bij het uitvoeren van een probleem assessment het geven van adviezen voor mogelijke oplossingen, maar dat de werkzaamheid van deze instrumenten lastig objectief vast te stellen is.

Summary

The aim of this dissertation is twofold. The first aim is to provide an overview of innovations used and/or developed in long-term care (LTC) organizations in the region of Limburg in the Netherlands. The second and major aim of this dissertation is to provide insight into the user-centered development of a decision support App for formal caregivers (district nurses and case managers) in community-based dementia care and to describe its efficacy and potential added value. In this chapter a summary of all studies presented within this dissertation is given.

Chapter 1 contains the general introduction describing the need for innovations as a means to deal with the future challenges of LTC for older people in terms of increased demand, decreased availability of workforce and changing expectations of LTC recipients. Moreover, the considerations leading to the development and evaluation of a decision support App for formal caregivers in community-based dementia care are described.

In **Chapter 2** the results of a cross-sectional innovation inventory are presented. The aim of the study was to provide an overview of potential labor-saving and quality-improving innovations, which were used and/or developed at that time in the LTC organizations in the region of Limburg in the south of the Netherlands. By means of semi-structured interviews with Chief Executive Officers, managers or staff members of LTC organizations, information about innovations was gathered, including information regarding: the content, the goal, the setting, the target group, the status (e.g. under development or implemented), the level of evidence regarding the effectiveness of the innovations, costs and contact details of the organizations. The innovation inventory resulted in a broad variety of different types of innovations, which were developed and/or used in Dutch LTC organizations at the time of the study. In total, 228 innovations were described. This overview contains 96 product innovations (e.g. supportive technology such as lifestyle monitoring or interventions to stimulate physical activity, such as exercise gardens), 75 organizational innovations (e.g. innovations related to business practices such as e-learning environments or innovations related to workplace organization such as self-managing teams), 42 process innovations (e.g. digitalization of administrative processes, such as digital planning and registration systems, or distance care such as video communication between clients and nurses), and 13 innovations combining elements of the three aforementioned types. However, the 22 participating organizations reported relatively little (scientific) evidence supporting the effectiveness of the innovations.

The results of the innovation inventory led to the conclusion that there is no one-size-fits-all solution to deal with future challenges of LTC but that it is important to facilitate a better use of the available innovations. Formal caregivers such as nurses play an important role in advising clients and informal caregivers about possible solutions for their practical problems. Therefore, it was decided to develop a decision support tool for formal caregivers, such as district nurses and case managers, in community-based dementia care. People with dementia (PwD) are an important target group in terms of increasing

numbers and extensive needs for LTC and a high risk of nursing home admission, which could profit from the existence of such a tool. To determine the scope of a decision support App for these formal caregivers, a study to examine the most important practical problems preventing PwD from living at home was conducted. In **Chapter 3** the results of this qualitative study, in which six focus group interviews with formal caregivers (e.g. district nurses, case managers), informal caregivers and patient representatives and experts in assistive technologies (e.g. occupational therapists, suppliers of assistive technology, researchers) were conducted, are described. This study showed that practical problems within the three domains, i.e. decreased self-reliance (e.g. inability to conduct activities of daily living, disrupted day/night rhythm), safety-related problems (e.g. wandering, fall incidents or improper use of electronic devices) and informal care/network-related problems (e.g. burden of informal care or lack of availability of informal care) are the most important problems that prevent PwD from living at home.

Based on the results of the prior study in which the most important practical problems preventing PwD from living at home were determined, it was decided that a decisions support app should focus on the three most important problem domains, namely decreased self-reliance, safety-related problems and informal care/network-related problems. The aim of the study presented in **Chapter 4** was to develop a usable decision support App for district nurses and case managers to facilitate aging in place of PwD. The App, developed in a stepwise/iterative user-centered design process, is intended to facilitate the detection of practical problems preventing PwD from living at home and to provide advice for possible solutions to deal with these problems. Four prototypes (one paper-based and three tablet-based) of the App were evaluated with regard to its usability by end users, researchers and experts using different methods (e.g. think-aloud approach and heuristic evaluation). This process resulted in a usable decision support App. The App contains two main parts. The first part contains a detailed problem assessment with regard to problems in the domains of decreased self-reliance, safety-related problems and informal care and network-related problems, which is partly based on validated questionnaires such as the Barthel Index or the Self-Perceived Pressure Informal Care questionnaire. The second part contains an overview of possible solutions for these problems.

In the randomized controlled laboratory experiment, presented in **Chapter 5**, the efficacy of the App was tested in a sample of 67 district nurses, case managers and nursing students. During the experiment, participants were asked to assess one of two cases of a PwD, consisting of written information and a simulated encounter with an informal caregiver. Participants needed to detect practical problems within the domains of self-reliance, safety and informal care, and provided suggestions for possible solutions for the detected problems. Participants used either their regular procedure combined with the App (intervention group) or without the App (control group) to conduct these tasks. Besides the primary outcome measure level of confidence in problem assessment and pro-

vision of advice on solutions, uniformity in problem assessment, number of possible solutions provided per problem detected, perceptions about added value and usability of the app were examined. The results indicated that the decision support App did not increase nurses' and case managers' confidence in problem assessment and providing advice on possible solutions. Moreover, the study showed that the app does not automatically lead to more uniformity in problem assessment or an increased number of possible solutions provided by nurses and case managers per problem detected. However, nurses and case managers were very willing to use the app in daily practice and emphasized its added value.

To explain the contrary results of the laboratory experiment, in which no evidence for the efficacy was found while the participants were very willing to use the app and described its added value, a qualitative study using semi-structured (group-) interviews was conducted. The aim of the last study, described in **Chapter 6**, was to gain deeper insight into the added value of the decision support App as perceived by nurses and case managers and to investigate how they would implement the App in their daily work procedures. The added value was described in terms of five major themes: 1) providing a broader/better overview of possible solutions; 2), supporting an in-depth problem assessment; 3) providing a guideline/checklist for problem assessment and providing advice on solutions; 4) being a support tool for inexperienced case managers/district nurses; and 5) providing up-to-date information. Nurses and case managers regarded the App as useful and as complementary to their current work procedure, which they would use based on their own judgment about the necessity of support (e.g. to search solutions for a specific problem or to use it as a guideline to conduct a full problem assessment) and at different stages in the care continuum (before, during or after a direct encounter with the PwD or the informal caregivers). However, nurses and case managers pointed out that an important prerequisite for the usage would be that the content is continuously updated.

Chapter 7 contains the main findings of this dissertation. In addition, a critical reflection on the chosen study designs in terms of a user-centered development process and a laboratory experiment is presented. In addition, the chosen measurements for evaluating the effects of a decision support tool are discussed. This is followed by theoretical considerations concerning the added value of computerized decision support tools and the use of evidence in innovation management. Finally, recommendations both for further research and practice are given, which include the necessity of careful evaluations of the effectiveness of innovations using suitable study designs to ensure that scarce resources in LTC are used in a responsible way. In addition, more research is needed to determine the effects of decision support tools in nursing. Decision support tools seem to be a promising means to facilitate problem assessments and the provision of advice on solutions according to users, but this is difficult to prove objectively.

Zusammenfassung

Die Zielsetzung dieser Dissertation war zweigeteilt. Der erste Teil hatte zum Ziel, einen Überblick über potenziell arbeitssparende und qualitätsverbessernde Innovationen, die Altenpflegeanbieter von, sowohl stationärer als auch häuslicher Pflege in Limburg/NL, entwickelt oder in Ihren Organisationen eingeführt haben, zu schaffen. Das zweite (Haupt)Ziel dieser Doktorarbeit bestand in der Entwicklung und Evaluierung einer Entscheidungshilfeanwendung, in der Form einer App, für Fachkräfte in der häuslichen Pflege von Menschen mit Demenz.

Kapitel 1 beinhaltet die allgemeine Einleitung dieser Dissertation. Hierin werden Innovationen als wichtige Ressourcen im Umgang mit steigenden Gesundheitsbedürfnissen, rückläufiger Verfügbarkeit von qualifizierten Mitarbeitern und den sich verändernden Erwartungen von pflegebedürftigen älteren Menschen positioniert. Darüber hinaus werden die Überlegungen beschrieben, die zur Entwicklung einer Entscheidungshilfe App für Fachkräfte mit einer koordinierenden Funktion in der häuslichen Pflege von dementen Menschen geführt haben. Diese Rolle wird in den Niederlanden häufig von sogenannten Case Managern oder ambulanten Pflegekräften mit einer koordinierenden Funktion übernommen.

Kapitel 2 beschreibt die Ergebnisse einer Querschnittsstudie. Das Ziel dieser Studie war es, eine Übersicht von potentiell arbeitssparenden und qualitätssteigernden Innovationen zu generieren, die zur Zeit der Datenerhebung in den Altenpflegeorganisationen in Limburg/NL entwickelt und/oder angewendet wurden. Mittels semi-strukturierter Interviews mit Leitern, Managern oder anderen für Innovationen verantwortlichen Mitarbeitern, wurden die Innovationen in einer Datenbank erfasst. Die Datenbank umfasst für jede Innovation die folgenden Informationen: Beschreibung der Innovation; Ziel der Innovation; Zielgruppe; Status der Innovationen (in Entwicklung oder umgesetzt); Nachweis der Wirksamkeit; Kosten und Kontaktdaten der jeweiligen Altenpflegeorganisation. Das Ergebnis dieser Studie ist eine breite Palette von verschiedenartigen Innovationen, die in diesem Bereich eingesetzt oder entwickelt wurden. Insgesamt wurden 228 Innovationen beschrieben, von denen 96 als Produktinnovationen klassifiziert werden können. Beispiele hierfür sind technische Hilfsmittel wie Infrarotbewegungssensoren oder Interventionen zur Förderung körperlicher Aktivität von älteren Menschen wie sogenannte „Bewegungsgärten". Die Übersicht enthielt des Weiteren 75 organisatorische Innovationen. Ein Beispiel hierfür wären E-Learning-Module zur Schulung von Mitarbeitern oder die Einführung von sogenannten „Selbstverwaltenden Teams" in der häuslichen Pflege. Zusätzlich wurden 42 Prozessinnovationen genannt. Diese beinhalteten beispielsweise die Digitalisierung von Verwaltungsprozessen durch den Einsatz digitaler Planungs- und Registrierungssysteme für die häusliche Pflege oder Formen von Telemedizin wie zum Beispiel Videokommunikation zwischen Pflegepersonal und Klienten. Des Weiteren wurden 13 Innovationen als sonstige Innovationen eingestuft, weil sie Elemente einer anderen Innovationsart kombinierten. Insgesamt berichteten die teilnehmenden Organisationen wenig über den Grad der (wissenschaftlichen) Evidenz für die Wirksamkeit der Innovationen.

Die Ergebnisse der ersten Studie führten zu der Schlussfolgerung, dass die Lösungen für die zukünftigen Herausforderungen in der Altenpflege nicht nur darin bestehen, einzelne Innovationen einzuführen oder weiterzuentwickeln, sondern vielmehr darin bereits vorhandene Innovationen besser zu nutzen oder zu kombinieren. Fachkräfte in der häuslichen Pflege spielen hierbei eine wichtige Rolle, denn sie beraten ältere Menschen und Ihre pflegenden Angehörigen über mögliche Lösungen für ihre praktischen Probleme des täglichen Lebens und damit auch über den möglichen Einsatz von Innovationen. Das Erkennen praktischer Probleme und die Beratung bezüglich möglicher Lösungsansätze sind komplexe und komplizierte Aufgaben für Fachkräfte in der häuslichen Pflege. Um Fachkräfte bei diesen Aufgaben besser unterstützen zu können, wurde beschlossen eine Entscheidungshilfe App zu entwickeln. Da eine allumfassende Entscheidungshilfe App nicht realisierbar ist, fiel die Entscheidung auf die Entwicklung einer zielgruppenspezifischen App. Immer mehr Menschen werden mit der Diagnose Demenz konfrontiert und haben in Folge dessen einen erhöhten Unterstützungsbedarf. Der erhöhte Unterstützungsbedarf hat zur Folge, dass demente Menschen häufig in ein Pflegeheim umziehen müssen, obwohl sie das häusliche Umfeld häufig als Wohnort bevorzugen würden. Auf Grund dessen wurde eine Entscheidungshilfe App für Pflegekräfte entwickelt, die in der häuslichen Pflege dementer Menschen tätig sind.

Um den Fokus der Entscheidungshilfe-App für Fachkräfte in der häuslichen Pflege dementer Menschen zu bestimmen wurde eine qualitative Studie durchgeführt. Ziel dieser Studie war es herauszufinden, welche praktischen Probleme das Leben von Menschen mit Demenz am meisten behindern. In **Kapitel 3** werden die Ergebnisse aus sechs Fokusgruppen-Interviews präsentiert, die mit Fachkräften der häuslichen Pflege dementer Menschen (zum Beispiel Case Managern oder ambulanten Pflegekräften mit einer koordinierenden Funktion), pflegenden Angehörigen und Patientenvertretern sowie Experten auf dem Gebiet von unterstützenden Technologien (zum Beispiel Ergotherapeuten oder Anbietern von Hilfsmitteln) geführt wurden. Die Studie zeigte, dass praktische Probleme, die die drei Bereiche „Selbstbestimmung/Autonomie", „Sicherheit" und „pflegende Angehörige/soziales Netzwerk" betreffen, die wichtigsten Probleme sind, die das Leben von Menschen mit Demenz in der häuslichen Umgebung gefährden. Bei Problemen im Bereich von Selbstbestimmung/Autonomie können die folgenden Probleme in Betracht gezogen werden: nicht mehr in der Lage sein die Aktivitäten des täglichen Lebens auszuführen oder ein gestörter Schlaf-/Wach-Rhythmus. Zu den sicherheitsrelevanten Problemen gehören beispielsweise zielloses Umherirren oder ein risikovoller Umgang mit elektrischen Geräten. Probleme in Bezug auf pflegende Angehörige können zum Beispiel eine hohe Belastung von pflegenden Angehörigen oder fehlende Empathie für die demente Person sein. Basierend auf den Ergebnissen dieser Studie wurde entschieden, dass eine Entscheidungshilfe App für Fachkräfte in der häuslichen Pflege dementer Menschen sich

auf den Verlust von Selbstbestimmung/Autonomie, Sicherheitsrisiken und auf die Probleme von pflegenden Angehörigen oder anderen Teilen des sozialen Netzwerks einer dementen Person konzentrieren sollte.

Kapitel 4 beschreibt den Entwicklungsprozess einer Entscheidungshilfe App für Fachkräfte in der häuslichen Pflege dementer Menschen. Während der gesamten Entwicklung der App standen die zukünftigen Nutzer im Mittelpunkt; dies wird auch „User-Centered Development" genannt. Der Entwicklungsprozess wurde in mehreren kleinen Schritten durchgeführt, in denen verschiedene Prototypen der App entwickelt wurden. Ziel der App ist es Fachkräfte in der häuslichen Pflege von Menschen mit Demenz zu unterstützen, die Probleme ihrer Klienten zu analysieren und ihnen zu helfen die Klienten über mögliche Lösungen zu informieren. Insgesamt wurden vier Prototypen der App entwickelt (ein Papierprototyp und drei digitale Prototypen). In vier aufeinanderfolgenden Runden wurden die Prototypen von zukünftigen Nutzern, Experten und Forschern hinsichtlich ihrer Benutzerfreundlichkeit bewertet. Verschiedene Methoden, wie eine "Think-Aloud"-Methode und eine "heuristische Evaluation", wurden verwendet. Dieser Prozess führte schließlich zu einer benutzerfreundlichen Entscheidungsunterstützungs-App, die für weitere Untersuchungen geeignet war. Global besteht die App aus zwei Teilen. Der erste Teil enthält eine detaillierte Problemanalyse in den Bereichen Selbstbestimmung/Autonomie, Sicherheit und pflegende Angehörige/soziales Netzwerk, die teilweise auf validierten Fragebögen wie dem Barthel-Index oder dem EDIZ-Fragebogen (Experienced Pressure Informal Care) basiert ist. Der zweite Teil enthält einen Überblick über mögliche Lösungen (z. B. in Form von Informationen, Pflegedienstleistungen oder (technologischen) Hilfsmitteln).

In **Kapitel 5** werden die Ergebnisse eines randomisierten Laborexperiments beschrieben. In dieser Studie wurde die Entscheidungshilfe App mit der Unterstützung von 67 ambulanten Pflegekräften mit einer koordinierenden Funktion , Case Managern und Studenten (aus den letzten beiden Studienjahren im Bachelorstudiengang Pflege) hinsichtlich ihrer Wirksamkeit getestet. Während des Experiments wurden die Teilnehmer gebeten, einen von zwei Fällen, der die Situation einer dementen Person im häuslichen Umfeld darstellte, zu analysieren. Hierfür erhielten die Teilnehmer eine kurze schriftliche Information über ihren Fall. Zudem erhielten sie die Möglichkeit ein Gespräch mit einem gespielten pflegenden Angehörigen zu führen. Alle Teilnehmer erhielten den Auftrag in dem Ihnen zugewiesen Fall die praktischen Probleme, die demente Personen und deren Angehörige im täglichen Leben erfahren zu analysieren. Hierbei sollten sie sich auf Probleme der folgenden drei Gebiete konzentrieren: Verlust von Selbstbestimmung/Autonomie, Sicherheitsrisiken und Probleme pflegender Angehöriger/dem weiteren sozialen Netzwerk. Des Weiteren erhielten sie den Auftrag für jedes Problem mögliche Lösungsansätze zu beschreiben. Die Teilnehmer wurden in zwei Gruppen eingeteilt. Die Teilnehmer der Kontrollgruppe analysierten den Fall mittels ihrer üblichen Arbeitsweise, während die Teil-

nehmer der Interventionsgruppe zusätzlich die App nutzen mussten. Als primäre Zielvariable wurde in dieser Studie das Gefühl von Sicherheit gemessen, das die Teilnehmer bezüglich ihrer Problemanalyse sowie ihrer Lösungsvorschläge empfanden. Darüber hinaus wurde der Grad der Einheitlichkeit bei der Problemerkennung, die Anzahl der Lösungen pro Problem, der wahrgenommene Mehrwert und die Benutzerfreundlichkeit der App ermittelt. Die Studie zeigte, dass die Teilnehmer der Interventionsgruppe sich hinsichtlich ihres Sicherheitsgefühls nicht signifikant von den Teilnehmern der Kontrollgruppe unterschieden. Es gab auch keinen Unterschied zwischen den beiden Gruppen bezüglich der Einheitlichkeit oder der Anzahl der empfohlenen Lösungen. Die Studie zeigte jedoch, dass die Teilnehmer der Interventionsgruppe die App gerne in der Praxis nutzen würden. Des Weiteren beschreiben sie einen deutlichen Mehrwert der App für ihre tägliche Arbeit.

Um die widersprüchlichen Ergebnisse des Laborexperiments besser erklären zu können, wurde eine Folgestudie durchgeführt. In dieser Studie wurde der Mehrwert der App sowie die Anwendbarkeit der App im Alltag mittels halbstrukturierter (Gruppen-) Interviews mit 7 ehemaligen Teilnehmern des Laborexperiments erfasst (**Kapitel 6**). Der von den Teilnehmern beschriebene Mehrwert wurde in fünf Themenbereiche zusammengefasst: 1) Bereitstellung eines umfassenderen/besseren Überblicks über mögliche Lösungen; 2) Unterstützung bei einer detaillierten Problemanalyse; 3) Bereitstellung einer Leitlinie/Checkliste für die Problemanalyse und Beratung bezüglich möglicher Lösungen; 4) Unterstützung für unerfahrene Mitarbeiter und 5) Bereitstellung von aktuellen Informationen über mögliche Lösungen. Die Teilnehmer beschrieben die App als nützliches Werkzeug und als wertvolle Ergänzung ihrer üblichen Arbeitsweise. Sie gaben an, dass sie die App zu unterschiedlichen Zeitpunkten des Pflegeprozesses (vor, während oder nach einem Hausbesuch) nutzen würden. Sie gaben zudem an, die App in Momenten, in denen sie selbst mehr Unterstützung benötigen, nutzen zu wollen. Darüber hinaus gaben die Teilnehmer an, dass eine wichtige Voraussetzung für die erfolgreiche Nutzung der App darin bestehe, dass dessen Inhalt immer auf dem neuesten Stand sei.

Kapitel 7 enthält eine Zusammenfassung der wichtigsten Ergebnisse dieser Arbeit. Darüber hinaus werden die gewählten Forschungsdesigns diskutiert sowie die Zielvariablen zur Evaluation der Wirksamkeit der Entscheidungshilfe App kritisch reflektiert. Es folgen theoretische Überlegungen zum Mehrwert von Maßnahmen zur Entscheidungshilfe in der Pflege und zur Rolle wissenschaftlicher Erkenntnisse im Innovationsmanagement. Schließlich werden Empfehlungen für weitere Forschungen und für die Praxis gegeben. Der Schwerpunkt liegt dabei auf der Erforschung der Wirksamkeit von Innovationen und der Nutzung geeigneter Studiendesigns, um einen verantwortungsvollen Umgang mit knappen Ressourcen sicherzustellen. Darüber hinaus wird der Schluss gezogen, dass Maßnahmen zur Entscheidungshilfe vielversprechende Mittel zur Unterstützung der täglichen Arbeit von Pflegekräften sind, deren Wirksamkeit jedoch nur schwer objektiv nachgewiesen werden kann.

Valorization addendum

Nowadays increasing attention is being paid to the impact of research findings on society, also referred to as valorization. Valorization can be defined as the "process of creating value from knowledge, by making knowledge suitable and/or available for social (and/or economic) use, and by making knowledge suitable for translation into competitive products, services, processes and new commercial activities."[1] In this chapter, the activities that have been undertaken so far to disseminate the findings of this dissertation will be outlined. Additionally, the societal impact of the research conducted as part of this dissertation will be addressed. As the aims of this dissertation were twofold, this section will address both the societal value of the innovation inventory and the development and evaluation of a decision support App.

DISSEMINATION OF FINDINGS

The findings of this research have so far been distributed via various channels to formal caregivers, care organizations, researchers, policy makers, students, and other stakeholders. Four of the five articles included in this dissertation have been accepted for publication or have already been published in international, peer-reviewed journals. The results have also been presented and discussed at national and international conferences focusing on research on aging in general or nursing. As such publications and conference presentations mainly reach researchers and international experts, other methods have been used to disseminate the findings locally to care organizations, caregivers, and policy makers. This has been done by presenting the findings at local symposia for formal caregivers, such as the yearly symposium of the Living Lab on Ageing and Long-term Care South Limburg and a symposium for district nurses and case managers. A report in Dutch for the Provincial Council for Public Health, which describes the innovation inventory, has also been published. In addition, an article in Dutch about the decision support App has been published in a journal for the employees of a long-term care (LTC) organization in the South of Limburg.

The results of the research conducted as part of this dissertation have also been integrated in different educational activities/programs. Lectures on the project have been given to the Master program Care & Technology and the Master Advanced Nursing Practice at Zuyd University of Applied Sciences. In addition, a web lecture was included in an international exchange program between Zuyd University of Applied Sciences and Chengdu Medical College (China). At Maastricht University, different bachelor students conducted their own research within the project and wrote theses, e.g. about interventions to reduce the burden of informal care, that could serve as input for the content development of the App.

Furthermore, a database containing an overview of innovations by LTC organizations has been published on the website of the Living Lab on Ageing and Long-term Care South

Limburg. On this website, the opportunity has been created for organizations to add new innovations to the database and share knowledge about them publicly. The database has been updated twice (two years after the initial inventory was carried out). However, no innovations have been added without an explicit call from us for updates. Moreover, the contact persons of organizations frequently change, making it difficult to ensure that the database remains updated. Therefore, new ways of sharing information about innovations should be considered.

POTENTIAL SOCIETAL VALUE AND IMPACT

Innovation overview

Internationally there is an increasing need for innovations to deal with the future challenges facing LTC, in terms of increasing demand for LTC, the changing expectations of care recipients, and the lower availability of skilled LTC workers. Both insights into innovations used and/or developed in LTC organizations for older people and the dissemination of this knowledge serve the societal need to find solutions to deal with these future challenges. The innovation database, which was set up as a result of the innovation inventory presented in chapter 1 of this dissertation and subsequently updated twice, makes knowledge about innovations available to the public and can be used by LTC organizations, caregivers, and policy makers. Sharing knowledge about innovations (e.g. in terms of goals, target population, effectiveness, and costs) can have an impact on the innovation management of LTC organizations and has several advantages. Organizations can learn from each other's experiences, which might prevent them from investing in parallel in similar developments or making the same mistakes. Another advantage of sharing knowledge is that it can accelerate the uptake of effective innovations and make more efficient use of promising ones. From a theoretical point of view, a database containing up-to-date information about innovations and their level of effectiveness seems an ideal medium for sharing knowledge and ensuring better use of scarce healthcare resources.

However, establishing and maintaining such a database is challenging as its content requires constant updating. Therefore, the database needs the constant attention of the organizations sharing their knowledge; hence, the process of updating the content needs to be embedded in their work processes. Finally, such a database should be highly user-friendly and as convenient to use as are other search engines, such as Google. The experience gained in this research may serve as a basis for developing other knowledge-sharing platforms. Developers of such a platform might find it useful to start thinking about updates and the integration of the platform/website into the work processes of organizations right from the beginning, in order to ensure that it is in line with the needs of the

target group. Even though the maintenance of a detailed database may be very time consuming and therefore, might not be the optimal measure for facilitating knowledge exchange, the idea of sharing experiences about innovations is still worthwhile. This is actively achieved within the organizations participating in the network organizations Living Lab in Ageing and Long-term Care (AWO) and the Centre of Expertise of Innovative Care and Technology (EIZT), for example by means of symposia, workshops, fact sheets, or projects in which innovations are developed through co-creation by healthcare professionals, researchers/teachers, and companies. In addition, knowledge exchange would ideally not be restricted to certain sectors, such as long-term care, or to a specific region, such as Limburg. It would be valuable to broaden the perspective and search for innovative practices in other sectors that could serve as examples of innovations in long-term care.

The decision support App

As a result of the increased prevalence of dementia, more and more people in society are being confronted with the complex and emotional challenges relating to a dementia diagnosis.[2] A dementia diagnosis not only affects the person diagnosed but also has a major impact on the life of members of that person's social network. Therefore, there is an increasing need for support on how to deal with the consequences of dementia on the daily lives of persons with dementia (PWD) and their informal caregivers/networks. Formal caregivers can play an important role in detecting practical problems in the daily lives of PwD and their informal caregivers and in advising them on possible solutions.

Detecting practical problems and providing well-informed advice on possible solutions are also complex and challenging tasks for formal caregivers. The results of this dissertation could help those with an advisory role in community-based dementia care, such as case managers and district nurses, in different ways. Equipped with knowledge about the most important practical problems preventing PwD from living at home, formal caregivers could pay particular attention to detecting these problems and ensuring that they are up-to-date regarding possible solutions. Ideally, this knowledge would be integrated in the standard work procedures of these professionals. This could be achieved by, for example, referring to the most important practical problems preventing PwD from living at home in the care standard for community-based dementia care. Moreover, this knowledge should be integrated into the curricula of nursing education and that of other formal caregivers with a coordinating role in community-based dementia care, such as general practitioners. General practitioners are often the ones responsible for the early detection of dementia and the referral of PwD to a case manager; therefore, they too should be aware of the practical problems that can prevent PwD from living at home. The focus on facilitating aging in place is also in line with the new program from the Dutch Ministry of Health, Welfare and Sports, "Longer at Home," which was recently proposed to the Dutch House of Representatives. The main goal of this program is to enable older

persons to grow old in their own, familiar, home environment with a good quality of life, by focusing on the major preconditions of good care and support at home—support from informal caregivers and volunteers, and suitable living conditions.[3]

In accordance with its definition, a core element of valorization is the process of making knowledge suitable and/or available for social (and/or economic) use. With the user-centered development of the App knowledge about practical problems preventing PwD from living at home was translated into a decision support tool for formal caregivers in community-based dementia care. Moreover, the App aims to provide tailored insight into problems and possible solutions based on various sources of (evidence-based) information (such as guidelines, databases for assistive technology, etc.). The App makes this knowledge available to formal caregivers at the point of care. Using it, formal caregivers can conduct a problem assessment that is partly based on validated questionnaires and then are automatically directed to an overview of possible solutions pertinent to the problems detected. An important prerequisite is that that the content of the tool be constantly updated, as knowledge is continuously evolving. The work of district nurses, who play a key role in community-based care in the Netherlands and are responsible for performing care needs assessments among other things, is expected to be evidence based.[4] This means that they should use validated instruments when making clinical judgments and be aware of the latest evidence when making decisions about nursing interventions. As the overall body of evidence is continuously growing and new solutions developed, it is very challenging for nurses to meet these expectations in everyday practice. Decision support tools can therefore be seen as an ideal medium for facilitating evidence-based problem assessment and advising on solutions.

The decision support App presented in this dissertation is, in its current version, a tool that can be used only for research purposes. However, the current prototype could serve as a basis for the development of a product that could be used in practice. However, before the practical implementation of the App could be realized, certain factors must be considered. First, a decision must be made on whether it is worthwhile investing in its further development. A lack of efficacy, on the one hand, could lead to the conclusion that it is not worthwhile. However, the enduring enthusiasm of formal caregivers and their perception of its potential added value on the other, underpin the strong need for the App amongst the target group. This need was recently articulated in a proposal for the Dutch quality framework for district nursing (de kwaliteitskader wijkverpleging),[5] which was submitted for approval to the National Health Care Institute on 1st May 2018. In this document, the need for information technology that can give nurses access to the latest information on care and support options, guidelines, and protocols, as well as technology to monitor the situation of clients, was stressed. The decision support App presented in this dissertation and specifically developed for this target group can be seen as one example of how ICT could be used to provide access to information and, moreover, allow the situation of a PwD living at home to be monitored over time. This could be the

motivation needed to pursue development of the App into a commercial product. The information gathered in this dissertation could be used to develop the business case. As part of that business case, what parties might be/are interested in being possible owners of the App and who can provide back-office support and constant up-dates of its content need to be investigated. For this purpose, collaboration between the eventual owner (e.g. an (ICT) company, LTC organization, network organization, interest organization for persons with dementia, health insurance company) and a research institute will be necessary, as ideally the App should ensure that the latest insights from research are available to formal caregivers working in community-based dementia care and ultimately PWD and their informal caregivers.

Overall, decision support tools in the form of apps can be seen as a valuable means of facilitating the dissemination of up-to-date knowledge. They can present information in a tailored way, at the point of care delivery, so it can be used immediately. With an ever-increasing body of (scientific) knowledge and greater pressure on formal caregivers to base their decisions on (scientific) evidence, the need for decision support is expected to increase. The development process of a decision support App for formal caregivers in community-based dementia care, as presented in this dissertation, could be seen as a blueprint for the development of decision support tools for other care problems. Several steps have been undertaken to develop a usable tool that would be of added value to users. First, the core problems to focus on were identified in consultation with the target group. In the second step, the content of the App was developed involving researchers as well as potential end-users. In the third step, the technical development, a step-wise process was followed in which ICT developers built several prototypes that were continuously improved based on feedback from usability evaluations by researchers, experts, and end-users. The continuous involvement of the target group in the different phases of development and evaluation of the App is regarded as the most crucial factor in developing a tool that will be embraced by the target group. The various district nurses and case managers involved in its development or its evaluation remained enthusiastic about it and can therefore be seen as ideal ambassadors for its implementation in practice. The involvement of users in its development ensures that the tool is in line with the professional norms and values of the target group and creates a sense of co-ownership. All these factors could facilitate the actual implementation of the App in practice. To further increase the chance of success, it is recommended that thinking about content updates and tool ownership begin early in the development phase. This could be done, for example, by means of co-creation between researchers, a commercial ICT company, the end-users, and the organizations for whom they work, all of whom share a common interest in implementing the App in practice.

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About the author

Theresa Thoma-Lürken was born on October 23, 1984 in Simmer-ath, Germany. In 2004 she completed secondary school at 'St. Michael Gymansium Monschau' and started her professional education in physiotherapy at the University Hospital Aachen ('Lehranstalt für Physiotherapie am Universiätsklinikum Aachen'). She finished her training in 2007 and received het certificate as state approved physiotherapist in Germany. Afterwards she worked as a physiotherapist for one an half years in Germany. In 2009 she started her bachelor study in 'Health Sciences' at Maastricht University. Alongside her bachelor study Theresa was enrolled in the two-years Honours program 'International Health'. In 2012 she successfully completed both the bachelor study and the Honours program. Theresa continued her education and in 2013 she graduated from Maastricht University with a Master's degree in Healthcare Policy, Innovation and Management. Alongside her studies Theresa worked as a student assistant at the Department of Health Services Research and as a junior staff member at the 'Center of Excellence for Geriatric Rehabilitation" at the Stichting Sevagram in Heerlen.

In 2013 Theresa started working as a PHD-candidate within the 'Living-Lab in Ageing and Long-Term care' at the department of Health Services Research at Maastricht University. During her PhD project she conducted research on (labor-saving) innovations in long-term care for older people and she developed and evaluated a decision support App for formal caregivers in community-based dementia care. Since June 2018 she has been working as a Postdoctoral researcher in the same Living Lab with a specific interest in community-based care and quality of care.

List of publications

INTERNATIONAL JOURNALS

Thoma-Lürken T, Bleijlevens MH, Lexis MA, Hamers JP, de Witte LP. An overview of potential labor-saving and quality-improving innovations in long-term care for older people. *J Am Med Dir Assoc.* 2015;16:482-489.

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Theresa Thoma-Lürken, Michel HC Bleijlevens, Monique AS Lexis, Jan PH Hamers: Efficacy of a Decision Support App for Nurses in Community-based Dementia: a Randomized Controlled Laboratory Experiment. As part of a symposium entiteld: The 'Dutch approach' in community-based nursing: four examples of innovations that aim to facilitate 'ageing-in-place' .1.st International Conference of the German Society of Nursing Science, 4-5 May, Berlin, Germany. Published abstract book available at https://www.egms.de/static/resources/meetings/dgp2018/Abstractband.pdf

Living lab in ageing and long-term care

This thesis is part of the Living Lab in Ageing and Long-Term Care, a formal and structural multidisciplinary network consisting of Maastricht University, seven long-term care organizations (Cicero Zorggroep, Envida, Mosae Zorggroep, MeanderGroep Zuid-Limburg, Sevagram, Vivantes and Zuyderland), Zuyd University of Applied Sciences and Gilde Zorgcollege, all located in the southern part of the Netherlands. In the Living Lab we aim to improve the quality of care and quality of life for older people via a structural multidisciplinary collaboration between research, policy, education and practice. Practitioners (such as nurses, physicians, psychologists, physio- and occupational therapists), work together with managers, researchers, students, teachers and older people themselves to develop and test innovations in long-term care.

ACADEMISCHE WERKPLAATS OUDERENZORG ZUID-LIMBURG

Dit proefschrift is onderdeel van de Academische Werkplaats Ouderenzorg Zuid-Limburg, een structureel, mulitdisciplinair samenwerkingsverband tussen de Universiteit Maastricht, zeven zorgorganisaties (Cicero Zorggroep, Envida, Mosae Zorggroep, MeanderGroep Zuid-Limburg, Sevagram, Vivantes en Zuyderland), Zuyd Hogeschool en Gilde Zorgcollege. In de werkplaats draait het om het verbeteren van de kwaliteit van leven en zorg voor ouderen. Zorgverleners (zoals verpleegkundigen, verzorgenden, artsen, psychologen, fysio- en ergotherapeuten), beleidsmakers, onderzoekers, studenten en ouderen zelf wisselen kennis en ervaring uit. Daarnaast toetsen en evalueren we vernieuwingen in de dagelijkse zorg. Praktijk, beleid, onderzoek en onderwijs gaan hierbij hand in hand.

PHD-THESES LIVING LAB IN AGEING AND LONG-TERM CARE / PROEFSCHRIFTEN ACADEMISCHE WERKPLAATS OUDERENZORG ZUID-LIMBURG

Mirre den Ouden. Every step counts, daily activities of nursing home residents and the role of nursing staff. 2018

Theresa Thoma-Lürken. Innovating Long-term care for older people. Development and Evaluation of a Decision Support App for Formal Caregivers in Community-Based Dementia Care.2018

Bram de Boer. Living at a green care farm. An innovative alternative for regular nursing home care for people with dementia. 2017

Nienke Kuk. Moving forward in nursing home practice. Supporting nursing staff in implementing innovations. 2017

Ramona Backhaus. Thinking beyond numbers. Nursing staff and quality of care in nursing homes. 2017

Irma Everink. Geriatric rehabilitation. Development, implementation and evaluation of an integrated care pathway for older patients with complex health problems. 2017

Martin Van Leen. Prevention of pressure ulcers in nursing homes, a big challenge. 2017

Mariëlle Daamen-Van der Velden. Heart failure in nursing home residents. Prevalence, diagnosis and treatment. 2016

Armand Rondas. Prevalence and assessment of (infected) chronic wounds. 2016

Hanneke Beerens. Adding life to years. Quality of life of people with dementia receiving long-term care. 2016 (Cum Laude)

Donja Mijnarends. Sarcopenia: a rising geriatric giant. Health and economic outcomes of community-dwelling older adults with sarcopenia. 2016

Tanja Dorresteijn. A home-based program to manage concerns about falls. Feasibility, effects and costs of a cognitive behavioral approach in community-dwelling, frail older people. 2016

Basema Afram. From home towards the nursing home in dementia. Informal caregivers' perspectives on why admission happens and what they need. 2015

Noemi Van Nie-Visser. Malnutrition in nursing home residents in the Netherlands, Germany and Austria. Exploring a nd comparing influencing factor s. 2014

Esther Meesterberends. Pressure ulcer care in the Netherlands versus Germany 0- 1. What makes the difference? 2013

Math Gulpers. EXBELT: expelling belt restraints from psychogeriatric nursing homes. 2013

Hilde Verbeek. Redesigning dementia care. An evaluation of small-scale homelike care environments. 2011

Judith Meijers. Awareness of malnutrition in health care, the Dutch perspective. 2009

Ans Bouman. A home visiting program for older people with poor health. 2009.

Monique Du Moulin. Urinary incontinence in primary care, diagnosis and interventions. 2008

Anna Huizing. Towards restraint free care for psychogeriatric nursing home residents. 2008

Pascalle Van Bilsen. Care for the elderly, an exploration of perceived needs, demands and service use. 2008

Rixt Zijlstra. Managing concerns about falls. Fear of falling and avoidance of activity in older people. 2007

Sandra Zwakhalen. Pain assessment in nursing home residents with dementia. 2007