Balanced and prepared

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BALANCED AND PREPARED

Development and evaluation of a supportive e-health
intervention for caregivers of people with early-stage dementia

Lizzy Boots

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Development and evaluation of a supportive e-health intervention for
caregivers of people with early-stage dementia

PROEFSCHRIFT

Ter verkrijging van de graad van doctor aan de Universiteit Maastricht,
op gezag van de Rector Magnificus, Prof dr. L.L.G. Soete,
volgens het besluit van het College van Decanen,
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**NUTRICIA
RESEARCH**

*“Soms is ’t beater iets moeis te verleeze. Beater
verleeze dan dat ge ’t nooit het gehad”*

(Rowwen Hèze – Heilige Antonius)

Voor Opa en Oma

CONTENTS

CHAPTER 1	General Introduction	9
CHAPTER 2	A systematic review of Internet-based supportive interventions for caregivers of patients with dementia <i>International Journal of Geriatric Psychiatry, 2014</i>	21
CHAPTER 3	A mismatch between demand and supply of social support in dementia: a qualitative study on perspectives of spousal caregivers and their social network members <i>Submitted</i>	55
CHAPTER 4	Qualitative study on needs and wishes of early-stage dementia caregivers: the paradox between needing and accepting help <i>International Psychogeriatrics, 2015</i>	79
CHAPTER 5	Development and initial evaluation of the web-based self-management intervention 'Partner in Balance' for family caregivers of people with early-stage dementia: an exploratory mixed-methods study <i>JMIR Research Protocols, 2016</i>	101
CHAPTER 6	Effectiveness of the blended-care self-management program 'Partner in Balance' for early-stage dementia caregivers: study protocol for a randomized controlled trial <i>Trials, 2016</i>	135
CHAPTER 7	Process evaluation to explore internal and external validity of the blended care self-management program 'Partner in Balance' for early-stage dementia caregivers	159
CHAPTER 8	Effectiveness of the blended-care self-management program 'Partner in Balance' for early-stage dementia caregivers: results of a randomized controlled trial	183
CHAPTER 9	General Discussion	203
	Summary	225
	Samenvatting	231
	Knowledge Valorization	237
	Dankwoord	243
	Curriculum Vitae	253
	Publications	255
	Thesis defenses from MHeNS	259

CHAPTER 1

General Introduction

Dementia and Mild Cognitive Impairment

Dementia is a generic term for deterioration in memory and other cognitive functions that facilitate a person's ability to function in everyday life. The most common cause of dementia is Alzheimer's disease, which is characterized by a slow and progressive course.¹

Prior to a dementia diagnosis a transitional state of limited cognitive symptoms and preserved function abilities can occur, also known as Mild Cognitive Impairment (MCI). While MCI is often regarded as the prodromal stage of dementia, a significant proportion of people with MCI remains stable or even improves.² Nonetheless, people in the MCI stage must adapt to their cognitive problems and cope with the uncertainty about their future, which can trigger symptoms of depression and anxiety.³

Informal caregiver under pressure

The majority of people with dementia is living at home and cared for by a family member, the informal caregiver. Informal care will be increasingly important as the number of people with dementia will rise to 65.7 million by 2030 and 115.4 million by 2050, together with a decrease of the working population.⁴

However, informal caregiving has a downside. Caregivers of people with dementia are vulnerable due to the chronic stress they experience in the caregiving process.⁵ Caregivers have an increased risk of becoming depressed compared to non-caregivers,⁶ and 24% of caregivers report clinically significant levels of anxiety.⁷ Moreover, caregivers are susceptible to physical health problems as stress decreases their immune function and increases their disease vulnerability.⁸ Experiencing caregiver strain can even increase the mortality risk by 63%.^{9,10}

Current caregiver interventions

Many caregiver support interventions have been developed to ameliorate negative caregiver consequences. The most promising caregiver interventions focus on the mild to moderate stages of dementia and combine multiple components. Intervention elements that can be distinguished are: psycho-education, psychotherapy (primarily cognitive behavioral therapy), counseling, support groups, and respite care. A meta-analysis of high-quality randomized controlled trials (RCTs) showed promising effects of multicomponent caregiver interventions on delaying institutionalization of the person with dementia.¹¹

Caregiver functioning in different stages of the disease

One of the essential elements in successful intervention programs is the focus on personal characteristics and resources. The efficacy of interventions increases if they are individualized to specific caregiver needs, competencies or characteristics, such as gender, age, educational background and relationship with the care recipient.¹² Another aspect that might influence intervention effects is the stage of the disease, in which the role of the caregiver per stage can be considered as a career consisting of 3 phases: role acquisition or adaptation, role enactment, and role disengagement (Fig.1).^{13,14}

In the role adaptation phase caregivers have to learn to adapt to the changes in their role as family member and learn to cope with losses and occurring issues. Not all caregivers respond similarly to the different phases. Caregivers who use a supportive care strategy are best able to adapt to the changes; they supervise and support the care recipient's activities, communicate calmly or cautiously and try to comply with behavioral problems.⁵ On the other hand, non-adapting caregivers may respond impatiently, irritated or angrily. This confronting care strategy is portrayed by difficulties in understanding and accepting the situation, and increases the risk of depressive symptoms in the caregiver and hyperactivity in the person with dementia.⁵ As a reaction to experienced stressors, some caregivers seek social support and share stressful experiences, which contributes to improved caregiver well-being^{15,16},

while others have low levels of social support, related to increased caregiver burden and depression.^{17,18} These differences in adaptation to the caregiver role and experienced stressors show that a diagnosis alone does not prepare caregivers for future care¹⁴

Early intervention

The timing of caregiver interventions might be crucial in maximizing the effects. Early support might help people with dementia and their caregivers adapt to the changes of early dementia and feel more competent to care. However, the current contrast between highly advanced timely diagnostic tools and the lack of available support to match this early diagnosis is troubling.¹⁹ Efficacious pharmacotherapies are not yet available to cure cognitive disorders, but an early diagnosis offers opportunities to improve early adaptation to the caregiver role. In turn, this may prevent high levels of burden and institutionalization of the person with the dementia in the later stages.

Early support interventions can aim at coping with an insecure future and preparing caregivers for the possibility of further decline and dependency.¹⁴ Early intervention for caregivers proved to be effective in reducing strain and delaying institutionalization of the person with dementia.^{20,21} However, the evidence for early-stage interventions is not yet conclusive and they may do more harm than good if they do not fit the personal situation of the caregiver and care recipient.¹⁴ Taking action might cause a fear of stigma.²² Interventions in the early phase should therefore not be problematizing, but may be particularly beneficial if they focus on adaptation to the caregiver role and actively involve caregivers to tailor the intervention to their needs.¹⁴

Self-management

Offering caregiver interventions in the pre- and early dementia stage asks for different approaches or skills. As levels of stress and burden are still low it provides more opportunities to empower the resources of caregivers.

Caregivers differ in their competence and skills to successfully manage day-to-day issues such as supervising or taking over daily tasks, managing cognitive problems, interpreting and managing behavioral changes, adapting to new social and economic circumstances, coping with relational and emotional consequences, and participating in care and treatment decisions. Those who feel that the demands of caring exceed their capacities will feel stressed, whereas those who feel equipped

will not.²³ The Stress and Coping paradigm by Lazarus and Folkman²⁴ and the Social Learning theory by Bandura²⁵ propose that taking charge of the changes in one's life has a positive effect on self-efficacy, and can therefore reduce caregiver stress and its negative impact on general wellbeing.²⁶ Self-management programs provide an excellent opportunity to actively involve caregivers and let them choose the themes and strategies that are best individualized to their needs. This suits the caring role transition, which sometimes means focusing on positively managing life with dementia rather than managing the dementia itself. There is substantial evidence in other chronic diseases that individuals and families who engage in self-management behaviors improve their health outcomes and quality of life.²⁷⁻²⁹ Teaching self-management techniques such as role management (e.g., balancing activities in daily life) and emotional management (e.g., dealing with fear and insecurity about the future) can foster self-care abilities and promote physical and mental wellbeing.³⁰

E-health technology to promote self-management

Aside from intervention timing, intervention delivery can also be essential to maximize intervention effects. E-health technology offers an opportunity for accessible tailored interventions, which might fill the expected gap in demand and supply caused by demographic aging and a decreasing working population.^{1,31} Additionally, e-health applications may facilitate self-management, as sending and storing self-reports can significantly improve an individual's ability to understand and manage his or her own behaviors.³²

Existing e-health programs for dementia caregivers are mainly aiming at dealing with dementia related problems such as neuropsychiatric symptoms in an advanced stage of the caregiver career. E-health self-management support could suit the early-stage facilitation to the adaptation process, by positively managing one's own life and increasing self-efficacy. It can also potentially bridge barriers to access support services for caregivers that would not utilize traditional healthcare services, due to for example practical reasons, refusal of the care recipient or fear of stigma.³³⁻

37

Aim of the thesis

The main aim of this thesis was to develop and evaluate an e-health self-management intervention for caregivers of people with early-stage dementia. In this thesis we address the following research questions:

1. What is the state of the art with respect to evidence of e-health interventions for caregivers of people with dementia?
2. What problems do caregivers of people with early-stage dementia experience and what are their needs for care and support?
3. How should an e-health self-management program for caregivers of people with early-stage dementia look like and to what extent is such a program feasible?
4. What are the process characteristics and effects of the blended-care self-management program 'Partner in Balance' on self-efficacy, mastery, and psychological complaints (stress, depression, anxiety)?

Outline of the thesis

In **Chapter 2** an overview is provided of the evidence for the effectiveness, feasibility, and quality of studies that focus on Internet interventions for dementia caregivers.

In **Chapter 3** we explore primary caregiver and social network members' needs, perceptions and experiences with respect to informal support.

In **Chapter 4** an in-depth analysis of the problems, needs and wishes of caregivers of people with early-stage dementia and their perspective on need for care during these early stages is provided.

Chapter 5 describes the development of an e-health self-management program for caregivers of people with early-stage dementia and the evaluation of its feasibility and preliminary effectiveness on self-efficacy and goal attainment.

In **Chapter 6** the design of a randomized waiting-list controlled trial investigating the effects and process of the blended-care self-management program 'Partner in Balance' is presented.

Chapter 7 assesses the internal and external validity of the 'Partner in Balance' program and trial and its implementation in a process evaluation.

Chapter 8 investigates if 'Partner in Balance' is superior to the waiting-list control condition as evidenced by improved subjective self-confidence (self-efficacy and mastery), and lower levels of psychological complaints (depression, anxiety, and stress).

In **Chapter 9** the main results are discussed together with a reflection on methodological issues and the clinical and scientific implications of our studies.

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CHAPTER 2

A systematic review of Internet-based supportive
interventions for caregivers of patients with dementia

International Journal of Geriatric Psychiatry, 2014

Lizzy M.M. Boots, Marjolein E. de Vugt, Rosalie J.M. van Knippenberg, Gertrudis
I.J.M. Kempen & Frans R.J. Verhey

ABSTRACT

Objective: Due to the expected increase in the number dementia patients, the unlikelihood of a cure in the near future, and the rising cost of care, there is an increasing need for effective caregiver interventions. Internet interventions hold considerable promise for meeting the educational and support needs of informal dementia caregivers at reduced costs. The current study aims to provide an overview of the evidence for the effectiveness, feasibility, and quality of Internet interventions for informal caregivers of people with dementia.

Methods: A systematic literature search of five scientific databases was performed, covering literature published up to January 10th, 2013. Twelve studies were identified. The quality of the included studies was assessed according to the Cochrane Level of Evidence (LOE) and the criteria list of the Cochrane Back Review Group.

Results: The intervention types, dosage and duration differed widely, as did the methodological quality of the included studies. The overall level of evidence was low. However, the results demonstrate that Internet interventions for informal dementia caregivers can improve various aspects of caregiver well-being, e.g., confidence, depression and self-efficacy, provided they comprise multiple components and are tailored to the individual. Furthermore, caregivers could benefit from interaction with a coach and other caregivers.

Conclusions: Internet interventions for informal dementia caregivers may improve caregiver well-being. However, the available supporting evidence lacks methodological quality. More randomized controlled studies assessing interventions performed according to protocol are needed to give stronger statements about the effects of supportive Internet interventions and their most promising elements.

INTRODUCTION

Worldwide, 36 million people live with dementia, and this number is expected to increase to an alarming 115.4 million by 2050. The global cost of dementia was estimated at 604 billion dollars in 2010.¹ Due to the major increase in the number of dementia patients in the near future, it is expected that the cost of care for dementia will increase by 85% in 2030, possibly making it the most expensive disease of our society.¹

Most patients with dementia live at home and are cared for primarily by their spouse or other family member, the informal caregiver. These informal caregivers often provide years of extensive care for their loved one and encounter continuously changing and demanding situations.² Caregivers of dementia patients often suffer from physical and emotional problems as a result of the stressful and burdensome caregiving process.²⁻⁴ Therefore, they could be referred to - as Brodaty and Donkin⁵ put it - “the invisible second patient”.

Due to the expected increase in the number dementia patients, the unlikelihood of a cure in the near future, and the rising cost of care, there is a growing need for effective caregiver interventions to adequately support the informal caregiver. Many psychosocial interventions have been developed to offer support for informal caregivers of patients with dementia^{6,7} and these interventions have demonstrated great potential in improving caregiver mood, improving caregiver quality of life and delaying the institutionalization of the care recipient. Olazaran and colleagues⁸ found that these interventions can delay institutionalization for up to 1.5 years. These results are noteworthy, considering that a single day at a nursing home in the USA costs approximately 200 Dollars.⁹ Therefore, interventions aimed at reducing care burden and depression and at increasing feelings of competence among informal caregivers might reduce dementia care costs.

Most currently available interventions are ‘face-to-face’ interventions, but the predicted increase in the number of people with dementia has led to concerns about whether the current labor force can cope with such an increased future demand.¹⁰ E-health interventions could be an efficient alternative to continue to provide education and support for the informal caregivers^{11,12} at reduced costs.¹³ In addition, interventions offered via the Internet likely exhibit a lower threshold of access for participation since informal caregivers can access help in the privacy of their own homes without leaving their loved ones alone. Technology can also reach people who are isolated and have difficulties accessing traditional services.¹⁴ Internet

interventions might help future informal caregivers cope with the challenges of caring for a person with dementia and, as a result, may keep patients at home as long as possible.¹⁵

This systematic review aims to assess the effectiveness and feasibility of Internet-based interventions for informal caregivers of people with dementia and to evaluate if such interventions indeed improve caregivers' well-being. Previous reviews^{16,17} that have discussed technology supporting the needs of people with dementia and their caregivers only covered literature up to February 2007. In addition, such studies focused more on assistive technologies for patients and formal caregivers¹⁶ or compared technology-based interventions with non-technology-based interventions.¹⁷ The rapid growth of older adults using the Internet in the last few years¹⁸ underlines the importance of investigating Internet interventions as a source of support for this group. The current review aims to address the following objectives: (I) to present an overview of the evidence of the effectiveness and quality of Internet interventions for the informal caregivers of patients with dementia; (II) to assess which types of interventions are most effective (i.e., provide the best outcome for the participants); and (III) to indicate the feasibility of such interventions.

METHODS

Search strategy

A systematic literature search was conducted in PubMed, Psycinfo, Cinahl, Web of Science and the Cochrane Library as well as searches of references listed in the reviewed papers and meta-analyses. The search was restricted to effect studies on Internet-based interventions for informal caregivers (e.g., spouses/children/children-in-law) of individuals with dementia or Mild Cognitive Impairment (MCI). For practical reasons, the search was limited to papers written in English and Dutch. We used MESH and Thesaurus terms, in addition to free text words, covering all studies published between January 1988 (start search engines we used, and Web of Science) and January 2013. For an overview of the search terms that were used, see Box 1.

Box 1. Search Strategy

Search terms	
1	<p>PubMed: Internet (MeSH) OR online (MeSH) OR electronic (MeSH) OR technology (MeSH) OR e-health OR telecomputing (title or abstract or keyword)</p> <p>Psychinfo and Web of Science: Internet (Thesaurus) OR Online Therapy (Thesaurus) OR Computer Mediated Communication (Thesaurus) OR Technology (Thesaurus) OR e-health (title or abstract or keyword)</p> <p>The Cochrane Library: Internet (MeSH) OR technology (MeSH) OR e-health (title or abstract or keyword)</p> <p>CINAHL: Internet (Thesaurus) OR online (Thesaurus) OR electronic (Thesaurus) OR technology (Thesaurus) OR e-health OR telecomputing (title or abstract or keyword)</p>
2	<p>PubMed: intervention (MeSH) OR program (title or abstract) or therapy (title or abstract or keyword)</p> <p>Psychinfo and Web of Science: Intervention (Thesaurus) OR Mental Health Programs (Thesaurus) or therapy (Thesaurus) (title or abstract or keyword)</p> <p>The Cochrane Library: program (title or abstract or keyword) OR intervention OR therapy (title or abstract or keyword)</p> <p>CINAHL: intervention (Thesaurus) OR program (Thesaurus) (title or abstract) or therapy (title or abstract or keyword)</p>
3	<p>PubMed: dementia (MeSH) OR Alzheimer disease (MeSH) OR MCI (title or abstract)</p> <p>Psychinfo and Web of Science: dementia (Thesaurus) OR Alzheimer's disease (Thesaurus) OR MCI (title or abstract or keyword)</p> <p>The Cochrane Library: dementia (MeSH) or Alzheimer disease (MeSH)</p> <p>CINAHL: dementia (Thesaurus) OR Alzheimer disease (Thesaurus) OR MCI (title or abstract or keyword)</p>
4	<p>PubMed: caregivers (MeSH) OR family (MeSH) (Title or abstract or keyword)</p> <p>Psychinfo and Web of Science: caregivers (Thesaurus) OR family OR family members (Thesaurus) OR spouses (thesaurus) (title or abstract or keyword)</p> <p>The Cochrane Library: caregivers (MeSH) OR family (MeSH) (title or abstract or keyword)</p> <p>CINAHL: caregivers (Thesaurus) OR family (Thesaurus) OR spouses (Thesaurus) (title or abstract or keyword)</p>
5	#1 AND #2 AND #3 AND #4

Selection of studies

The papers selected for this review met the following criteria: (1) reported the effects (quantitative and qualitative) of an intervention; (2) were Internet-based; and (3) were aimed at informal (non-professional) caregivers of (4) patients with MCI/ dementia. No methodological quality restrictions were imposed. Papers were excluded if the intervention was solely aimed at the patient instead of the caregiver. Based on the above criteria, the titles and abstracts of the obtained studies were assessed by two authors (LB, MdV). When the title and abstract did not provide sufficient information concerning the criteria, full copies of the articles were retrieved and screened. The corresponding authors of the studies were contacted when additional information was required to assess whether the studies met the criteria for inclusion. Two reviewers (LB, RvK) screened the full copies of the selected studies for their eligibility. Any disagreement about the inclusion of papers was discussed in a consensus meeting with a third reviewer (MdV). Figure 1 presents a flowchart illustrating the selection process. The initial search resulted in a total of 219 intervention studies, of which 49 met the inclusion criteria. These studies were further analyzed and resulted in nine studies that described Internet-based interventions aimed at informal dementia caregivers. All reviewers (LB, RvK, MdV) checked the reference lists, which resulted in the inclusion of three additional articles.

Quality assessment

To assess the methodological quality of the included trials, we used the criteria list of the Cochrane Back Review Group¹⁹ to specifically rate descriptive, statistical and internal validity aspects. Because it is impossible in psychosocial intervention trials to blind the therapists to the intervention, this item was not included as one of the quality criteria, but blinding of outcome assessors was included. Scores on validity items theoretically ranged from zero to nine per study. Each item was scored positive (+), negative (-), or undefined (?) if information was not provided or was unclear. Studies were considered to be of “higher methodological quality” if at least four items scored positively.²⁰ In addition to the criteria of the Cochrane Back Review Group, we used the level of evidence (LOE) grade according to the Oxford Centre for Evidence-Based Medicine guidelines²¹ to broadly categorize the study designs of the selected articles displayed in Table 1. The LOE rates studies based on their design, proposing a hierarchy of study designs in ascending order of bias control.

Figure 1. Flowchart of The Search Strategy

For instance, the presence of randomization, prospective follow-up and replication of evidence raises the ranking of a study within the hierarchy and thereby the level of evidence. Level one is the highest level of evidence, including high-quality systematic reviews; level five is the lowest level of evidence, including the so-called expert opinion. The grading system is widely accepted and often used to apply weights to individual studies according to their methodological quality²²⁻²⁴. Finally, the process characteristics of the interventions were reviewed by checking whether the

intervention studies provided information on the following: (a) the characteristics of the facilitator; (b) the compliance of participants with the intervention; (c) the dropout rate during the intervention; (d) the reasons for dropout during the intervention; (e) the performance of intervention according to its protocol; (f) the feasibility of the intervention; and (g) recommendations for improving the intervention. A similar approach was used by Zijlstra and colleagues²⁵.

Two authors (LB, RvK) independently reviewed the methodological quality of the included studies. Disagreement between the researchers was resolved in a consensus meeting together with the second author (MdV), who gave the decisive judgment.

Data extraction

Relevant studies were examined for their study characteristics, participant characteristics, setting and content of the intervention, methodological quality, process characteristics and the outcome data or results found. To this end, we used a standardized data extraction form, as suggested by the Cochrane Handbook for Systematic Reviews of Interventions²⁶. Because the studies were expected to be heterogeneous in terms of design, sample sizes, methods, and interventions (Table 1), we decided not to statistically pool the data to perform a quantitative meta-analysis.

RESULTS

Study characteristics

The search resulted in 12 articles that were included for review. All studies were aimed at improving informal caregiver functioning; however, the selected studies were heterogeneous in various aspects (Table 1). The design of the studies differed substantially, as did the number of study samples, ranging from 11²⁷ to 700.²⁸ Table 1 shows a more detailed description of the participants. In addition, the studies differed in terms of study duration, setting and intervention characteristics. The following intervention types were identified: a website with information and support on various aspects of caregiving,²⁸⁻³⁵ a website with additional caregiving strategies,³⁶ a website combined with telephone support,³⁷ a website with additional e-mail support,^{28,29} and a website with a combination of individual work and exchange with other caregivers online.^{27,28,30-32,35}

In four of the 12 interventions the program was tailored to the individual needs of the informal caregiver,^{30,34,37,38} and in two of these studies, participants were guided by a coach.^{30,37} Five studies included a control group. Control conditions consisted of care as usual,^{34,35} waitlist controls,³⁸ an onsite workshop conducted in seven weekly face-to-face sessions,²⁷ and placebo online training to identify local services and resources.³³ The dosage and duration of the interventions varied greatly; some intervention programs were available for a longer period of time, but the actual time spent online was not mentioned or limited,^{28,33,34,38} whereas others^{27,30,37} comprised a fixed intervention dosage in the form of weekly sessions. All studies focused on more than one caregiver functioning-related outcome. The most commonly addressed topics included self-efficacy, stress/burden, depressive symptoms, coping, social contact/support, knowledge, utilization of health services, and general (mental) health. A few included studies focused on additional topics, including positive aspects of caregiving, needs met or goals attained and caregivers' quality of life.

Validity and methodology

The second-to-last column of Table 1 contains the level of evidence (LOE) as graded by the Oxford Centre of Evidence-Based Medicine.²¹ The LOE for the studies included in this review ranged between two and three. Three papers^{27,33,38} received an evidence score of two. Most studies (n=9) exhibited level three evidence. Of the 12 selected studies, three were randomized controlled trials,^{27,33,38} four used mixed methods designs with qualitative and quantitative measures,^{28-30,32} and one made use of a single-group pretest-posttest design.³⁷ There was one quasi-experimental study,³¹ two pretest-posttest multiple groups designs,^{34,35} and one formative evaluation.³⁶

Table 1. Characteristic, Measures and Outcomes of Internet Intervention for Dementia Caregivers

Author/year	Design	Setting	Study population	Control group	Intervention	Measures	Findings	Level of evidence*	Comments
Brennan et al., 1995	RCT, randomized field experiment with 12-month follow-up.	In-home website access. Recruited via resource registry of Alzheimer's disease research center, support groups, self-referral.	Dementia family caregivers (N = 102), mean age = 64, female (67%), spouses (68%) or children (28%).	CG (N = 51), received a placebo training experience	Initial home interview (time 1), 90-minute training session, monthly phone calls on service use + final interview at 12 months (time 2). 24-hour access to ComputerLink: website (information, decision support, communication). Enhancing self-care; understanding	DCS, DMS, IESS, monthly telephone calls on service use.	Difference in decision-making confidence ($F(1,93) = 9.73$, $p < .01$), NS difference in decision-making skills ($F(1,95) = 1.69$, $p = .20$), social isolation ($F(1,95) = .43$, $p = .51$), health status ($Z = .327$; $p > .05$), and use of total number of community and medical services by	2	

of AD; promoting health management of the care recipient.						caregivers ($t = -.45$, 82 df; $p = .65$).
Beauchamp et al., 2005	Pretest-posttest RCT with a 30-day follow-up.	Web-based support, on-screen informed consent and online pretest (T1) and posttest (T2) surveys. Recruited via wire service, advertising, contact notices, e-mail announcements, newsletter articles and website	Employed (at least part-time) family caregivers of persons with dementia (N = 299), mean age = 46.9, female (73%), spouses (7%), children (67%),	CG (N=149) consisted of waitlist controls with no attention-placebo. After T2, controls were also free to view Caregiver's Friend.	Dealing with Dementia: web-based multimedia intervention, text material and videos. Tailored to the individual through a questionnaire. Three module; aimed at knowledge, cognitive, and behavioral skills, affective learning, Only online modules and reminder e-mails.	CSI, PAC, CES-D, STAI. Difference in self-efficacy ($F = 5.87$, $p = .016$), intention to get support ($F = 9.76$, $p = .002$), caregiver gain ($F = 5.35$, $p = .021$), caregivers stress ($F = 15.19$, $p < .001$), caregiver strain ($F = 4.90$, $p = .028$), depressive symptomatology ($F = 6.83$, $p = .009$), state anxiety ($F = 4.78$, $p = .030$). NS change in self-reported frequency of employing specific stress-reduction

	promotional flyers.	other relatives (23%), nonrela- tives (3%).	strategies ($F = 0.01$, $p = .971$).	
Chiu et al., 2009	Mixed method design, usability + intervention study, 6- month- intervention, with pre- and posttest measureme nt and follow-up interviews.	Website, password- protected with e-mail. Usability study conducted in a laboratory, interviews + online questionnair e. Participants recruited from non- profit senior organization	No CG. Caregiver-therapist e-mail support and bilingual information Web portal.	BSFC, RMBPC, CES-D, SRH, MSPSS, PAC, CCS. NS change in BSFC score. NS difference in BSFC change score between three groups of non-users, occasional users, frequent users ($F =$ 1.78 , $p = .019$). Difference on BSFC change score between non-users and frequent users ($t(17) = 2.50$, $p =$ 0.02).

	intervention, quantitative measures pre-test and post-test, qualitative measures post-test.	week, online coaching by health care professional, SOS contact button, online registry for participation. E-mail screening for eligibility.	s (N = 26), mean age = 61.3, female (88%), children (58%), spouses (19%).	exchange with other caregivers online; 7 psycho-educational sessions (60-90 minutes, once a week); exercises with specific individual objectives and learning activities. Online coaches, 3 times per week online Q&A at set times.	qualitative interview.	1.62(3.58), $p = .03$, challenge (1.32(3.12), $p = .05$), self-control (1.31(2.81), $p = .04$), health risk (-0.87(1.52), $p = .007$), goal attainment (GAS > 0). NS change in coping skills (1.48(6.95), $p = .31$); (2.04(6.49), $p = .12$), stress management (0.36(2.74), $p = .57$).	coach, convenient access to program, anonymity. Negative: Lack of interaction with other participants
Glueck et al., 2004	16-week single-group pre-test (1 week prior to the start) and post-test (1 week after	In-home online classes once per 2-3 weeks in groups. Recruited via senior	Dementia caregiver s (N = 21), mean age = 64.4, female	No CG. Alzheimer's Caregiver Support Online (AlzOnline): Tel and Internet: Six 45-minute live, interactive classes on stress, interpersonal	R-CSES SRGS, CAI.	Difference on all R-CSES subscales ($F = 6.90$, $F = 6.07$, $F = 6.91$, $p = 0.02$), subjective burden ($F = 8.16$, $p = 0.01$), perceived self-efficacy. NS change	Only preliminary assessment.

<p>its completion) design.</p> <p>service, dementia care, caregiver consumer groups via e-mail and fax. Screening and assessment via telephone.</p>	<p>(86%), spouses (62%), children (38%).</p>		<p>communication + family relationships, emotional well-being and setting/ implementing personal caregiving goals.</p>		<p>on positive dimensions of caregiving experience ($F = 1.18, p = 0.29$; $F = 2.50, p = 0.13$), perceptions of time burden in providing caregiving assistance ($F = 1.55, p = 0.23$).</p>	
	<p>Secure website with personal password with 24-hour access.</p>		<p>Link2Care: information library: fact sheets, articles, website links, "Ask the Expert", personal consultation with technical experts in caregiving, law and health; peer-moderated support</p>		<p>Increased knowledge (66%), increased coping with caregiving and reduced feelings of isolation (60%). Internet availability very helpful (80%), website recommended to other caregivers</p>	
<p>Kelly, 2004</p>	<p>Client satisfaction study, 1 year, mixed design quantitative/ qualitative.</p>	<p>Secure website with personal password with 24-hour access. Participants recruited via Caregiver Resource Centers.</p>	<p>Dementia caregiver s ($N = >700$ between 2003 and 2004), age: 40-79 (87%), female 75%.</p>	<p>No CG.</p>	<p>Client satisfaction surveys.</p>	<p>3 Top 5 features: updated news and research, information articles and fact sheets, online discussion</p>

	Online intake screening.	Primary dementia caregivers (N = 11).	CG (N = 8) consisted of onsite workshop, 7 weekly 2h face-to-face sessions, facilitated by social workers or nurses.	Ginkgo: website; 7-week online training workshop + online support forum.	CES-D, GHQ-30, Alzheimer's Disease Knowledge Test, Zarit Burden Interview, WHO-QoL-brief version, individual interview.	Between groups: Difference in knowledge ($p = 0.03$) for online group. NS difference in depression/burden, well-being, quality of life. <i>Control group</i> : Decrease in anxiety, depression, well-being ($p = 0.03$), quality of life ($p = 0.03$). Internet convenient, gained knowledge, skills.	2	Pilot study, only 3 participants in intervention group.	groups, "Ask the Expert" + local educational event listings.
Lai et al., 2013	Pre-test post-test RCT, 7-week intervention period.	Website with online workshop.							

Lewis et al., 2010	Iterative process on content development and formative evaluation.	Caregivers recruited via Alzheimer's Association and advisory board members. Online consent form, demographic information.	Dementia caregivers (N = 47), mean age = 55 (SD = 9, range 32-87). Female (85%), college graduate (65%).	No CG.	Internet-Based Savvy Caregiver (IBSC) program: Internet-based program: 4 modules: effects of dementia, taking charge and letting go, providing practical help and managing daily care and difficult behavior. Videos, written descriptions, examples of typical caregiver responses + strategies for caregivers to use.	and positive coping.		
						CS, PS + strengths and weaknesses	Percentage participants scoring agree (4) to strongly agree (5)	Formative evaluation.
						length, usefulness, suggestions for improvement	CS: Confidence on caregiver skills (93.6%), knowledge on caring (95.7%), knowledge on disease changes (76.6%), confidence/comfort in communication with care recipient (100%), confidence/comfort in caring (87.2%).	3
Marziali and Garcia, 2011	Quasi-experimental study, 2 groups:	Multisite (3 cities), bilingual (English and	Dementia caregivers (N = 91, CG N =	No CG, Comparison between	Online Dementia Caregiver Information Handbook; e-mail	HSQ 12, CES-D, SMAF, current	Both groups: Change in self-efficacy (F = 4.3, p ≤ .04) post-	3 RCT not used: Different levels of

Chat Group	French Canadian study. Pass-word protected	40: VG N = 51). Mean age = 65.51, female (72%), spouses (74%), children (26%).	CG and VG.	list of group members, chat forum, video conferencing link for group meetings, library of educational videos.	service use, EPO-R, R-CSES, MSPSS	intervention. NS change in utilization of health and social services. <i>Between groups</i> : VG: Change in mental health ($F = 5.69, p \leq .02$), distress ($F = 5.65, p \leq .02$). CG Change in distress scores associated with managing IADL ($F = 5.79, p \leq .02$).	comfort with- and commitment to using technology among dementia caregivers.
Torp et al., 2008	Multimethod evaluation model, 7-month intervention; pretest +	In-home intervention on PC + group meetings + 'help' call-	Informal caregiver s of frail elderly (dementia, stroke)	No CG. ACTION: ICT course, three 3-hour classes (in 3-week period): disease information, care for patients, nutrition,	ICT use, need for knowledge, FFCS, RSS, GHQ-20) + 4 focus	ICT use: several times a day (47%), once a day (32%), several times a week (11%), once a week (5%). Change in	Small N, pilot study.

12-month follow-up.	center. Participants recruited by general practitioners, hospital physicians, and nurses + newspaper advertisement	living at home ($N = 19$), mean age = 73, female (42%), spouses (100%).	social services, being a family carer + online discussion forum. Option to interact with other participants via videophone + 3 hour- Internet training in using and collecting information.	group interviews 1 individual interview.	need for information ($p = 0.01$), social support (SS) ($p = 0.04$), sense of SS ($p = 0.01$). Supported in focus groups (FG). NS increase in stress, mental health problems ($p = 0.3/p = 0.4$). Not supported in FG.			
van der Roest et al., 2010	Pretest-posttest control group design, baseline measurement and 2-month follow-up.	In-home intervention: 2-month access online. Recruited via general practitioners, various dementia centers, and children	Informal dementia caregivers ($N = 28$), mean age = 65.05, female (79%), children	CG ($N = 14$) received care as usual.	DEM-DISC (DEMENTIA-specific Digital Interactive Social Chart): clarifying needs to specific demands in a 3-step procedure, general and tailored information on available dementia care and welfare	CANE, use + knowledge of services list, SSCQ, PMS, QoL-AD.	<i>Patients and carers:</i> Change in met needs ($F = 3.26$, $p = 0.05$; $F = 3.26$, $p = 0.00$), unmet needs ($F = 3.93$, $p = 0.03$; $F = 2.97$, $p = 0.05$). <i>Carers:</i> Change in feeling of competence ($F = 4.11$, $p = 0.03$), NS	3 Pilot study, regional restriction to 2 Amsterdam districts.

newspaper articles.	(43%), spouses (39%), other (18%).	services, information on caregiving.	change in number of needs, self-efficacy, care use, quality of life, services knowledge.
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* Levels of evidence were rated according to the Oxford Centre for Evidence-Based Medicine guidelines³⁹⁻⁴¹ and range from 1 to 5, with lower numbers indicating higher quality.

CG = control group; NS = not significant.

BSFC = Burden Scale for Family Caregivers; CAI = Caregiver Appraisal Inventory; CAMI = Carers' Assessment of Managing Index; CANE = Camberwell Assessment of Need for the Elderly; CCS = The Caregiver Competence Scale; CES-D = Center for Epidemiological Studies Depression Scale; CS = The Caregiver subscale; CSES-R = The Revised Caregiving Self-efficacy Scale; CSI = Caregiver Strain Instrument; DCS = Decision confidence scale; DMS = Decision-making skill; EPO-R = The Eysenck Personality Questionnaire Revised; FFCS = Family and Friendship Contact Scale; GAS = Goal Attainment Scale; GHQ-20 = General Health Questionnaire – 20; GHQ-30 = General Health Questionnaire – 30; HSQ-12 = Health Status Questionnaire – 12; HRA = Health Risk Assessment; IESS = The Instrumental and Expressive functions of Social Support; MSPSS = Multidimensional Scale of Perceived Social Support; OARS MFAQ = The OARS Multidimensional Functional Assessment Questionnaire; PAC = The Positive Aspects of Caregiving (PAC); PMS = Pearlin Mastery Scale; PS = Program subscale about usability, clarity, amount of information and format; RMBPC = The Revised Memory and Behavior Problems Checklist; RSS = Relative Stress Scale; SAM = Stress Appraisal Measure; SRGS = Stress-related Growth Scale; SRH = The Self Rated Health index; SSCQ = Short Sense of Competence Questionnaire; STAI = The State-Trait Anxiety Inventory; SES = Self-efficacy Scale; SMAF = Functional Autonomy Measurement; QoI-AD = Quality of Life Alzheimer's Disease Scale; WHO-QoI-brief version = World Health Organization Quality of Life Measure.

Table 2. Methodological Quality of Included Intervention Studies

<i>Author/year</i>	Brennan et al, 1995	Beauchamp et al, 2005	Chiu et al, 2009	Couhehan, 2011	Ducharne et al, 2011	Glueckauf et al, 2004	Kelly, 2004	Lai et al, 2013	Lewis et al, 2010	Marzilli and Garcia, 2011	Torp et al, 2008	V/d Roest et al, 2010
Descriptive items												
Eligibility criteria clearly specified	+	+	+	-	+	+	+	+	-	+	+	+
Index and control interventions explicitly described	+	+	¹	-	¹	¹	¹	+	¹	+	¹	+
Description of adverse effects	+	-	-	-	+	-	-	-	+	+	+	-
Short-term follow-up measurement (directly post intervention)	+	+	+	+	+	+	?	+	+	+	+	+
Long-term follow-up measurement ($\geq$ 6 months post intervention)	-	-	-	-	-	-	?	-	-	-	-	-
Statistical items												
Sample size for each group described	+	+	¹	+	¹	¹	¹	+	¹	+	¹	+
Point estimates and measures of variability presented	+	+	+	+	+	+	-	-	+	+	+	+
Validity items												
Method of randomization performed	+	+	-	?	-	-	-	+	-	-	-	-
Treatment allocation concealed	-	?	NA	?	NA	NA	NA	?	NA	-	NA	-
Groups similar at baseline regarding age, sex and outcome variable	+	+	NA	?	NA	NA	NA	-	NA	-	NA	-
Co-interventions avoided or comparable	?	?	?	?	+	-	?	+	?	?	?	?
Compliance acceptable in all groups	+	+	?	?	?	?	?	?	+	?	?	?
Outcome assessor blinded to the intervention	?	?	NA	?	NA	NA	NA	?	NA	-	NA	?
Withdrawal/dropout rate acceptable ^b	+	+	+	-	-	-	?	?	-	?	+	+
Timing of outcome assessment in both groups comparable	+	+	NA	+	NA	NA	NA	+	NA	+	NA	+
Intention-to-treat analysis	?	-	+	+	?	-	?	?	-	+	-	+
Total internal validity items (+) (range 0-9)	5	5	2	2	1	0	0	3	1	3	1	3

+ = criterion fulfilled; - = criterion not fulfilled; ? = data not provided or unclear; NA = not applicable ^a no control group ^b max. 20% for short-term follow-up and 30% for long-term follow-up

Table 3. Process Characteristics of the Interventions

<i>Author/year</i>	Brennan et al., 1995	Beauchamp et al., 2005	Chiu et al., 2009	Coultan, 2011	Ducharme et al., 2011	Glueckauf et al., 2004	Kelly, 2004	Lai et al., 2013	Lewis et al., 2010	Marzalli and Garcia, 2011	Torp et al., 2008	v/d Roest et al., 2010
<i>Is information provided on:</i>												
Characteristics of the facilitator	+	+	+	-	+	-	+	+	-	+	+	+
Compliance of participants to the intervention	+	+	+	-	-	+	-	-	+	+	-	+
Dropout during the intervention	+	+	+	+	+	+	-	-	+	-	+	+
Reasons for dropout during the intervention	+	-	+	-	+	+	-	-	-	-	+	+
Performance of the intervention according to protocol	-	-	+	-	-	+	-	-	-	+	-	-
Feasibility of the intervention	+	+	+	+	+	-	+	+	+	+	+	+
Recommendations for improvement	-	-	+	-	-	-	-	-	+	-	+	+
Total of fulfilled items (range 0-7)	5	4	7	2	4	4	2	2	4	4	5	6

+ = criterion fulfilled, - = criterion not fulfilled

As shown in Table 2, the methodological quality of the included studies varied. The observed total internal validity score ranged from zero to five out of nine. Two of the 12 included trials fulfilled five criteria and were considered to be of good methodological quality.^{33,38} Five of the 12 studies included a control group,^{27,33-35,38} but only three used a random assignment procedure.^{27,33,38} Concealment of treatment allocation, avoided or comparable co-interventions, blinding of the outcome assessor and an intention-to-treat analysis were often not described, or were unclear. None of the selected studies included, or did not clearly specify, a long-term follow-up period. In contrast, all of the studies described the sample size, and most of the studies explicitly specified eligibility criteria,^{27-34,37,38} performed a short-term follow-up measurement,²⁹⁻³⁸ and presented point estimates and measures of variability.²⁹⁻³⁸

Process characteristics

Table 3 presents the reported process characteristics of the interventions. The observed total number of fulfilled items ranged from two to seven. Of the seven process items across the 12 trials, 58% (49/84 items) were fulfilled. On average, nine of the included trials presented clear information on the facilitator conducting the intervention,^{27-34,38} 11 on feasibility of the intervention,^{13,27-35,38} and seven on the compliance of the participants.^{29,31,33,34,36-38} Recommendations for improvement of the intervention were specified in four articles^{29,32,34,36} and information on the performance of the intervention according to protocol was less commonly reported; three papers^{29,31,37} provided this information.

Outcomes

Quantitative outcomes

Overall, (small) significant primary outcome effects of the intervention were observed in six studies. Specifically, improvement of the caregiver's well-being was observed in measures of depression,^{35,38} sense of competence,³⁴ decision-making confidence,³³ self-efficacy,^{30,31,37,38} and burden.^{35,37} Then again, caregiver burden did not decrease significantly in all studies.^{27,29} Chiu and colleagues²⁹ did, however, observe significant differences in caregiver burden between non-users and frequent users of the program. Additionally, increased intention to seek support was reported,³⁸ as well as caregiver gain³⁸ and self-control,³⁰ whereas caregiver stress and strain decreased.³⁸ Furthermore, in one study, caregivers reported being able to achieve their previously set objectives.³⁰

Lack of effect was also reported. For instance, no significant effects between groups or within the treatment group were found with respect to quality of life³⁴ or coping skills.³⁰ Additionally, the use of stress management techniques among caregivers³⁰ and social isolation and health status did not improve.³³ In addition, one study reported improvements in the control group (onsite workshops) rather than the intervention group. In this control group, anxiety and depression decreased significantly and well-being and quality of life increased. People in the online intervention group did not improve with respect to these outcomes.²⁷

Qualitative outcomes

Several studies reported carers' experiences as additional outcomes of their interventions, collected through individual- and focus group interviews post-intervention. Increased knowledge of the disease and caring was described in some papers,^{27,28,36} in addition to increased coping with caregiving,^{27,28} confidence in caregiver skills^{27,30,36} and reduced feelings of isolation.²⁸

DISCUSSION

In this review, we aimed to provide a systematic overview of the effectiveness and feasibility of supportive Internet-based interventions for informal caregivers of patients with dementia. We identified 12 studies that investigated the effectiveness of different dementia caregiver-oriented interventions delivered through the Internet. The outcomes demonstrate that Internet interventions can result in positive effects on the well-being of informal dementia caregivers. In particular, multicomponent programs that combined information, tailored caregiving strategies and contact with other caregivers resulted in positive effects on confidence, self-efficacy, stress, burden and depression.^{30,31,35,37,38} Internet interventions that focused primarily on providing caregivers with information were less likely to improve caregiver well-being.^{33,34} These results are consistent with the conclusions of Gitlin and colleagues,⁴² emphasizing the need for tailored and multicomponent interventions. The results also demonstrate that guidance by a coach could be a noteworthy extension to an online intervention for informal dementia caregivers.^{30,37} The importance of a coach or therapist has also been demonstrated in Internet treatments for depression.⁴³ Furthermore, caregivers themselves stressed the benefits of guidance by a coach; they stated that these exchanges increased their commitment to the intervention and boosted their confidence to implement learned strategies.³⁰

Moreover, Lai and colleagues²⁷ mentioned that the support function of online interactions between caregivers should not be overlooked. The latter is supported by the findings of Ducharme et al.³⁰; caregivers who followed their program also mentioned a specific need for contact with other caregivers, specifically to break their isolation and to feel more 'normal'. Nonetheless, assessment of the process characteristics in the included studies indicates that performance according to protocol is often ignored or not reported, making it more difficult to interpret specific intervention effects and feasibility.

It should be noted that the methodological quality of the majority of the included studies was limited. Only five studies^{27,33-35,38} compared the results of the intervention with a control group, and most studies (n=9) exhibited a LOE of three or lower, indicating a low quality of evidence. However, since we used two quality appraisals to rate and categorize the investigated studies, it is possible that some studies received too negative ratings. In addition, even though two reviewers rated methodological quality and process characteristics independently, we should remark that it was difficult to score all items for the included studies. For instance, compliance with the intervention was difficult to assess because most studies failed to mention compliance and because the studies that did report compliance failed to indicate when compliance was considered acceptable. It can be difficult to state what acceptable compliance is, as it is very hard to determine the acceptable intensity, duration or number and frequency of sessions for Internet interventions. Most studies did not state how often participants should visit the website, and one study³⁸ identified favorable outcomes with an average of only 32 minutes of exposure to the program. A possible explanation is that participants in the treatment group may have gone on to visit other websites or seek resources outside the intervention, which also can be seen as a positive consequence of the program³⁸. In addition, our results demonstrate that none of the included studies described or concealed treatment allocation. This might be because it is nearly impossible to blind the participants in psychosocial intervention trials with respect to the intervention to which they have been assigned. Overall, the studies with a higher evidence quality based on the LOE and the criteria list of the Cochrane Back Review Group^{33,38} supported the findings of the importance of multicomponent, tailored Internet interventions to improve caregiver functioning on confidence, self-efficacy or depression. Nevertheless, it is possible that only positive results were published, indicating a publication bias in the available evidence. More research with randomized controlled samples assessing

interventions performed according to protocol is needed to make stronger statements about the effects of supportive Internet interventions and their most promising elements.

The current review is not without limitations. First, the included studies consisted of complex and inconsistent interventions and designs, making pooling of the data impossible. Therefore, it was more difficult to compare the outcomes of the studies. However, we did strengthen the consistency of the results of the present study through the use of a standardized data extraction form²⁶. Second, as we wanted to achieve a comprehensive coverage of literature and as high-quality studies were scarce, we included many low-quality studies, resulting in the possibility of bias in a number of areas. For our conclusions, we focused mainly on studies of higher quality and, as mentioned, some studies may have received too negative ratings. Nevertheless, the results should be interpreted with caution.

Despite these limitations, we can conclude that Internet interventions to support dementia caregivers are a relatively new but promising extension to the currently offered care as usual. Caregivers of patients with chronic diseases, such as brain damage⁴⁴ and heart diseases,⁴⁵ already use supportive technology and report positive effects on well-being. At present, the growth of remote support for dementia caregivers is increasing, given the current development of new Internet interventions^{46,47} and telephone interventions.^{39-41,48} Although telephone interventions are qualitatively different, research on effects of telephone interventions concurs with the outcomes of the currently reviewed Internet-based studies. Combining tailored information with the help of a coach and the possibility to interact with other caregivers results in successful outcomes for dementia caregivers.³⁹⁻⁴¹ These recent developments could provide a promising prospect for the digital generation of supportive interventions.

This review might cause healthcare professionals to consider online support for informal dementia caregivers in addition to the already provided care as usual. However, given the limited number of studies of high methodological quality, we can conclude that there is a need for further investigation in the field of Internet-based support for informal dementia caregivers in order to contribute to cost-effective care and improve the well-being of dementia caregivers around the globe, as well as lower the threshold of seeking help.

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CHAPTER 3

A mismatch between supply and demand of social support in dementia: a qualitative study on the perspectives of spousal caregivers and their social network members

Submitted

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ABSTRACT

Objectives. This qualitative study integrates the dyadic data from spousal caregivers and their social network members to investigate reciprocal perspectives on barriers and facilitators to supply and demand of social support.

Methods. Ten spouses completed an ecogram, a social network card and an interview. The ecogram aimed to trigger subjective experiences regarding social support. 17 network members were interviewed. The qualitative analyses identified codes, categories and themes.

Results. Using an ecogram before the interview effectively triggered subjective experiences regarding social support. Four major themes emerged: (1) partners' needs and demand for support, which are divided into subthemes: (a) barriers to ask for support and (b) facilitators to ask for support; (2) network supply of support, which is divided into subthemes: (a) barriers to offer support and (b) facilitators to offer support; (3) a mismatch between supply and demand; and (4) openness in communication to repair the imbalance.

Discussion. Integrating social network perspectives was highly effective. A model identifying a mismatch between the supply and demand of social support was proposed, strengthened by a cognitive bias: caregivers reported to think for other social network members and vice versa. Openness in communication in formal and informal care systems might repair this mismatch.

INTRODUCTION

Dementia has a major impact on the lives of family caregivers and social network members, especially on the persons providing primary care to the people with dementia (PwD) living in the community. The caregivers are faced with physical, emotional and economical challenges during the different phases of the disease. Consequently, they are prone to depression, social isolation and even physical complaints.¹

Clearly, social support for informal caregivers is essential for improving their health and quality of life. Research has demonstrated that social support and the sharing of stressful experiences contribute to improved caregiver well-being^{2,3} and buffers against experienced stressors. In contrast, lower levels of informal social support are associated with increased caregiver burden and feelings of depression.^{4,5} Nevertheless, primary caregivers of PwD often find it difficult to initiate requests for assistance and support from their own social network, thus increasing their risk for social isolation and burden. Although the non-use of formal services is often caused by the PwD's refusal, a lack of awareness on the part of the caregiver, or no perceived need for such services,^{6,7} only few studies have been conducted regarding the factors involved in the acceptance of informal support. Research has indicated that caregivers do not always accept offers of help because of the associated stigma⁸ or fear of the PwD's reactions.⁹

To lower the high caregiver threshold to seek support and to improve the current caregiver interventions, we need to examine the factors contributing to the acceptance of informal support. In this qualitative study, we explored the barriers and facilitators for both supply and demand of informal support in the context of the caregiver's social network. To date, few qualitative studies have incorporated the perspectives of both the spousal caregivers and their social network members. This assessment is important because informal caregivers must provide longer care in the community^{10,11} and increasingly must rely on the assistance and support from their social network.

In sum, we aimed to (1) explore spousal caregivers' needs, perceptions and experiences regarding informal support; (2) gain insight into the social network members' needs, perceptions and experiences regarding informal support towards spousal caregivers; and (3) identify the barriers and facilitators to the supply and demand of informal support within the informal care network.

METHODS

Participants

Ten spousal caregivers of PwD and two members of their social network (n=17) were recruited by the memory clinic of Maastricht University Medical Centre (MUMC+). Two network members were included to gain insight into the perspectives of both near and, when available, more distant network members. A selection of 10 participants was considered to be sufficient to obtain data saturation.¹² All of the recruited spousal caregivers and PwD shared a household. There were no restrictions for the duration and type of dementia diagnosis. The clinician invited the spousal caregivers for participation in the study while visiting the memory clinic, and/or the researcher called them directly. Subsequently, they received a letter regarding their participation. In case the spousal caregiver provided permission, two members from his or her social network were approached and invited by a letter to participate in an interview. It was not possible to recruit the network members of two spousal caregivers. They either could not think of a significant other or the network members themselves did not accept the invitation because of their busy schedule or unwillingness to participate in the research. One spouse provided three network members for inclusion. The ethical committee of the faculty of Psychology and Neuroscience of Maastricht University approved this study (ECP-150 22-03-2015).

Data collection

First, written informed consent was obtained. Second, 1- to 2-hour semi-structured interviews were conducted. Depending on the participant's preference, the interviews were conducted either at the MUMC+ or in the participant's home. The interviews were structured according to a topic list based on the extant literature and experience from clinical practice. At the commencement of the interview with the spousal caregivers, an ecogram and social network card based on the Maastricht Social Network Analysis¹³ were completed. On the ecogram, the spousal caregivers named the people who were (1) very closely involved/or essential in providing support to the spousal caregiver, (2) somewhat less closely involved in providing support to the spousal caregiver on a regular basis, and (3) acquaintances who provided support only sporadically. Figure 1 shows the average ecogram size. Subsequently, a social network card was completed describing the characteristics of the persons listed on the ecogram, including the relationship to the spousal caregiver, age, geographical distance, type of support, frequency of support (face-to-face, telephone and e-mail)

and the importance of that person using a visual analogue scale (VAS) ranging from 0 (not important) to 100 (extremely important). The ecogram and network card were not only completed to map the social network but more specifically to probe the caregivers' thoughts and feelings regarding the availability of the support persons and experienced informal support. Using sensitization techniques is a proven method to elicit perspectives and experiences on a topic from past memories.^{14,15} We applied the ecogram as an innovative tool to sensitize and capture personal support experiences. The ecogram served as a guide throughout the interview and was referred to, in the second part, in the request for open-ended questions. The topics in the interviews with both the spousal caregiver and their network members included types of support received or provided, barriers and facilitators associated with spousal caregiver needs for social support, or social network member's supply of support. When necessary, the participants were stimulated to elaborate or clarify some thoughts and feelings.

Additionally, data were collected on age, gender, education, total time spent on caring, satisfaction with the social network and burden scored using a VAS scale that ranged from 0 (no burden at all/not satisfied) to 100 (the highest imagined burden/very satisfied).

Data analysis

We performed a qualitative analysis to identify the codes, categories and themes in our data.¹² The interviews were transcribed verbatim and scored independently by two authors (AD and LB), using Atlas.ti 1 for a Mac computer (Scientific Software Development GmbH, Berlin). Both researchers used an inductive content analysis in which the codes and categories were derived from the data employing constant comparison and inductive reasoning. First, open codes were created covering all text fragments. Second, overlapping codes referring to a similar phenomenon were grouped into categories. Subsequently, higher-order themes were identified.¹² After coding the 27 interviews, saturation occurred because no new codes emerged from the data.

Figure 1. The ecogram that was completed during the interview with the spousal caregiver.

n = the mean number of contacts in every circle (i.e., with either individuals, couples or leisure clubs), followed by the range.

The categories and interpretations from both independent analyses were discussed in a meeting with the last author (MdV) to reach consensus regarding the categories, themes and emerging relationships.

RESULTS

Participants

The characteristics of the 10 spousal caregivers (mean age = 73.7 years) and their 17 network members (mean age = 58.4 years) are depicted in Tables 1 and 2. The majority of the spouses (70%) and network members (82.4%) were female. The care recipients' diagnosis included Alzheimer's dementia ($n = 6$) or other dementias ($n = 4$); the duration of time from the diagnosis ranged from 3 months to 5 years.

Table 1. Background characteristics of the spousal caregivers (n = 10) and care recipients (n = 10)

	Total Group
Gender caregiver female, n (%)	7 (70)
Age caregiver, mean (range)	73.7 (63-82)
Education level caregiver, mean (range) ^a	4.5 (1-8)
Living together with care recipient (%)	10 (100)
Years of caring (range)	4 (1-9)
Hours of caring per week, mean (range)	37.6 (10-98)
Subjective burden, mean (range) ^b	53.5 (20-95)
Satisfaction with social network, mean (range) ^b	78.5 (50-100)
Gender care recipient female (%)	3 (30)
Age care recipient, mean (range)	77.0 (64-83)
Care recipient dementia diagnosis (%)	
Alzheimer (%)	6 (60)
Vascular (%)	3 (30)
Mixed (AD/vascular)	1 (10)
Years since care recipient's diagnosis (range)	3.03 (0.30-5)

^a Educational level ranges from 1 (unfinished primary education) to 8 (university degree), a mean of 4.5 corresponds to an average education level.

^b Mean score on a visual analogue scale (VAS), ranging from 0 to 100.

Table 2. Background characteristics of the interviewed network members (n = 17)

	Total Group
Gender female (%)	14 (82.4)
Age, mean (range)	58.5 (36-75)
Education level, caregiver, mean (SD) ^a	4.5 (2-8)
Relationship to spousal caregiver (%)	
Friends	3 (17.7)
Neighbors	2 (11.8)
Others	2 (11.8)
Son	3 (17.7)
Daughter	2 (11.8)
Daughter-in-law	1 (5.9)
Sister	3 (17.7)
Niece	1 (5.9)
Years of caring (range)	4.9 (0-25)
Mean # hours of caring per week (range)	2.9 (0-12)
Mean subjective burden (SD/range) ^b	24.7 (0-80)

^a education scores range from 1 (unfinished primary education) to 8 (university degree), a mean of 4.5 corresponds to an average education level.

^b Mean score on a visual analogue scale (VAS), ranging from 0 to 100.

Table 3 shows the network members' characteristics (e.g., frequency of contact, type of support), as reported on the network card. The spouses were satisfied with their social network (VAS = 78.5) and reported a moderate level of burden (VAS = 53.5), which was indicated on a VAS (i.e., 0, not satisfied/ no burden vs. 100, very satisfied/high burden).

Interviews with spousal caregivers and their social network members

Four major themes were identified: (1) partners' needs and demands for support, which were divided into two subthemes: (a) barriers to ask for support, and (b) facilitators to ask for support; (2) network supply of support, which were divided into two subthemes: (a) barriers to offer support, and (b) facilitators to offer support; (3) a mismatch in the supply and demand of support; and (4) openness in communication to repair the imbalance.

An overview of themes and categories is provided in Table 4 and Figure 2, and they are clarified by the quotations in the following sections. Each quotation is marked by a code specifying the participant (e.g., P = partner vs. N = network member).

Partners' needs and demand for social support

The spousal caregivers clearly experience a need for social support. Respite care and practical support enable the spousal caregivers to continue their social activities and lead a normal life in addition to their caregiver role:

"I am convinced it is important to be able to escape from the situation. For example, by going to a music rehearsal. It is important for caregivers to be able to have different experiences. However, then you need to be able to flip a switch. I experience that when I close the door. It is not that I don't worry anymore, but I arranged something with the people around me, I can rely on them when something happens. As a caregiver, you need this; imagine how it would be if you have a small circle of people around you" (points to the ecogram, Fig. 1). (P, 1)

Social support is not only considered to be practical, it also contributes to positive emotional caregiver experiences. Maintaining a social network can preserve feelings of usefulness, worthiness and belongingness:

"I take care of my contacts, I don't want to be only the partner of

Figure 2. The proposed model of the mismatch between demand and supply of social support

Table 4. Overview of categories and major themes

Themes	Categories
Partners' needs and demands for support	Types of support (emotional, practical, company, and respite) Social participation and connectedness Distraction/re-charging personal batteries
a) Barriers to ask for support	Maintaining autonomy Preventing becoming a burden to others Protection and love towards the PwD Incomprehension by the social environment Feelings of isolation/loneliness Practical factors (energy, time, and distance) Not experiencing an urgent need for help
b) <i>Facilitating factors to ask for support</i>	Awareness of need for support is a necessity Positive experience with support Good quality relationships
Networks' supply of support	Willingness to help Being meaningful and enjoying and enriched relationship
a) <i>Barriers to offer support</i>	No insight into support needs and at which moment Rejection or confrontation with the spouse and the PwD Fear to stigmatize partner or PwD Practical factors (time, and distance)
b) <i>Facilitating factors to offer support</i>	Support for better or for worse (positive focus) Good quality and cooperating relationships within the network Observed decline in health and mood
Mismatch between supply and demand	
Repairing the imbalance	Cognitive bias regarding each other's intentions Early social network mobilization and involvement Openness in communication Early education and raising awareness by healthcare professionals Reciprocity in relationships

my husband with dementia. I always want to maintain a part of my own life and interest for others and in life itself ... and I am also afraid that it is not good for me. I always have been a very active person with lots to talk about. And I think it is also not good for my husband because then I might put pressure on him.” (P, 4)

Barriers to seek support

Despite the need for support, spousal caregivers often experienced barriers to ask for support because of practical factors, such as time and distance, as well as personal values or norms. For example, autonomy and independence were values deeply rooted in one’s upbringing. Spouses often insisted on managing their own care tasks to prevent them from being a burden to others:

“Why it is difficult? Because I am a person capable of arranging my own affairs. And then you somehow have to be humble. Do you want to do that? (Sigh) Argh ... and then I think I can do it myself. I prefer that.” (P, 6)

Another hindering factor for asking for support was that spouses delayed asking for help to protect the PwD and maintain their long-lasting bond:

“We’ll cross that bridge when we get to it. I can manage it at the moment. Therefore, in my view you don’t ask other people for a favor. I think we are married for 52 years, if you truly love someone, then everything is possible. If you don’t love someone, it would be very difficult to carry on.” (P, 10)

Furthermore, spouses experienced misunderstanding with respect to their situation, leading to feelings of stigmatization, isolation or loneliness:

“It is in my nature, trying to prevent burdening others with the problems of my wife. On the one hand, I don’t want to burden others and simultaneously if you rely on that help, people will sympathize with my wife and will really treat her likewise (as a PwD). I want to avoid or postpone this. I don’t want to hide things, but I want to keep people from offering support that is disproportionate. Then, you stop addressing her own abilities. Additionally, I don’t want to burden my children because I feel I can manage the situation myself.” (P, 1)

“Few people show understanding; they can be counted on one hand. Because

they have not experienced the same situation, you avoid those people or you stop talking about it at all. It makes no sense. Also, they don't need that, you notice that, is even the case in the family. They say my mom this, my father that ... and they don't even let you finish talking. Then, I wonder... don't you understand? I want to tell something about myself. Thus, I automatically keep silent.” (P, 3)

Facilitators to seek support

In addition to the barriers to seeking support, several facilitators were identified. Especially because of the growing awareness that support is essential, positive support experiences and good quality relationships stimulated support-seeking behavior:

“Let's say the longer it takes, the easier it gets to call on people. I can't do everything ... I have to accept things; I have no choice, so to say. That is what I call a lesson in humility, it was necessary, I saw and felt that I had to be wise and had no choice. So, that means that I can ask for help more easily.” (P, 4)

“It changed, when I was ill myself, I noticed that people spontaneously would call me and say: ‘I heard you are ill, can I do something for you?’ If I had not experienced that, it would be more difficult for me. I am not that kind of person. I am used to fighting my own battles, that's part of me, as long as I can do it, I will do it myself. Now I see, it is getting easier. I think experience is the best teacher. The next time I will not be afraid to ask.” (P, 6)

In sum, spousal caregivers often did not acknowledge support needs because they were afraid to lose autonomy or put a burden on others. Additionally they were confronted with feelings of loneliness and stigma due to changing relationships and incomprehension by individuals in the environment. However, several caregivers reported positive experiences that changed their willingness to seek support earlier.

Network perspectives on supply of social support

People in the social environment were often willing to help. They aimed to relieve the pressure for the spousal caregiver, and they considered support to be an enriching experience:

“She always has been busy, now you can do things for her...especially provide emotional support. I would like to bring her outside her safe environment, to walk with her and talk with her. Then, you can give something back and make her life a little bit better. Especially by emphasizing emotional support, you can enrich life. We could lower the threshold by emphasizing that we don’t doubt his abilities, but we want to do something fun to unburden and add something.” (N, 13, daughter-in-law)

Barriers to offering support

Nevertheless, providing support was hampered because the social network members often had no insight into what kind of support was needed at which moment in time:

“There is kind of a ‘debt of honor, like my mother-in-law cared for him for years, now the roles are reversed and he protects her very strongly, but imagine my father-in-law won’t be there anymore. We don’t know what is happening, we don’t know which care strategies he uses, what he did. I was shocked that there is no plan for when he cannot be there anymore. So, I mentioned this a few times to my brothers-in-law, talk about this together how to break through the shield.” (N,13, daughter-in-law)

“For us, the point is, we are searching for the most appropriate moment and the best approach to offer support. We are confronted with this for the first time, and this is our first experience.” (N, 12, son)

Moreover, the involved network members were afraid of violating privacy or stigmatizing the spouse in the caregiver role:

“The problem or the only danger I see is that I don’t want to intervene in their daily life with each other. So, he has to be open for support. I mean that remains the point.” (N, 12, son)

Other hindering factors were rejection of support by the spouses or PwD and emotional confrontation through role change inherent to dementia:

“We ran into a wall, my sister and I. So, we said we can’t do anything. We noticed aversion. She is suspicious that my sister arranges things behind her back. Since we ran into this wall, we changed to a hands-off approach and just

try to be son and daughter and nothing else.” (N, 27, son)

Facilitators to offering support

Several factors contributed towards the provision of support, especially a prevailing attitude that you offer support for better or for worse. Other factors include a positive focus towards providing support, good quality relationships, and observed health decline:

“Whether or not the caregiver can ask for help depends on the relationship of the caregiver with the environment and vice versa. In my situation, we are the youngest in this neighborhood. We are open-minded; there are two ways of looking at people: you can just look at people and say hello or you can really care about people, you know what I mean?” (N, 11, neighbor)

In sum, although the involved network members were willing to offer support, there was a lack of insight into the exact type of support needs. They faced practical limitations as well as confrontation and rejection. A positive and open view towards caring as being a normal process and a focus on opportunities, instead of limitations, facilitated involvement.

A mismatch between supply and demand of informal support

The data demonstrated a mismatch between the supply and demand of social support (Fig. 2). Frequently, intentions to ask for support or provide support were not translated into action. This mismatch was strengthened by a cognitive bias observed in the spouses and their network members. They tended to think for others and might hold incorrect or unverified presumptions concerning each other's needs and intentions, which prevented tangible support seeking and support provision:

“We contemplate things in advance: what should I do? On which day? Can I do it? Am I able to live up to what I promised to do? And he might think exactly the same ... such as how will they treat my love, they are already busy, they have this and that and already have enough worries.” (N, 13, daughter-in-law)

“People might think she is able to handle the situation. That also makes a difference. I think if you let your head hang down and are shaky, then people will

come over more quickly. That might be possible. However, I am not like that.”
(P,3)

Spouses and network members did not always communicate their thoughts and feelings. Consequently, they experienced unfulfilled expectations leading to reciprocal disappointment:

“One of the biggest disappointments was with one of our friends. They were the first couple I told about the situation when my husband was present. They both work in dementia care settings and then you expect ... and I think that is wrong to expect that they would just come by ... like ‘How are you doing and can we help you? We might take your husband for a walk so you have some spare time.’ I think I expected too much. However, if I asked them, they probably would help. However, other stupid things happened. Then, I think I wouldn’t have expected that. So there I experience some kind of disappointment.” (P,4)

In sum, the observed mismatch in care networks is strengthened due to cognitive biases. People make unverified presumptions about each other’s needs and abilities, leading to unfulfilled expectations and disappointment.

Openness in communication to repair the imbalance

Bridging the gap between spousal caregivers and their social network members emphasized that more openness in communication is required in both informal social networks and formal healthcare settings in an earlier phase of the disease. Sharing experiences, needs and wishes and mapping support opportunities within (online) family networks might increase involvement and awareness of support needs:

“I think it is important to share information, especially to stimulate each other. Let me put it this way, I told you about an online tool to schedule a date. That, in my opinion, is perfect. I imagine I would be the organizer of the network of my mother-in-law. And I had asked someone to go somewhere with her; then, I send that specific person a link asking, ‘How did it go?’ Following completing the link and posting a small blog with her experience, she would be able to read messages from the others. This way you might trigger an interaction with each other. In my opinion, it is the first priority to share things. Additionally, that would

have the intention to enrich the life of others and share that with others. For example, a beautiful moment can be shared by ten people, and those ten beautiful moments can in turn inspire other people.” (N,13, daughter-in-law)

“At an early stage, you must start building a network. Get people involved before it becomes essential. In that way, a network will be in place when you need it most. Look, if you must start building a network when you already really need it, then it is more difficult for the people who have to provide the support.” (N,20, daughter)

Additionally, healthcare professionals should play a role in creating awareness that support is essential. The caregivers tend to accept an independent expert opinion more easily as opposed to informal advice from a close network member:

“It should not come only from informal helpers. However, also from let’s say the medical side, they have to manage that caregivers are triggered to think about which persons can help you, with what kind of tasks and would you be able to share your support needs. When there is one person to help, then it might get more easy to examine which other people can be involved to set the stage.” (N,11, neighbor)

Moreover, the relationships based on equality and openness were highly valued. The caregivers not only want to depend on the kindness of others , but they also wish to return something for their support:

“I find it difficult to offer support because the caregiver is reluctant. She does not want to ask for support. She wants to maintain our relationship as it used to be. That is a sore point. ‘You can lead a horse to water, but you can’t make him drink.’ My friend wants to continue our relationship and needs the enjoyment our friendship offers. She does not want to be judged as being a burden or a person in need. She wants to maintain an equal friendship.” (N,19, friend)

In sum, to resolve the observed mismatch, it seems that an openness in communication in both informal and formal care networks is required. Furthermore, to maintain quality care relationships, equality and reciprocity are prerequisites.

DISCUSSION

A model of the mismatch between supply and demand of support

The aim of this study was to explore the needs, perspectives and experiences regarding informal support of both spousal caregivers and social network members. Furthermore, we examined the barriers and facilitators regarding the supply and demand of informal support. Four themes were identified: (1) spousal caregivers had different support needs, such as the need for emotional support, practical support, respite care or company and relaxation. Such support enhanced the caregivers' social integration and the feeling of being meaningful in daily life. (2) Social network members were willing to supply support because support was considered to be a rewarding experience that led to enriched relationships. (3) Nevertheless, a mismatch between the supply and demand of informal support was demonstrated. Although the spouses reported explicit support needs and the network members were often willing to help, frequently no actual support was delivered because of the outlined barriers. The hindering factors were partly similar to those identified in earlier research, such as a fear of stigma¹⁶, or negative attitudes towards accepting support, such as a sense of responsibility and unwillingness to relinquish support to others.¹⁷ The identified mismatch was strengthened by an observed cognitive bias. Both the spousal caregivers and the social network members tended to think for others and exhibited unverified and sometimes incorrect thoughts concerning each other's intentions. Consequently, both parties may not explicitly communicate their support wishes and opportunities because of a concern for an anticipated burden, rejection or violation of privacy, thus causing disappointment and unfulfilled expectations. (4) Our data highlighted that open communication in formal and informal care systems could repair the observed mismatch between the supply and demand of informal support.

Practical implications

Our results suggested that it is essential that healthcare professionals raise awareness regarding the importance of mobilizing informal support at an earlier stage of the disease. Previously, caregivers found it difficult to acknowledge and accept care needs in an early phase of the disease.¹⁵ The healthcare professionals should not only emphasize the significance of social support but also focus on the positive aspects of support and reciprocal interaction so that caregivers can come to terms with their social network involvement.

Our findings revealed that cognitive biases play a role in support behavior; the caregivers reported thinking for other social network members and vice versa. According to Beck's cognitive theory, people can become susceptible to interpreting the intentions of others in a distorted or biased way because meanings are derived from personal experiences and the way people structure the world.^{18,19} Our findings confirmed that caregivers make unverified presumptions. As shown in previous studies, multi-component family meetings²⁰ or remote interventions^{21,22} might effectively improve support and open communication to prevent these cognitive biases. Additionally, support interventions may include cognitive behavioral techniques that address maladaptive thoughts regarding caregiver support. For example, cognitive restructuring and positive reappraisal techniques may shed a more positive light on seeking informal support, such as the realization that providing or asking for support does not only impose a burden or stigma but, in contrast, might lead to a reciprocal enrichment of relationships and increased social functioning. Consistent with this finding, future caregiver intervention research might increasingly focus on strengthening aspects of social health. The newly developed concept of social health emphasizes people's capacity to fulfill their potential and obligations, manage their life with some degree of independence and engagement in social activities, despite their medical condition.²³ From this perspective, health is a dynamic balance between opportunities and limitations. Our data confirmed that participation in social activities parallel to the process of caregiving are highly valued and that a positive focus on opportunities, rather than limitations, might facilitate positive social interactions and supportive behavior.

Methodological strengths and limitations

This study is unique in integrating the perspectives of both the spousal caregivers and the involved network members. By using an ecogram as a sensitization technique, we collected more in-depth information on the social network processes. The spousal caregivers were triggered to reflect on and disclose present and past experiences within the context of their social network, which guided the interview process.¹⁴ A drawback was that interviewing acquaintances might have prompted a response bias. However, the interviewer explicitly emphasized that the data would remain anonymous. To increase the homogeneity of our sample, we only included spousal primary caregivers from

the southern regions of the Netherlands. Although the literature indicated that the majority of dementia caregivers are spouses,²⁴ additional perspectives of other primary caregivers with more diverse backgrounds would have enhanced the generalizability of the results. Previous studies have demonstrated that social support differs across ethnicities and cultures.²⁵ Therefore, it might be interesting to repeat this study in another cultural context.

Conclusion

Our novel method was highly effective in identifying integrated perspectives on social support in dementia caregiver networks. We identified a model explaining the mismatch between supply and demand of support. A new finding is that openness in communication might repair the observed mismatch. This finding underscores the importance of early education and social network interventions to facilitate positive interactions. Innovative online communication tools, such as social media platforms, might be a new venue for improving the openness in communication and encouraging positive involvement in dementia care networks. This may yield opportunities to overcome the experienced barriers, such as the fear of burdening and stigmatizing others, and enhance access to social support.

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CHAPTER 4

Qualitative study on needs and wishes of early-stage dementia caregivers: the paradox between needing and accepting help

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ABSTRACT

Background: Early individualized interventions for informal dementia caregivers can prevent overburdening in the later stages. However, the needs of early-stage dementia caregivers (EDC) remain largely unknown. This study aimed to explore the needs and wishes and need for care of EDC to maximize the benefit of potential programs for EDC and tailor interventions accordingly.

Methods: Four focus group interviews with 28 informal caregivers of people with dementia (PwD) were analyzed using inductive content analysis. Both EDC and caregivers in the later stages were included to compare perceived EDC needs from different points in the caregiver career.

Results: Four themes were identified: the early-stage needs paradox, barriers in acceptance, facilitators in acceptance and a transition from loss to adaptation. The retrospective view provided by later-stage caregivers differed from the view of EDC; EDC struggled with acknowledging needs due to fear of stigma and low acceptance. EDC stressed the importance of acceptance as a prerequisite for adequate adaptation, but were hindered by lack of knowledge, difficulty acknowledging changes and focus on loss. In contrast, better understanding of the disease, increasing personal time, structuring ones day and using appropriate humor can reduce negative communication, increase positive encounters and caregiver-confidence, contributing to positive interaction with the care recipient and an increase in well-being.

Conclusions: Early therapeutic interventions could help caregivers identify their needs, increase knowledge about changes in roles and relationship reciprocity, and focus on enhancement of the positive, intact experiences to prevent caregiver burden.

INTRODUCTION

The ageing of the population is expected to lead to a substantial increase in the prevalence of dementia¹ and significant concerns exist about whether the current labor force can cope with such an increased future demand.² Consequently, the care for people with dementia (PwD) will largely depend on informal caregivers, usually spouses. Informal caregivers often provide years of extensive care for their loved one, and must adapt to continuously changing and increasingly demanding circumstances. This challenging role may cause chronic stress, making caregivers highly vulnerable for being overburdened and developing psychological symptoms such as depression and anxiety.³ Even in the very early stages, for example in the Mild Cognitive Impairment (MCI) phase, caregivers often experience distress and depressive symptoms.⁴

Clinicians, researchers and Alzheimer societies stress the importance of a timely diagnosis in dementia, and this is also advocated by most international dementia strategies.⁵ A timely diagnosis in the early or prodromal phase, may offer caregivers the opportunity to prepare for their future caregiving task in the early stages of the disease and prevent high levels of burden in the later stages.⁶ Early intervention and support for caregivers can be effective in reducing strain and may delay institutionalization of the person with dementia.^{7,8} As levels of stress and burden are relatively low in the early, including prodromal, stages of dementia, interventions at that time present an opportunity for professionals to help caregivers cope with an insecure future and prepare themselves for the possibility of further decline and dependency.⁹ However, the specific needs of early-stage dementia caregivers (EDC) remain largely unknown.⁶ The needs of PwD and their caregivers in later stages of the disease have already been examined extensively. These include the need for emotional, social and financial support, information about the disease and information about appropriate care facilities.¹⁰⁻¹³ Caregivers also report a lack of competence to provide care and difficulty to plan ahead for their relative's future care needs.¹² This demonstrates the importance of supporting EDC to prepare them for their difficult future task.

To maximize the benefit of EDC interventions, the needs of caregivers should be carefully assessed to determine whether and which interventions in this stage are desired and to tailor interventions accordingly.¹⁴ The present study therefore focuses on an in-depth analysis of the needs of EDC. More specifically, we sought to (1) gain insight into the problems, needs and wishes that caregivers of PwD encounter during

the early stages of the disease, (2) explore if an early-stage intervention for dementia caregivers would be helpful and (3) explore which factors influence caregivers' perspectives on early-stage need for care.

METHODS

Study participants

Purposeful sampling was used to describe the EDC needs that cut across participants with a range of variation on disease severity, gender, age, and relationship with the relative.¹⁵ The maximum variation sampling strategy was also successfully used in previous research on informal caregiver needs¹² and allowed us to select participants with these different characteristics to look for common patterns and capture the EDC perceived needs from different points in the caregiver career. A minimum of four focus group interviews with 6-8 participants per group was planned; sampling ended when data saturation was achieved, e.g. no new themes emerged.¹⁵ Between August 2012 and January 2013, 40 informal caregivers were recruited; 14 early, including prodromal, stage dementia caregivers were purposively selected by professional caregivers from the pool of informal EDC associated with the (1) Memory Clinic of the Maastricht University Medical Center; and 26 later stage dementia caregivers were purposively selected by professional caregivers from the pool of later stage informal caregivers associated with the (2) Alzheimer Café Roermond (monthly meeting spot for people with dementia (PwD), caregivers and professionals); and (3) Regional Committee Healthcare (RCH) Proteion, which is a care home for older people. Participants were included if they were (1) the informal caregivers of a person with dementia or prodromal dementia (MCI due to AD, based on the etiological diagnosis expected to convert to dementia), and (2) involved in the daily care of the care recipient at least once a week. The inclusion of caregivers affiliated with different institutions fostered maximum variation of the sample. Twenty-five informal caregivers agreed to participate. Eight caregivers declined participation due to a busy caregiving schedule; six caregivers were not interested in a group meeting and one caregiver declined due to work-related commitments. Three secondary informal caregivers of already represented care recipients requested to join the primary participating caregiver in the focus group interview. The Medical Ethics Committee of the Maastricht University Medical Center approved this study (#12-4-059).

Procedures

Focus group interviews were used to explore caregiver perceptions, opinions and beliefs, because focus groups are an ideal method to reveal various perspectives on a topic and to uncover new insights and unanticipated issues.¹⁶ Four focus group interviews were scheduled, applying triangulation of sites: two groups (A and B) of six participants in the city of Maastricht and two groups (C and D) of seven and nine participants respectively in the city of Roermond (both cities are located in the southern part of the Netherlands). Methodological guidelines suggest that most issues around a research topic will be captured after the fourth group discussion.¹⁶ The point of saturation was checked after the fourth group discussion independently by two authors (LMMB, CAGW) to confirm that a sufficient number of focus groups had been conducted as no new themes emerged. Written informed consent was obtained prior to participation in the study. This included explaining the procedure to be followed and the roles of the moderator (MEdV) and assistant (LMMB; taking additional notes). Participants were encouraged to share their expertise (e.g. life experiences) and to view the focus groups as a social event as a means of encouraging open discussion.¹⁷ A semi-structured guide was used during the focus group sessions. It included topics derived from clinical practice that identified needs and wishes expressed by EDC to prevent possible overburdening in the later stages, EDC need for care or experiences with received care, and EDC need for communication of care. Brief summaries of the key points were made throughout the focus group sessions as a method for obtaining participant verification.¹⁶ All focus group interviews were videotaped, and tapes were stored in a locked area. Triangulation of within-method data sources was applied¹⁵; video recordings were used in addition to the field notes taken by the assistant to ensure identification of potentially relevant non-verbal information or cues presented by the participants. Interviews lasted approximately 120 minutes.

Context-mapping approach

For the preparation and execution of the focus group sessions a context-mapping approach was used. This approach presumes that information about the context of people's interactions in their everyday life is needed to reveal experiences and emotions in a group environment. Prior to the interview, participants were asked to think, reflect, and explore aspects of their personal context and current situation.¹⁸ Therefore, we provided them with packages comprising a booklet to capture parts of

their history and current life with their spouse two weeks before the interview. To elicit thoughts and feelings of participants during the group meetings, participants were asked to elaborate on their experiences based on generative techniques such as collage making (Figure 1).¹⁸ This indirect approach was chosen to minimize the risk of increasing feelings of distress caused by directly confronting caregivers with the memory impairment of their loved one.¹⁹ The material was developed in collaboration with an expert in context-mapping to verify its quality and suitability for the present study.

Figure 1. Collages of themes created by participants during a focus group

Data analysis

The videotapes of all focus group interviews were transcribed verbatim. Analyst triangulation was applied¹⁵; the transcripts and observations combined with additional notes taken during the focus group interviews and the collected context mapping materials were analyzed independently by two authors (LMMB, CAGW) using the qualitative analysis software ATLAS.ti (version 7.0). An inductive content analysis approach was adopted,²⁰ in which common themes and categories emerge using inductive reasoning and constant comparison. The texts were thoroughly read and open codes were applied to describe all aspects of the content.²¹ Codes referring to the same phenomenon were grouped into categories and these categories were grouped into higher-order themes. Categories and themes were combined into general statements to describe the phenomenon.²⁰ Discrepancies in coding and interpretation were discussed in a meeting together with a third author (MEdV) to

reach consensus regarding the categories and themes. The video recordings were compared with the written transcripts to be able to identify potentially relevant additional non-verbal information or cues presented by the participants. Saturation was established as none of the categories or themes shown in Table 2 (Results) emerged after the third focus group interview. The quotations described in the results section to clarify the major themes were based on those categories that were coded most often by authors LMMB and CAGW. Quotes were selected by the first author (LMMB), verified by the second author (CAGW) and checked for relevance by all authors.

RESULTS

Participants

Table 1 represents the characteristics of the 28 informal caregivers (mean age = 63.6 years) that participated in the study. Six participating caregivers (children $n = 2$, children-in-law $n = 2$, spouse $n = 1$, friend $n = 1$) were responsible for the care of three care recipients. The majority were females (75%), spouses (78%), and lived together with the care recipient (75%). Care recipients ($n = 25$) were diagnosed with Mild Cognitive Impairment due to AD (32%), Alzheimer's dementia (44%), and other dementias (24%) and were in the (very) early stages of the disease (52%) or had more advanced dementia (48%). The duration of diagnosis ranged from 0.5–10 years. Two groups comprised spousal caregivers only and two groups included a mixture of both spousal caregivers and other informal caregivers. Both authors (LMMB and CAGW) independently concluded that the quotes of prodromal dementia caregivers (MCI due to AD) and early-stage dementia caregivers were covered by the same codes and categories. Therefore, the results of this study did not separate MCI as a separate group from early-stage dementia caregivers (EDC). EDC and caregivers in the later stages were equally represented in all groups.

Focus groups

Four major themes covering the problems, needs and wishes experienced in the early stage of caregiving were identified: (1) The early-stage needs paradox; (2) Barriers in the acceptance process; (3) Facilitators in the acceptance process; and (4) Shift of focus: from feelings of loss to adaptation. An overview of the categories and themes is provided in Table 2 and Figure 2, and elaborated below by means of quotations. Each quotation is assigned a code; the letter stands for the location and

sequence of the focus group interview, while the number indicates the specific participant. After each code caregivers are assigned to either the EDC or LDC group; EDC stands for early-stage dementia caregiver and LDC stands for later-stage dementia caregiver, as based on the clinical judgment of the referring professional caregiver. Both authors (LMMB and CAGW) concluded that no discrepancies could be discovered between the written transcripts and potentially relevant non-verbal cues brought forward by the participants.

Table 1. Background characteristics of the caregivers (N=28) and the care recipients (N=25)

AGE (MEAN)	63.6 YEARS	
Gender	Men	7 (25%)
	Women	21 (75%)
Relationship to the care recipient	Spouse	22 (78%)
	Child	2 (7%)
	Child-in-law	2 (7%)
	Sibling	1 (4%)
	Friend	1 (4%)
Living together with care recipient	Yes	21 (75%)
	No	7 (25%)
Care recipient diagnosis	MCI due to AD	8 (32%)
	AD	11 (44%)
	Vascular Dementia	3 (12%)
	Parkinson	1 (4%)
	Dementia NOS ^a	2 (8%)
Stage of the disease ^b	(Very) early stage	13 (52%)
	Later stage	12 (48%)
Care recipient years of diagnosis	0-5	5 (20%)
	1-3	9 (36%)
	4-6	10 (40%)
	7-10	1 (4%)

^aNOS = Not Otherwise Specified

^bbased on clinical judgment of the referring professional caregiver

Table 2. Overview of categories and major themes

THEMES	CATEGORIES
Early-stage needs paradox	Caregiver needs in early stages Difficulties concerning roles and relationship changes Early-stage available support
Hindering factors in the acceptance process	Denial and difficulty accepting Loss and grief Future expectations
Facilitating factors in the acceptance process	Acceptance process Need for information Support and tips
Shift of focus: from loss to adaptation	Maintaining a good quality of life together with patient Adapting care to personal situation Individual differences

Figure 2. Schematic representation of the early-stage need paradox and acceptance process

Early-stage needs paradox

Retrospectively looking back at the early stages, caregivers in the later stages stressed the need for care that would have facilitated their acceptance process. They indicated that they would have benefited from talking to someone who could understand their situation and recognize their problems earlier. They also stressed the importance of timely guidance tailored to their individual needs as an intervention that would have helped them cope with the situations and worries they experienced.

“Now I think it would have been better for me if I received some guidance in the beginning, just someone helping me find my way. Not telling me: ‘this is what you can expect’, but asking me what I experience or worry about and helping me how to cope with certain situations or incidents. I had to figure that out all by myself and sometimes that worked out but sometimes it really didn’t.” (D6, LDC)

“I would have liked to have received some information that was important for me at that moment. I hear a lot of different stories and some do apply to our situation but others really don’t. It’s all so different and it needs to be relevant for your situation at that specific time” (A3, LDC)

However, EDC did not recognize the needs underlined by the later stage caregivers. EDC found it difficult to accept help, because they did not want to stigmatize their situation or did not want to be seen as in need of professional help.

“I don’t like to be called the ‘caregiver’, that makes me feel like a patient and I’m not. He’s my husband and of course I take care of him. I don’t like to feel pathetic, like I have a problem.” (B6, EDC)

Also, the information that was available for caregivers had a negative, stigmatizing nature, which made it more difficult for EDC to identify with.

“When I go online to find more information about certain things, I get so much information and especially negative information. It seems that I can’t find anything positive. That creates a negative image and that’s what I take home after reading. All that information really emphasizes the negative... but it’s not all negative” (B1, EDC)

Despite their difficulty in acknowledging needs and accepting help, EDC did encounter many changes and struggles and found it difficult to cope with and accept the situation.

"I think it's exhausting that my husband forgets so many things. He keeps asking the same thing over and over, places things different than I'm used to or just forgets where he located it. This sometimes irritates me, and afterwards I regret feeling irritated. I don't know... I don't like the fact that I might need help." (A2, EDC)

In sum, a clear paradox existed between the retrospective view provided by caregivers in the later stages of the benefits that early care tailored to personal needs would facilitate the acceptance process and the EDCs' lack of acknowledging a need for care due to difficulties in accepting the changes, fear of stigma and the stigmatizing character of the available information.

Barriers in the acceptance process

Acceptance was seen as a prerequisite for caregivers to cope with the changes of the disease. However, besides fear of stigma, several factors hindered the acceptance process and prevented EDC from being able to find an effective way to handle the changing situation. Not acknowledging the disease and a lack of knowledge about the manifestations of the disease seriously hindered the acceptance process.

"As long as you deny it you can't cope with it. As soon as you accept it, you can learn to turn to yourself and think: 'how can I cope best with this new situation?'" (C6, LDC)

"To cope with the diagnosis you need to know what to do and what not to do. Only when you know how to do it right you can learn to accept it. That's a difficult process, before you can set the problem aside for a bit and accept it, but once you've accepted it you are not always thinking about it and you can get on with your life." (A3, LDC)

Because of this lack of knowledge about the possible disease manifestations, EDC often took the changes in behavior personally, which led to insecurities, unnecessary misunderstandings and discussions.

"I really have to get used to the fact that his head is busy, that he thinks differently. It always escalates when I go on, but it's really hard to understand that he sees it differently. I often push through and we end up in discussion." (A4, EDC)

Furthermore, lack of knowledge in people surrounding the care recipient and caregiver caused EDC to feel insecure about their own actions.

"It's just the worst feeling in the world when others say: 'what's wrong with him, he looks just fine?' That devastates me, then I start to question myself." (D3, EDC)

Caregivers were confronted with the negative feelings and losses because misunderstandings occurred frequently in the early stages. These feelings of loss hindered the acceptance of the disease and its implications for their lives. Consequently, negative emotions got the upper hand.

"I find it very difficult to accept everything and I can't really cope well with the new situation. I also find it difficult what to do with myself... I don't feel like doing anything and I don't enjoy things anymore. That's where I am right now" (D5, EDC)

When negative EDC emotions outweighed the positive, the likelihood of disruptive encounters with the care recipient increased, and this was followed by even more negative emotions. This vicious circle made it increasingly difficult to control the negative interaction with the care recipient.

"The fear of failing and suspicion is constantly present and that makes her restless. The smallest comment can push her over the edge and cause the situation to escalate. You don't want it to, but it happens... all the time. Unfortunately in the beginning it happened daily. That really hurt." (A1, EDC)

In sum, denying the disease, a lack of knowledge and a focus on loss increased negative emotions and feelings of uncertainty in EDC. When negative experiences outweighed positive emotions the acceptance process was furthered hampered.

Facilitators in the acceptance process

The process of accepting the disease and its changes could be also facilitated. Disease-specific knowledge was identified as crucial in helping caregivers understand the manifestations of the disease and its changeable nature in the early stages. Information helped caregivers avoid taking the changes personally and improved their ability to empathize with the care recipient.

"You need to realize that your spouse is not doing these things on purpose, they happen because of their inability. He is not doing this to hurt me. That really changes the way you look at the situation. If you realize that, you can stay calm and it won't escalate." (B6, EDC)

Furthermore, caregivers reported that designating personal time was important for maintaining a healthy balance between caring for the care recipients and caring for themselves. Taking a break helped caregivers to recharge their energy level and it improved their ability to cope with the demanding situation.

“Your resilience just decreases during the day. Then, when something happens, I respond irritated and say something wrong. Whenever I feel my resilience declining, I do something to recharge it; I withdraw myself from the situation, we still sit together but I start to read something or do a puzzle while recharging myself and thinking about the fact that it’s not her fault. It gives you the time to think about what you’re going to say and avoid restlessness or worse...” (A1, EDC)

However, caregivers found it difficult to set aside personal time when the care recipient demanded their attention. Establishing structure and routine in daily life with the care recipient provided personal time for caregivers and simultaneously decreased restlessness and uncertainty in the care recipient.

“I go hiking every week and he knows that. If he starts to get agitated about me leaving I just refer to the calendar and remind him that it’s my hiking day today. He doesn’t always like that, but he accepts it because it’s in our routine.” (A3, LDC)

Dementia obliged caregivers to take on different roles in the relationship with the care recipient. This change in roles was difficult to adapt to. Acknowledging the change in roles and relationship decreased negative encounters. This new role as a caregiver demanded a certain level of confidence that could be increased by positive experiences, such as spending time alone, with the care recipient or with people from the caregivers’ social network.

“I tried working on my confidence by taking walks and going to the gym and talking to others, just being able to say what’s on my mind... that helps.” (B5, LDC)

Humor, when appropriate, was also mentioned as an approach that lessened the negative impact of the disease and helped caregivers identify positive rather than negative aspects of living with the care recipient.

“When I do something wrong, she usually says: ‘who has Alzheimer’s, you or me?’ Or when something small goes wrong I call it Alzheimer’s light... that kind of sly jokes help lighten the situation.” (A6, LDC)

In sum, understanding disease manifestations, applying structure and routine and designating personal time aided the acceptance of the disease and buffered its

consequences on daily life. Acknowledging the changes in roles and relationship reduced negative communication. Using appropriate humor increased positive encounters with the care recipient and helped caregivers expand their caregiver-confidence.

Shift of focus: from loss to adaptation

The facilitators in the acceptance process provided caregivers with the opportunity to adjust their expectations and to focus more on the positive aspects such as new or other possibilities in their life together with the care recipient. Their focus shifted from what they had lost to what was still possible with the proper alterations.

“You learn by trial and error. When the same thing happens over and over you start to adjust your expectations so that the situation isn’t looking so bad after all.” (B5, LDC)

When caregivers focused more on their possibilities, positive feelings increased, and this facilitated positive interactions with the care recipient and increased the well-being of both the caregiver and the care recipient.

“You keep on adjusting to what fits his changed needs. Because when he is happy with the situation, I feel that I’m also happier. That really works both ways.” (D1, LDC)

However, the process of how spousal dyads adapted to their new situation varied by personality, individual coping mechanisms and the premorbid relationship.

“Every man is different and has a different character. And every woman is also different towards her husband. There is no solution that works for everyone.” (D9, LDC)

In sum, acceptance led to adjusting expectations and a focus on possibilities rather than on loss. This created opportunities for positive interaction with the care recipient and an increase in well-being. However, the process of adaptation was different for each individual spousal dyad.

DISCUSSION

The aim of this study was to explore the needs and wishes of informal caregivers of people in the early stages of dementia from different perspectives in the caregiver career. The analysis revealed four major themes. The first was the early-stage paradox in needs. The retrospective view of caregivers in the later stages on need for early care tailored to personal needs to facilitate the acceptance process contrasted

with the early-stage dementia caregivers (EDC) view. EDC struggled with acknowledging needs and accepting help due to difficulties in accepting the changes, fear of stigma and the stigmatizing character of the available information. The second theme identified factors hindering the acceptance process. These included denying the changes, lack of knowledge, and a focus on loss. These barriers led to negative emotions and negative encounters with the care recipient and blocked positive emotions. The third theme identified factors facilitating the acceptance process. These include understanding disease manifestations, designating personal time, acknowledging and gradually establishing changes in roles, structuring their time and appropriately using humor. These facilitators appeared to reduce negative communication and increase positive encounters and caregiver-confidence. The fourth theme highlighted the importance of acceptance as a prerequisite for adapting expectations and focusing on possibilities to be able to maintain a positive caregiver-care recipient interaction and well-being.

In the current study, no differences were found between prodromal dementia and early-stage dementia caregivers in the assigned codes and categories. It is possible that no differences were seen between these two groups of caregivers because MCI due to AD can be viewed as the very early stage of dementia.⁹ Also, caregivers are often aware of the condition of their loved one long before the actual diagnosis is disclosed.²²

Our results suggest that the early needs retrospectively identified by later stage caregivers contradict the needs for care emphasized by EDC, who actually struggled with acknowledging specific needs. It is conceivable that EDC also relate their need for care to their currently experienced objective burden opposed to their subjective burden. Objective burden refers to aspects like the amount of time spent on caregiving and the type and number of caregiving tasks that are performed, often predicted by behavioral problems and impairments in daily function and cognition.²³ Subjective burden refers to the emotional response of the caregiver to the demands of the situation, such as feelings of incompetence or exhaustion.²⁴ In EDC the objective burden might be lower, given the level of impairment and the lower amount of practical and behavioral problems in dementia compared to the later stages of the disease. EDC might experience subjective burden, but this may be more complex to translate into specific needs as compared to objective burden. Brodaty et al.¹⁰ also

found that, despite a low level of life satisfaction and high levels of subjective burden, EDC as well as caregivers in the later stages felt that they did not need services or help. In addition, caregiver experienced stressors are often not directly related to their self-reported needs.²⁵

Our results propose that the willingness and ability to accept the disease is required to acknowledge needs and can also be seen as a prerequisite to maintain an acceptable level of well-being together with the care recipient.²⁶ However, the current study emphasizes the struggle EDC experience with accepting the changes due to the disease and our results showed that several factors could hinder or facilitate this acceptance process. Previous research confirms that disease-specific knowledge and knowledge on roles and relationship changes can increase caregiver confidence and understanding and facilitate acceptance^{22,26} When caregivers manage to accept the changes in reciprocity, they can shift their focus from loss to opportunities. A strong focus on the intact parts of the relationship and life's simple joys may help to increase the number of positive experiences with the care recipient.²⁶ This change in attitude enables caregivers to effectively cope with the changes and increase their well-being.²⁷ This explanation is in line with the dual-process theory on coping with loss.²⁸ This theory proposes that adaptation to chronic or life-threatening diseases is characterized by two types of adaptation, namely loss-oriented or restoration-oriented. EDC can be seen as in the early phase of adaptation, where their focus lies more on loss as caregivers first have to appraise a stressor before they can formulate adaptations to it. An increased level of distress and anxiety accompanies this focus on loss. According to the theory, stimulation of the adaptation process towards the restoration-oriented adaptation can lead to an increase in well-being. However, the process of adaptation and level of well-being also depends on individual characteristics of the EDC, such as coping mechanisms, personalities and premorbid relationships. Previous research confirms that even in apparently similar situations, caregiver experiences can differ depending on the interpretation or meaning caregivers apply to their situation.²⁶ Also, a negative premorbid relationship is associated with negative caregiver experiences.^{26,29} Negative caregivers were not able to express empathy and compassion because they interpreted behavior of the care recipient as a continuity of what they considered negative behavior in their relationship, as opposed to a manifestation of the disease. In addition, personality characteristics such as neuroticism are associated with a non-adaptive care strategy

resulting in higher levels of negative emotions such as depression.³ It is essential to take these personal characteristics and the premorbid relationship into account when addressing needs in tailored intervention programs.⁶

The current study is not without limitations. First, all focus group interviews were held in the southern part of the Netherlands. As caregiver needs may differ based on practical aspects such as the care organization per region,¹¹ this may have threatened the transferability of our results. However, to reduce the effect of local factors peculiar to one setting, triangulation of sites was carried out with different institutions in the southern part of the Netherlands.³⁰ Second, the present study did not apply methodological triangulation of qualitative methods, which could have compensated for the limitations of individual interviews and focus group interviews separately. The use of solely focus group interviews may have caused not all participants to be equally represented in the results.¹⁶ However, the focus group moderator (MEDV) is an experienced clinician with more than ten years of clinical experience and ample experience as moderator of group interviews who ensured that all participants were provided the opportunity to express their views. Also, the present study applied within-method triangulation combining data from the written transcripts, videotapes, and the concept mapping approach, which allowed us to derive information from the context outside of the focus group interviews and allowed participants to reflect on their situation beforehand, possibly increasing the information depth during the focus group interviews.^{15,19} Finally, the present study applied purposive sampling to capture EDC needs from different backgrounds and different points in the caregiver career. Purposive sampling is often used in qualitative research and has been used and justified in previous research on caregiver needs.¹² Although random sampling helps to ensure that any unknown influences are distributed equally amongst groups and can reduce researcher bias in the selection of participants, it can also lead to a sample that is not representative for the measured phenomenon.¹⁵ As we wanted to ensure a broad sample in terms of background, care recipient stage of the disease and institution, the current approach fitted the research question.

Conclusion

This study showed that difficulties with acknowledging needs in the early stages can be attributed to a struggle with accepting and adapting to the new role caregivers

need to take on in the relationship with the care recipient. This underlines the importance of early stage interventions aimed at the facilitation of the adaptation process.²⁷ But early stage interventions may do more harm than good if they do not fit the situation and are stigmatizing for the caregiver and care recipient.⁶ Currently available information and support for caregivers is often of a negative, stigmatizing character, which makes it difficult for early-stage dementia caregivers (EDC) to identify with and may frustrate acceptance. Early therapeutic interventions should not be problem-oriented or stigmatizing, but should help caregivers identify their needs based on their individual situation, increase their knowledge on changes in roles and focus more on the enhancement of the positive, intact experiences. With that focus in mind, early therapeutic interventions may strengthen the relationship and reduce negative consequences of caregiving at later stages.^{6,8,26,27}

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CHAPTER 5

Development and initial evaluation of the web-based self-management program 'Partner in Balance' for family caregivers of people with early-stage dementia: an exploratory mixed-methods study

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ABSTRACT

Background: People with dementia increasingly depend on informal caregivers. Internet-based self-management interventions hold considerable promise for meeting the educational and support needs of early-stage dementia caregivers (EDC) at a reduced cost.

Objective: This study aimed (a) to develop an online self-management program for EDC to increase self-efficacy and goal attainment, and (b) to evaluate the program's feasibility and report preliminary data on effectiveness.

Methods: Based on the Medical Research Counsel (MRC) framework for the development and evaluation of complex interventions, a stepwise approach was adopted to explore potential user needs and develop and validate the content by means of (1) focus group discussions with dementia caregivers (N=28), (2) interviews with dementia care professionals (N=11), and (3) individual think aloud usability tests with EDC (N=2) and experts (N=2). A pilot evaluation was conducted with EDC (N=17) to test the feasibility and establish preliminary effects. Self-report measures of feasibility were completed at post-intervention. Self-efficacy and goal attainment were completed pre- and post-intervention.

Results: The different steps provided useful information about the needs of potential users regarding the content and delivery of the program. This resulted in the newly developed 'Partner in Balance' program. At the start, system failures resulted in a high non-completer rate (41.2%), but at the end, a good feasibility score of 209 (range 54-234) was found. The convenience of completing the program at home, the tailored content and the guidance (face-to-face and online) were appraised positively. Preliminary effects on caregiver self-efficacy ($P<0.05$) and goal attainment ($T>50$) were promising.

Conclusions: Adaptations were made to the program to limit the amount of system failures and prevent high non-completer rates. As recommended by the MRC framework, confirming the feasibility and preliminary effectiveness is a valuable step toward examining the effectiveness of this newly developed intervention.

INTRODUCTION

Nowadays, chronic illness and decreased wellbeing are expected to become global public health challenges,¹ with dementia being one of the most common disorders in elderly.² With less formal healthcare available and more people in need of care, the caring role has shifted to the informal caregivers at home.³ However, dementia caregivers are at increased risk for burden, stress, and have a fourfold risk of becoming depressed compared to non-caregivers.^{4,5} As such, this transition into the caring role increases the need for effective caregiver interventions to improve their mood and quality of life.

Although recent face-to-face caregiver interventions appeared to be promising,^{6,7} the increasing gap between care supply and demand calls for alternative and cheaper methods for providing education and support to informal caregivers.^{3,8} Internet interventions may help caregivers cope with the challenges of caring for a person with dementia.⁹ A recent literature review showed that currently available Internet interventions for dementia caregivers have promising effects on caregiver confidence and burden, given that they comprised of multiple components and were tailored to the individual participant.¹⁰ In addition, internet-delivered caregiver support may prevent accessibility problems for informal caregivers who are isolated or have difficulties accessing traditional healthcare services.^{11,12}

At present, remote support for dementia caregivers is increasing, and new Internet interventions are being developed.¹³⁻¹⁹ These programs are, however, mainly focused at dealing with dementia-related problems (e.g. neuropsychiatric symptoms) that occur at an advanced stage of the caregiver career, whereas early-stage interventions can prepare caregivers for their future tasks at a stage where stress and burden are relatively low.²⁰ Early intervention and support for caregivers has proven to be effective in reducing strain, increasing caregiver confidence, and delaying institutionalization of the person with dementia.²¹⁻²³ Moreover, early therapeutic interventions may help caregivers identify their needs based on their individual situation and facilitate the adaptation process.²⁴ The Stress and Coping paradigm by Lazarus and Folkman²⁵ and the Social Learning theory by Bandura²⁶ propose that taking charge of the changes in one's life increases self-efficacy, and can therefore reduce caregiver stress and its impact on general wellbeing.²⁷ Following these theories, an early-stage support program for caregivers should focus at positively managing life with dementia rather than managing the dementia itself.²⁸ Self-management programs suit the caring role transition and have previously been

used to support informal caregivers of several chronic diseases with promising results.^{12,29,30}

Iterative development process

The present study describes the development of an online self-management program for EDC to improve self-efficacy and goal attainment. We closely followed the iterative process of the new Medical Research Counsel (MRC) Framework for the development of complex interventions.³¹ The first two steps in the intervention development are described elsewhere.^{10,24} The current paper describes the next four steps spread over a 2-year time period (2012-2014) (See Figure 1). These steps are described below.

Figure 1. Iterative development process informed by MRC framework

Step 1: Explore potential user views: focus groups

METHODS

In-depth exploratory focus group interviews were used to explore EDC views on the content and format of an early-stage intervention (See Ref²⁴ for detailed methodology). A context-mapping approach³² was used; a booklet examining personal Internet- and computer use and a collage displaying chosen themes based on significance during the early stages.³² Available themes were preselected based on existing interventions, early-stage dementia care literature,^{21,33} and expert knowledge. Blank cards were also provided. The most often selected and highest appraised themes were compiled. Focus group interviews were transcribed verbatim and analyzed independently based on deductive content analysis by authors LMMB and MEdV. Topics that were mentioned frequently and explicitly served as the basis for the categorization. Categories were merged into common themes in a consensus meeting (LMMB and MEdV).

RESULTS

Participant characteristics (N=28) are displayed in Table 1. The booklet on computer use was completed by 18 participants. Reasons for non-completion were (1) overlooking the booklet (N=7), and (2) not understanding its value (N=3). Participants used the computer for multiple purposes, e.g., finding information (83%), e-mail (78%), financial transactions (78%), writing (78%), viewing photos (50%), playing games (44%), (video) chatting with family members (17%), and shopping (11%). Three participants did not use a computer and were not inclined to do so in the near future. During the focus groups, the majority of the participants considered Internet interventions as efficient due to the high level of accessibility, especially when feeling pressed for time or being bound to one's home. Receiving answers to urgent queries was also considered very positive.

"The advantages are no travelling time and the possibility to search what I want to know when it is convenient for me." (P9)

"I would like to be able to extract the information that is important for me at that particular moment, because we're all so different. When you're in need of an answer, a personal response would be great." (P13)

Blended care (face-to-face care combined with online modules) was preferred over online care only, due to the personal contact with a professional.

"People experience emotions, while a computer is just an object. Seeing the person you are talking to is really important. Once you know each other, email or telephone is fine for information exchange." (P5)

All participants (N=28) completed the collage of themes during the interviews. Participants stressed the importance of an intervention tailored to the stage of the disease and the individual caregiver's situation, with less focus on coping with dementia and negative stigmatizing information about the future. Learning how to stay healthy by positively managing one's life and learning to accept the changes were considered important, as well as the significance of information provided by other caregivers. A more flexible choice of themes, based on personal needs and areas of interest, was considered desirable. The themes most often mentioned and

highest appraised are listed in Table 2.

Table 1. Background characteristics of the caregivers (N=28) and the care recipients (N=25)

Age (mean)	63.6 years	
Gender	Men	7 (25%)
	Women	21 (75%)
Relationship to the care recipient	Spouse	22 (78%)
	Child	2 (7%)
	Child-in-law	2 (7%)
	Sibling	1 (4%)
	Friend	1 (4%)
Living together with care recipient	Yes	21 (75%)
	No	7 (25%)
Care recipient diagnosis	MCI due to AD	8 (32%)
	AD	11 (44%)
	Vascular	3 (12%)
	Dementia	
	Parkinson	1 (4%)
	Dementia NOS ^a	2 (8%)
Care recipient years of diagnosis	0-5	5 (20%)
	1-3	9 (36%)
	4-6	10 (40%)
	7-10	1 (4%)

^aNOS = Not Otherwise Specified

Table 2. Themes most often selected and highest appraised by family caregivers (N=28)

Themes	Selected, n (%)	Appraised most important, n (%)
Practical tips	27 (96%)	14 (50%)
Role and relationship changes	22 (79%)	5 (18%)
Information about the disease	21 (75%)	12 (43%)
Balance in activities	19 (68%)	2 (7%)
Focus on the positive	19 (68%)	5 (18%)
Communication	18 (64%)	5 (18%)
Acceptance	16 (57%)	9 (32%)
Insecurities and worrying	12 (43%)	3 (11%)
Social relationships and support	12 (43%)	1 (4%)
Emotions and tension	10 (36%)	1 (4%)

Step 2: Develop and validate program content and structure

Consulting dementia care experts

METHODS

Individual in-depth interviews were conducted to explore dementia care experts' views on EDC Internet support. Experts from different institutions and regions within the Netherlands were recruited via email. Inclusion criteria were (1) professional caregiver in the Dutch dementia care field, (2) daily interaction with people with dementia (PwD) and their caregivers, and (3) ample experience with supporting EDC. The number of participants (N=11) was determined by data saturation; the redundancy of themes emerging from interviews [34]. Professional backgrounds consisted of psychiatrists (N=1), clinical neuropsychologists (N=3), registered health psychologists (N=4), occupational therapists (N=1), social psychiatric nurses (N=1), and nurse practitioners (N=1), with an average of 13.64 (SD 7.43) years of professional experience. A semi-structured interview guide was developed by authors LMMB and MEdV, validated by author FRJV. Topics included EDC needs, relevance and feasibility of EDC support, and themes for an EDC intervention. Brief summaries of the key points were made throughout the interview to obtain participant verification.³⁵ All interviews were audiotaped. The content of the verbatim transcriptions of the interviews was analyzed by summarizing common themes based on deductive content analysis.

RESULTS

The experts emphasized that caregiver support needs to be tailored to the dementia stage. Concerns were raised about providing early support in the absence of later-stage problems, when caregivers are not in need of help yet and could possibly reject early-stage support. Experts considered education on the disease and its course as most important. Other important themes involved accepting the disease, coping with relationship changes, stress, role management, and rumination. The importance of interaction between PwD, caregivers and environment was also stressed. Correcting or accepting care recipients' mistakes and notifying social network can be primary stressors in daily interaction. Too much negative information not fitting the early stages, e.g., behavioral problems, care homes and end of life decisions, could lead to adverse reactions and should be avoided in EDC support.

Combining the themes chosen by the experts and the caregivers resulted in 9 separate themes (Table 3). The theme 'practical tips' was incorporated in the module structure to provide tips thematically.

Table 3. Modules of 'Partner in Balance' and their key points

<i>Module</i>	<i>Key points</i>
Acceptance	<ul style="list-style-type: none"> - Identify changeable and unchangeable situations - Adapt expectations and learn to let go
Balance in activities	<ul style="list-style-type: none"> - Change in daily and pleasant activities - Identify personal carrying capacity and burden
Communication with family member and environment	<ul style="list-style-type: none"> - Communication changes due to memory problems - Effective communication with adaptations
Coping with stress	<ul style="list-style-type: none"> - Relationship between stress and health problems - Identify and cope with stress in daily life
Focusing on the positive	<ul style="list-style-type: none"> - Identify activities and situations that are still possible - Find alternatives and accept adaptations
Insecurities and rumination	<ul style="list-style-type: none"> - Recognize rumination signals and control thoughts - Prevent looking ahead; live in the moment
Self-understanding	<ul style="list-style-type: none"> - Self-evaluation in caregiver encounters - Personal strengths and areas of improvement
The changing family member	<ul style="list-style-type: none"> - The changing memory and behavior - Influence of memory decline on daily life together
Social relations and support	<ul style="list-style-type: none"> - Value and maintenance of social relations - Types of support

Content proposal: evidence and conceptual frameworks on self-care

METHODS

Intervention content was proposed by authors LMMB and MEdV based on a literature review,¹⁰ EDC needs,²⁴ identified themes in Step 1, and conceptual frameworks on self-management. The Stress and Coping paradigm²⁵ served as the theoretical basis for the content of the modules. According to this model, stress is experienced when a person perceives that the demands (caring for a person with dementia) exceed their personal and social resources. Caregivers' responses to their stress situation might be mediated by their understanding of the situation and their beliefs about their ability to cope. The latter fits Bandura's²⁶ concept of self-efficacy (belief in one's capabilities). Consistent with this theory, models of dementia management

emphasize the need to maintain self-worth and control.²⁸ An intervention aimed at increasing self-efficacy should not only educate the caregiver, but should foster self-management by combining education with problem-solving skills, and work towards a change in behavior.³⁶

RESULTS

The proposed self-management intervention program 'Partner in Balance' encourages caregivers to actively manage their lives and identify solutions for their specific needs.³⁷ Increasing knowledge, identifying and setting goals, and learning skills to achieve these previously set goals served as the basis for the intervention program. Module content was focused on role management (e.g., balancing activities in daily life) and emotional management (e.g., dealing with fear and insecurity about the future).³⁸ Formulating, planning and executing personal goals can be learned using a pro-active 5-step change plan (Textbox 1) often used in self-management,³⁸ which was integrated into each module. By formulating and planning a personal change plan, caregivers learn to anticipate on stressful situations and gain confidence in their ability to take care of the situation and themselves.³⁸ Because caregivers greatly varied in their needs, personal goals and interest, a flexible choice of modules was used. Successful elements that were identified in the literature review,¹⁰ including tailored caregiving strategies and contact with a coach and/or other caregivers, were included in the program content likewise.

Textbox 1. The self-management 5-steps applied per module

5 Steps to create an action plan and obtain goals

Step 1: Recognize areas that you wish to change or to maintain

Step 2: Recognize additional conditions and barriers

Step 3: Generate alternative strategies for the problem(s)

Step 4: Write down your final plan SMART

(Specific, Measurable, Attainable, Realistic and Timely)

Step 5: Evaluate when you will be satisfied with your progress

Validating proposed program content

METHODS

Dementia care experts (N=4) not involved in the initial interviews were asked to read the material and provide comments with respect to language, tone, amount of

information and significance and propriety of the content. They worked as clinical neuropsychologist (N=1), registered health psychologist (N=1), occupational therapist (N=1), and social psychiatric nurse (N=1), with an average of 9.75 years (SD 2.22) years of professional experience.

RESULTS

The experts provided comments for the content of each module. Stigmatizing, complex, or unclear language was reported and alternatives were provided. The textual content of the program was adapted accordingly.

Step 3: Testing the feasibility and preliminary effectiveness

Think Aloud Usability Testing

METHODS

A web-based fully operational program was developed based on the senior-friendly website checklist.³⁹ Initial usability flaws were tested with the 'think aloud' method.⁴⁰ Potential users were asked to think aloud while using the system, allowing the researchers to understand the reasons behind their usage behavior. Participants (N=4) were randomly selected from the focus group interviews (N=2) and the expert interviews (N=2). All aspects of the senior-friendly website guidelines were checked (e.g., font size, contrast, menus and navigation, button style and size, phrasing, illustrations and videos, and web-assistance) and additional comments on user-friendliness were explored in depth. The interviews were audiotaped and the verbatim transcripts were combined with field notes made by author LMMB on experienced difficulties during the walk-through. A coding scheme based on the interview protocol was used.⁴⁰

RESULTS

All participants (N=4) commented on the lay-out, font size, contrast, tone, and navigation. The website lay-out was considered professional and attractive, although a uniform composition of all pages was proposed to foster cohesion. Alterable font sizes and increased contrast with the background color were suggested. Vignettes of caregivers were considered useful, but addressing people with their given name instead of their family name was considered more appealing. The tips from other caregivers were perceived as crucial. It was suggested to conclude every module with these tips to increase lay-out uniformity.

Piloting feasibility

METHODS

An uncontrolled pre-post-intervention pilot study with EDC was conducted to establish feasibility, as this is recommended before moving on to a larger scale effect study.^{31,41} The Medical Ethics Committee of the Maastricht University Medical Centre (MUMC+) approved this study (#NL44475.068.13, Dutch trial register: #NTR4217). Caregivers were included in the study if they (1) were spousal caregivers of people with Mild Cognitive Impairment (MCI)⁴² or mild dementia of all subtypes,⁴³ and (2) had access to the Internet. Exclusion criteria were (1) insufficient cognitive abilities to engage in the online self-management program, (2) overburdening, (3) severe health problems (determined by study staff), or (4) caring for PwD caused by human immunodeficiency virus, acquired brain impairment, Down syndrome, Huntington's chorea, or alcohol abuse. Participants were recruited at memory clinics and ambulatory mental health clinics. Based on comparable feasibility studies, we aimed to include 10 participants.^{44,45} Of those contacted, 17 out of 43 caregivers (40%) were willing to participate and signed the informed consent.

Feasibility was evaluated face-to-face at the caregiver's home by a semi-structured interview developed for this study, the Program Participation Questionnaire (PPQ). The PPQ was based on measurement scales for perceived usefulness and ease of use and overall acceptance of information technology^{46,47} and included 30 items on usability, clarity, comfort with and acceptability of the format on a 7-point Likert scale ranging from 1 (strongly disagree) to 7 (strongly agree). For the individual PPQ items, see Multimedia Appendix 1. Mean scores were calculated with descriptive statistics. As there were no external criteria to properly define feasibility,⁴⁸ we followed the conventional strategy of using the median score of the questionnaire as a cut-off. This approach was previously adopted in a Delphi study as evidence of agreement of intervention feasibility.⁴⁹ Based on the PPQ scale (range 54-234, median 144), scores of 145 or higher were considered as acceptable feasibility. Mean item scores (range 1-7) will be used to make decisions on positively and negatively appraised aspects of the program. Mean item scores of 5 (slightly agree) or higher will be considered positive, mean item score below 4 (slightly disagree or lower) will need further revisions. Participants were asked to elaborate their scores. Comments were audio recorded and transcribed verbatim. Meaningful data units based on the PPQ items were identified and derived independently from the qualitative data by authors LMMB and HEJW with deductive content analysis.

Furthermore, the actual accessed data use of the program (number of log-ins and features used) was compared to self-report data.

RESULTS

The study population consisted of 17 participants, of whom ten completed the post-intervention assessment. Participants who did not complete the post-intervention assessment were replaced to still meet the sample size suggested by previous studies [44, 45]. The main reasons for not completing the program and the post-intervention assessment were difficulties with the online aspect of the program (N=4), private circumstances (N=2), and disagreements with the care recipient (N=1). Completer and non-completer characteristics are listed in Table 3.

The PPQ showed a good internal consistency ($\alpha=0.89$) and a mean sum score of 209 (SD 22.14). Given the threshold of 145 or higher, this score indicated an acceptable feasibility. Mean item scores above 5 (slightly agree or higher) were found for convenience of completing the program at home (5.9, SD 1.8), clarity of the website (6.0, SD 1.2), module structure (6.1, SD 0.6) and content (6.6, SD 0.5), privacy (6.6, SD 1.3), tailored assignments (6.1, SD 1.3), guidance by the coach (6.6, SD 0.5), and general contentment (6.4, SD 0.9). A mean item score below 4 (slightly disagree or lower) was found for usefulness of the discussion forum (2.8, SD 2.7). Table 4 shows the positive, negative and neutral themes derived from the additional comments. Self-report usage data were comparable to tracked usage data; 106.41 (SD 96.15) minutes spent per module, including scoping the website (4.4 minutes, SD 4.13), completing the assignments and change plan (79.14 minutes, SD 77.16), contacting the personal coach (15.31, SD 16.96) and visiting the discussion forum, spread out over 2.38 (SD 1.38) weeks.

Piloting preliminary effects

METHODS

Preliminary understanding of the effectiveness of the program was based on the baseline- and post-intervention assessment 8 weeks later, completed at the participant's own convenience in an uncontrolled pilot study. At participant request, paper questionnaires were used. The Caregiver Self-Efficacy Scale (CSES) was used to measure domain-specific caregiver self-efficacy.⁵⁰ The subscales include four items on service use and six items on care management, with scores ranging from 1 (not at all certain) to 10 (very certain). We found a good internal consistency

Table 3. Participant characteristics for completers and non-completers of the intervention

	Completers (N=10)		Non-completers (N=7)	
	Mean	SD	Mean	SD
Age caregiver	68.10	6.54	67.43	5.65
Age care recipient (PwD)	69.90	4.33	71.57	8.46
Hours care per week	44.20	56.85	76.43	71.98
Gender (N,%)				
Male	7 (41%)		2 (12%)	
Female	3 (18%)		5 (29%)	
Education (N,%)				
High school	1 (6%)		3 (18%)	
College	7 (41%)		4 (23%)	
Graduate school	2 (12%)		0 (0%)	
PwD diagnosis (N,%)				
MCI	7 (41%)		5 (29%)	
Alzheimer dementia	3 (18%)		1 (6%)	
Vascular dementia	0 (0%)		1 (6%)	

^anon-completer rate = 41.2%

for both service use ($\alpha=0.73$) and care management ($\alpha=0.87$). Paired samples t-tests were conducted to evaluate pre-post intervention changes. The Goal Attainment Scaling (GAS)⁵¹ method was used to rate treatment-related change and to compare relative success of previously set personal goals. Baseline scores were set at -2. Post-intervention scores can range from -2 (much lower than expected) to +2 (much better than expected), with a score of 0 meaning goal attained. Raw scores were transformed into an individual mean GAS score (T-score) to determine goal attainment with a potential weight assigned to the goal(s).⁵² T-scores of ≥ 50 (SD 10) indicate effective goal achievement.

RESULTS

Post-intervention, participants (N=10) had significantly higher scores on both the CSES care management subscale ($M=41.1$, $SE=2.5$; $t(9) = -2.5$, $P=.03$) and service use subscale ($M=32.6$, $SE=1.7$; $t(9) = -3.5$, $P=.01$) compared to pre-intervention ($M=36.1$, $SE=3.2$ and $M=23.2$, $SE=3.4$, respectively), although effect sizes were small ($d=0.14$ and $d=0.41$, respectively).

Table 4. Positive, negative and neutral evaluation of different features of Partner in Balance (N=10)

Feature	+	-	+/-	Quotes ^a
<i>Online</i>	At home	Writing personal situations feels more confronting than verbalizing them		"I thought it was useful to have the ability to do it at my own convenience and only when I was in the mood for it." (P10)
	Work in own time			
<i>Website</i>	Quick response during problems	Technical problems: login and communication		"It was pleasant that the information was presented in parts" (P8)
<i>Personal coach</i>	Supporting	Goal setting during intake difficult	Help of coach during goal setting necessary, not able to do it alone	"It is important that you have someone you can rely on during the program. It stimulates you even more and you know you are not alone." (P8)
	Indispensable			
	Feedback boosts self-confidence and motivation			
<i>Video clips</i>	Relatable examples	Not applicable to every individual	Background of caregivers unclear	"I could not identify with the video clips because it was not clear who was talking and I cannot relate to the addressed problems just yet." (P3)
	Personal aspect	Confronting		

<i>Discussion forum</i>		Too difficult to use Purpose unclear Difficult to start conversation No non-verbal communication	Coaches could feed the forum, ask questions or outline situations	"I am not going to write something out of the blue on a discussion forum. You might say the wrong things, even if you have good intentions." (P2)
<i>Change plan</i>	Useful	Felt like an obligation	Difficult to set personal goals	"The self-management assignment teaches you a lesson. How are you going to solve these things?" (P10)
	Increases awareness			
<i>Application in daily life</i>	Communication tips		Already apply tips in daily life	"The coach provided me with very good tips that I applied in daily life" (P12)
<i>General contentment</i>	Boosts confidence	No focus on practical decisions possibly faced in the future		"On moments that you are feeling insecure, this program gives you some kind of confirmation. It makes you doubt yourself less" (P10)
	Recommend to other caregivers			

^aP(number): participants number in the feasibility study

Eight program completers set 13 goals in total. Two program completers were not able to set goals due to personal difficulties verbalizing the desired change. Two goals (of 2 participants with multiple goals) could not be scored post-intervention, because the goals changed during the course of the study. Eight goals were attained (2 attained, 5 higher than expected, 1 much higher than expected), and 3 goals were not attained (1 much lower than expected, 1 lower than expected). The mean T-score at baseline (set at -2 level) was 27.8 (SD 3.04). The mean achieved T-score at post-intervention was 53.7 (SD 12.03). Table 5 shows the number of goals for each domain, with most goals set on communication with the care recipient, followed by maintaining positive activities together, obtaining social support and planning time alone.

Table 5. Number of set goals, attainment scores and domains in which goals were set (N=8)

	<i>Mean</i>	<i>SD</i>	<i>Range</i>
<i>Number of set goals per participant</i>	1.6	1.06	1.0 - 4.0
<i>GAS^a score at baseline</i>	27.8	3.04	22.6 - 30.0
<i>GAS^a score achieved</i>	53.7	12.03	30.0 – 70.0
<i>Number of set goals per domain (N)</i>			
- Communication with care recipient	7		
- Activities with care recipient	2		
- Social support	2		
- Time alone	2		

^aGAS = Goal Attainment Scaling

Step 4: Adapting the program: final intervention

Following the iterative development process, the program was adapted according to the results obtained in the feasibility study. The discussion forum was expanded with regular posts from personal coaches with practical tips, literature and events related to EDC. The role and background of the person in the video clips was clarified. Additionally, the content of often-mentioned early-stage situations and problems²⁴ was expanded and later-stage problems were made less prominent in the video clips. Furthermore, technical issues with logging in and communicating with the personal coach were resolved with the team of web experts.

Final intervention

Partner in Balance consists of 3 elements: (1) face-to-face intake session with a personal coach, (2) online period guided by the personal coach (psychologist or psychiatric nurse with ample experience with dementia caregivers), and (3) face-to-face evaluation session with the personal coach.

Intake session

In the intake session participants are introduced to the website and the self-management concept of the program. The coach and participant set personal goals by using a motivational interviewing technique frequently used to identify change objectives and enhance intrinsic motivation.⁵³ Based on the discussed areas for improvement, participants select 4 out of the 9 modules that were previously identified by experts and caregivers. Participants are provided with personal login codes to access their selected modules and edit their personal information. After the online period, participants will discuss their personal goals and their ability to cope with future difficulties in the evaluation session.

Online period

During the online period of the intervention, participants follow the chosen modules during an 8-week period. The website consists of a (1) homepage with a short description of the goal of the program, personal login option, contact information of the researcher and the institutional affiliation (Maastricht University), (2) personal page with a link to the chosen modules and a mailbox for exchange with the personal coach, and (3) online forum to interact with other caregivers, moderated by the researcher and personal coaches.

Every module has a fixed design of 4 components; (1) video clip of fellow family caregivers, (2) education, (3) self-reflection assignment, and (4) the 5-step change plan, guided by the personal coach who will provide individualized online feedback after completion of each module and offers assistance when needed. For every module, two weeks are reserved as a starting point. However, participants are allowed to complete the modules at their own pace as informed by the self-management approach.³⁸ The first week of a module addresses component 1-4. Participants can send their assignment and 5-stepplan to their coach. The second week of every module is reserved for feedback from the coach, after which participants can adjust their 5-stepplan if necessary.

Personal coach

The personal coach is an experienced dementia care professional (psychologist or psychiatric nurse). Coaches will receive a one-day training in self-management techniques and online help before the start of the intervention. They will receive experienced supervision from an experienced professional in psychology and self-management during the course of the intervention period to ensure quality and alignment of the feedback of the coaches according to self-management principle. Coaches are asked to support participants in choosing modules that fit their personal situation, help participants identify feasible goals, offer techniques to achieve goals and provide participants with general constructive feedback on their assignments. Via a personal login code, coaches will be matched with the participants assigned to them.

DISCUSSION

In this paper the iterative development process of the web-based self-management program 'Partner in Balance' (PiB) for EDC was presented. Use of the MRC framework enabled us to develop an intervention based on existing research, theoretical frameworks, and user and professional input. Including potential users during the design process enabled us to gain unique insights into usage behavior and challenges in order to adapt the technology to the needs of the target audience. A similar design has been successfully used in previous studies.⁵⁴⁻⁵⁶

During the exploration phase, caregivers greatly varied in their need for information. Previous self-management studies confirm that personal caregiver needs should be used as a starting point.⁵⁷ Blended care was preferred over online care only, due to the personal contact with a professional. Previous studies support the value of this format as participants highly appreciated the connection with their coach or therapist⁵⁸ and felt more motivated to complete web-based interventions.⁵⁹ On the other hand, adding face-to-face contacts increases the costs of the online program and reducing the number of face-to-face contacts might harm treatment outcomes when online components are not used.^{60,61} However, blending online modules with regular face-to-face therapy can increase the adherence and effectiveness of the treatment. Scientific validation of blended care interventions is warranted for the development and adaptation of future treatments⁶⁰ and can provide important support for the use of blended care interventions rather than online therapy only. The former can be more easily implemented by health services, therapists and

clients than online therapy, as they can be integrated in existing treatment and care settings.⁶²

Our results showed acceptable rates of satisfaction with PiB. Caregivers greatly appreciated the use of online resources due to the convenience of completing the program from their homes, which is in line with previous studies on web-based caregiver interventions.^{46,63-65} Furthermore, PiB supported the participants in the process of caregiving and boosted their self-confidence, probably due to the combination of support, self-management, and a tailored approach.^{66,67} However, the non-completer rate was high due to initial technical difficulties, which were resolved later on in the study. Unfamiliarity with using the website also caused difficulties among the older age group, resulting in a relatively young sample. A recent study confirmed that younger dementia caregivers were more likely to use the Internet for health-related purposes [68]. However, other research showed that homebound older adults with limited computer skills who receive computer training at the start of an intervention can participate without difficulties.⁶⁹ Also, including more potential users in the thinking aloud procedure could be helpful.⁴⁰

The discussion forum was negatively reviewed and hardly used, due to the unclear purpose, the anonymity of participants and the high threshold for starting a conversation. However, other studies suggest that forums can serve as a valuable addition to share experiences and support.^{39,45,70} Adding new tips or developments for caregivers could increase the use of a forum since the aspect of reading posts was already considered useful.⁷⁰ Furthermore, participants reported struggles with goal setting. This could be due to the relatively lower objective burden of EDC, compared to caregivers of people in later stages of the disease. EDC might experience more subjective burden, which is more difficult to translate into specific needs. Problems with accepting and adapting to their new role may also have hindered goal setting.²⁴ Therefore, goal setting for EDC should focus on the enhancement of positive overall experiences and facilitation of the personal adaptation process, rather than exclusively aiming for change. This approach may help to reduce or prevent negative consequences of caregiving (e.g., overburdening) at a later stage.²⁴

Preliminary effects on caregiver self-efficacy and goal attainment were small, yet positive. This finding is in line with Bandura's theory on self-efficacy, stating that caregivers' objective understanding of the situation and belief in one's capabilities (i.e., the self-efficacy level) can increase if provided with the right tools.²⁶

Furthermore, this finding is congruent with previous research on online support for dementia caregivers.^{21,71,72}

The program in this study was evaluated in a homogenous group of primary caregivers (e.g. spousal caregivers), with specific attention for the spousal relationship. However, the themes may apply to a broader target group, as demonstrated by previous studies.¹³⁻¹⁹ PiB could potentially be suitable for other primary carers, which should be further investigated in the upcoming effect study using a larger sample.

Limitations

The small sample size, the lack of a control condition and a possible sampling bias based on caregivers with access to the Internet, make it difficult to generalize the results. However, previous studies adopting a development and feasibility approach have used similar methodology and sample sizes,^{15,73} fitting the purpose of formative research.³¹ Also, users and experts were closely involved in the development of the intervention, and the content and adaptations relied on in-depth participant and expert feedback. Future research should consider inclusion of caregivers in the proposed content validation, to ensure potential user feedback in every step of the development. Furthermore, drawing conclusions from the adopted median cut-off score, which is an arbitrary value, may not be justified. However, in the present study the overall feasibility score was not leading. Mean item scores were used to make program improvements.

The present study used paper questionnaires. Although seniors' use of the Internet is expected to increase over time,⁷⁴ dementia caregivers seem to be less active in health-related Internet use compared to the population at large.⁶⁸ The high non-completer rate resulted in missing post-test data from the non-completers as this was collected after the last module. However, reasons for non-completion and characteristics of non-completers were provided, giving insight into their possible motives. Future effectiveness studies should include non-completer data at post-treatment and follow-up and consider using web-based questionnaires, with the advantages of low costs, no missing data or data entry errors and time flexibility.⁷⁵

Conclusion

Our tailored intervention approach appeared to be feasible for informal EDC and provided them with important support when dealing with the difficulties of caregiving.

Feasibility results were used to improve the intervention. Confirmation of the feasibility and preliminary effectiveness is a valuable step towards examining the effectiveness of this intervention, as recommended by the MRC framework.³¹ The PiB course is currently (November 2015) available for caregivers who are interested in participating in the effectiveness study. At the course website (www.partnerinbalans.nl) they can express their interest by emailing the researcher, after which they will receive additional information about the course and the effectiveness study.

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Appendix 1. Program Participation Questionnaire

Rate each item on a scale from 1 (strongly disagree) to 7 (strongly agree)	Please elaborate your item score
1. It was convenient to follow the program online	- What made it (not) convenient?
2. The website was easy to use	- What was specifically easy/difficult?
3. I was able to read the texts perfectly	- Comments on font, size, contrast?
4. The website indications were clear to me	- Why were they (not) clear?
5. The amount of information presented was good	- Points for improvement?
6. The content of the modules was clear	- Video clip length, amount of text
7. I was satisfied with the amount of time I spent per module	- Comprehensible?
8. The face-to-face contact with my personal coach, aside from the online period, was desirable	- Points for improvements?
9. I was satisfied with the goal-setting together with my coach	- How much time did you spend per module?
10. The oral explanation of the website was clear to me	- What was the most time-consuming?
11. The written explanation of the website was clear to me	- Would you have liked modules to be more/less time-consuming?
12. I was satisfied with the amount of time between modules (1-2 weeks)	- Why was this (not) desirable?
13. I was satisfied with the number of modules (4)	- What was the added value?
14. I was satisfied with the structure of the modules (video clip, education, self-reflection assignment, 5-stepplan)	- Why where you (not) satisfied?
	- What could be improved to make it easier?
	- Points for improvement?
	- Points for improvement?
	- Longer or shorter and why?
	- More or less and why?
	- Did it feel natural to follow the steps in this order?
	- Why (not)?
	- Points for improvement?

15. I made use of:	
15a. The video-clips	<ul style="list-style-type: none"> - <i>Why (not)?</i> - <i>Why did it (not) appeal to you?</i> - <i>Why (not)?</i> - <i>Why did it (not) appeal to you?</i>
15b. The educational introductions	
15c. The self-reflection assignments	<ul style="list-style-type: none"> - <i>Why (not)?</i> - <i>Why did it (not) appeal to you?</i>
15d. The 5-step change plans	<ul style="list-style-type: none"> - <i>Why (not)?</i> - <i>Why did it (not) appeal to you?</i>
15e. The discussion forum	<ul style="list-style-type: none"> - <i>Why (not)?</i> - <i>Reading/posting?</i> - <i>Why did it (not) appeal to you?</i>
15f. The 'help' button	<ul style="list-style-type: none"> - <i>Why (not)?</i> - <i>Why did it (not) appeal to you?</i>
16. I have experienced privacy issues:	
16a. In general	<ul style="list-style-type: none"> - <i>What made you feel (un)safe?</i> - <i>How could this be improved?</i>
16b. In communication with my coach	<ul style="list-style-type: none"> - <i>What made you feel (un)safe?</i> - <i>How could this be improved?</i>
16c. At the discussion forum	<ul style="list-style-type: none"> - <i>What made you feel (un)safe?</i> - <i>How could this be improved?</i>
17. In general, I am satisfied with the program	<ul style="list-style-type: none"> - <i>Why (not)?</i> - <i>Points for improvement?</i>
18. The modules I choose were useful for me	<ul style="list-style-type: none"> - <i>Why (not)?</i> - <i>Points for improvement?</i>
19. The content of the modules was interesting	<ul style="list-style-type: none"> - <i>Why (not)?</i> - <i>Points for improvement?</i>

20. The tone of the text was appealing to me	<ul style="list-style-type: none"> - Why (not)? - Points for improvement?
21. I used the information that was offered in the program in my daily life	<ul style="list-style-type: none"> - Why (not)? - Points for improvement?
22. After following the program, I am more confident that me and my family member can cope with the memory impairment	<ul style="list-style-type: none"> - Why (not)? - Points for improvement?
23. The video clips were a valuable addition to the program	<ul style="list-style-type: none"> - Why (not)? - Points for improvement?
24. The written introduction was informative and helpful	<ul style="list-style-type: none"> - Why (not)? - Points for improvement?
25. The self-reflection assignments helped me to carefully review my own situation	<ul style="list-style-type: none"> - Why (not)? - Points for improvement?
26. The 5-step plan helped me to systematically tackle situations that I wished to change	<ul style="list-style-type: none"> - Why (not)? - Points for improvement?
27. The discussion forum was a valuable addition to the program	<ul style="list-style-type: none"> - Why (not)? - Points for improvement?
28. After following the program, I know how to tackle unwanted situations in the future more easily	<ul style="list-style-type: none"> - Why (not)? - Points for improvement?
29. I would recommend the program to other family members of people with memory impairment	<ul style="list-style-type: none"> - Why (not)? - What aspects of the program would you recommend in particular?
30. Remaining remarks	

CHAPTER 6

Effectiveness of the blended care self-management program
'Partner in Balance' for early-stage dementia caregivers: study
protocol for a randomized controlled trial

Trials, 2016

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ABSTRACT

Background: The benefits of e-health support for dementia caregivers are increasingly recognized. Reaching early-stage dementia caregivers could prevent high levels of burden and psychological problems in the later stages of dementia. An iterative step-wise approach was employed to develop the blended care self-management program 'Partner in Balance' for early-stage dementia caregivers. The design of a study evaluating the process characteristics and effects is presented.

Methods/design: A mixed method single-blind, randomized controlled trial with 80 family caregivers of community-dwelling people with (very) mild dementia will be conducted. Participants will be randomly assigned to either the 8-week blended care self-management program 'Partner in Balance' or a waiting-list control group. Data will be collected pre- and post-intervention and at 3-, 6- and 12-month follow-ups. Semi-structured interviews will be conducted post-intervention. A process evaluation will investigate the internal and external validity of the intervention. Primary outcomes will include self-efficacy and symptoms of depression. Secondary outcomes will include goal attainment, mastery, psychological complaints (feelings of anxiety and perceived stress), and quality of life. Possible modifying variables such as caregiver characteristics (quality of the relationship, neurotic personality) and intervention aspects (coach) on the intervention effect will also be evaluated. A cost-consequence analysis will describe the costs and health outcomes.

Discussion: We expect to find a significant increase in self-efficacy, goal attainment and quality of life and lower levels of psychological complaints (depression, anxiety and stress) in the intervention group, compared with the control group. If such effects are found, the program could provide accessible care to future generations of early-stage dementia caregivers and increase dementia care efficiency.

INTRODUCTION

Family caregivers are currently becoming the main source of care for people with dementia.¹ However, dementia caregivers are at risk for depression, anxiety and other health problems.² Interventions aimed at reducing the burden of care might reduce dementia care costs in the long term if institutionalization can be postponed.³

Many face-to-face caregiver support interventions have proven to be effective on caregiver distress (random effect size = 0.3), caregiver knowledge (random effect size: 0.5),⁴ and self-efficacy (effect sizes ranging from 0.3 – 0.9),⁵ but the expected future increase in the number of people with dementia raises concerns about whether care professionals can cope with this demand.⁶ E-health interventions could serve as cost-effective alternatives for dementia caregiver support,⁷⁻⁹ both increasing caregivers' access to support and extending the reach of such support.¹⁰⁻¹³ The benefits of e-health are increasingly recognized, and remote support for dementia caregivers is growing.¹⁴⁻¹⁶

Previous e-health studies on dementia caregivers show positive effects on caregiver confidence, stress, depression, and self-efficacy with effect sizes ranging from 0.2-0.3.¹⁷ Provision of tailored information, a coach and the opportunity to interact with other caregivers shows the most promise.¹⁷ Blending face-to-face guidance with online modules increases caregivers' connection with the therapist and adherence.^{18,19} However, research on the effects of e-health on dementia caregivers lacks methodological rigor,¹⁷ and adverse effects of caregiving are often addressed in the later stages of dementia, when caregivers already feel overburdened.²⁰ Despite their low levels of life satisfaction and high levels of overload, caregivers do not use services in early stages because they do not feel the need for such services or because they struggle with acceptance due their experience of stigma.²⁰⁻²² Supporting caregivers in an early stage of dementia could prevent high levels of burden and psychological problems in the later stages and delay institutionalization.²³⁻²⁶ However, early-stage dementia caregiver support can be experienced adversely if the care does not suit the caregiver's personal situation or the stage of the disease. Negative and stigmatizing information can make it difficult for caregivers to identify with and may hamper acceptance.²⁰ Learning to positively manage life with dementia instead of managing the dementia itself in a self-management program could facilitate caregivers' adaptation to their new caregiving role. A focus on enhancing positive, intact experiences that are tailored to the

individual caregiver's situation may be more effective in increasing caregiver self-efficacy and reducing the negative consequences of caregiving at later stages.²⁰

Study aim and hypotheses

The current paper presents the design of a randomized waiting-list controlled trial investigating the effects of the blended care self-management program 'Partner in Balance'. Alongside the effectiveness study, a process evaluation will be conducted to evaluate internal and external validity. As recommended by the Medical Research Council (MRC) Framework for the design and evaluation of complex intervention,²⁷ the program was based on existing literature,¹⁷ theory, and user and professional input.²⁸ In a pilot evaluation, caregivers reported increased feelings of self-efficacy and goal attainment post-intervention. Feedback from the feasibility study was used to adapt the intervention to increase user-friendliness.²⁸ The next objective is to evaluate the process characteristics, effectiveness and cost-consequence of 'Partner in Balance'. Specifically, we aim to investigate (1) the internal and external validity of the intervention based on sampling quality (recruitment, randomization and reach) and intervention quality (relevance, feasibility, and performance according to protocol) prior to the effect analysis to evaluate credibility and generalizability,²⁹ (2) whether 'Partner in Balance' is superior to the waiting-list control condition in terms of participants' subjective well-being, as evidenced by improved subjective self-confidence (increased self-efficacy) and goal attainment and lower levels of psychological complaints (depression, anxiety and stress) following the self-management intervention, and (3) whether the effects are maintained after 3, 6 and 12 months. Lastly, (4) the cost-consequence of Partner in Balance is calculated to estimate the impact of the intervention on resource use, costs, and health outcomes.

METHODS

The Medical Ethics Committee of the Maastricht University Medical Center+ approved this study (#12-4-059). The study is a randomized waiting-list controlled trial. This study was designed to maximize acceptability and adherence to the research protocol in the control group and minimize attrition effects. Data will be collected pre- and post-intervention and at 3-, 6- and 12-month follow-ups. See Figure 1 for the flow diagram.

Figure 1. CONSORT flow diagram

Population

Recruitment

The study population will consist of family caregivers of community-dwelling people with (very) mild dementia of all subtypes (Clinical Dementia Rating (CDR) score 0.5-1).³⁰ No age limit will be applied; however, only adult family caregivers will be solicited. Participants will be recruited from memory clinics (MUMC+, Elkerliek Hospital Helmond, Catharina Hospital Eindhoven) and ambulatory mental health clinics (Virenze-RIAGG Maastricht, MET ggz Roermond) in the south of the

Netherlands. Caregivers will be approached by the clinician or therapist who is treating their family member. Prior to participating, caregivers will provide written informed consent.

Eligibility

Family caregivers of people with (very) mild dementia of all subtypes (CDR score 0.5-1) who are >18 years, have access to the Internet at home, and have basic skills in the use of computers are eligible to participate in the study. Potential participants that have insufficient cognitive abilities to engage in the online self-management program; are overburdened or have severe health problems, as determined by study staff; or care for people with dementia caused by human immunodeficiency virus (HIV), acquired brain impairment, Down syndrome, chorea associated with Huntington's disease or alcohol abuse will be excluded from participation.

Randomization

Following the baseline assessment, participants will be randomly assigned to either the self-management intervention or the waiting-list control group using a computer program operated by an independent statistician. Block randomization will be conducted to reduce the risk of unbalanced assignment to the experimental and control groups. We will use randomly permuted blocks and several block sizes (4, 6 and 8). The block size and order of allocation will be randomly chosen at the beginning of each block. This reduces the risk of predicting group assignment and keeps research staff blind to the randomization process. An independent research assistant who is unknown to the allocation of the treatment will conduct the post-intervention and follow-up assessments, and will be asked to evaluate success of blinding and reason for possible unmasking on the Case Record Form.

Intervention

Experimental group

The 'Partner in Balance' intervention consists of a face-to-face intake session with a personal coach, an online period, and a face-to-face evaluation session with the personal coach. The basis of the intervention is learning to identify areas of change and creating personal goals. The development and final intervention are described in detail elsewhere.²⁶ The goal of the intake session is to familiarize participants with the program and set goals that they wish to accomplish through their participation

using the motivational interviewing technique frequently used to identify change objectives and enhance intrinsic motivation to change.³¹ Goals and strategies to achieve these goals are individually determined and depend on the participants' personal problems, motivation, and capabilities. Given that it is not usual for elderly to reflect on their problems or concerns thematically, a 'toolbox' of themes should be developed to aid the discussion of these issues with the participants.³² Based on their personal needs and areas of interest, participants will select four out of nine modules in the toolbox, and they will be briefed individually to ensure that they understand the online procedure. The module themes are provided in Box 1. The module contents are described elsewhere.²⁸ Following the intake, participants will complete their chosen modules online during an 8-week period. Two weeks are allocated for each module, but participants will be allowed to complete the modules at their own pace in accordance with the self-management approach.³³ After the online period, participants will meet with their coach face-to-face to discuss their ability to accomplish goals and cope with future difficulties. Participants will continue to have access to their personal page and modules after the intervention period.

Box 1. Themes of the available 'Partner in Balance' modules

Partner in Balance modules
1. Acceptance
2. <i>Balance in activities</i>
3. <i>Communication with family member and environment</i>
4. <i>Coping with stress</i>
5. <i>Focusing on the positive</i>
6. <i>Insecurities and rumination</i>
7. <i>Self-understanding</i>
8. <i>The changing family member</i>
9. <i>Social relations and support</i>

The personal coach

The personal coach is an experienced professional (psychologist or psychiatric nurse) from one of the participating sites. Coaches will receive a one-day training on self-management techniques and online help before the start of the intervention. They will receive supervision from an experienced professional in the fields of psychology and self-management to ensure high-quality feedback.

Coaches support participants in choosing modules that fit their situation, help identify feasible goals, offer techniques to achieve goals and provide general constructive feedback on their assignments. Coaches will be matched with the participants assigned to them via a personal login code.

Control group

Participants in the control group will be placed on a waiting list for 8 weeks. After they complete the post-test assessment, they will receive the online self-management intervention. They will receive the same pre-test and post-test attention from the research team as the experimental group.

Procedure

Participants will be assessed at 5 time points: (T₀) baseline assessment, (T₁) post-intervention or waiting list assessment (8 weeks), (T₂) post-intervention assessment for waiting-list (8 weeks after T₁), (T₃) 3-month follow-up, (T₄) 6-month follow-up, and (T₅) 12-month follow-up. Figure 2 shows the schedule of enrollment, procedures and mixed method assessments per condition.

Questionnaires

Primary outcomes

*The Caregiver Self-efficacy Scale (CSES)*³⁴ is based on a Dutch version of Lorig et al.'s³⁵ self-efficacy instrument and measures care management self-efficacy (4 items) and service use self-efficacy (5 items). Item scores range from 1 (not at all certain) to 10 (very certain). Total care management self-efficacy scores range from 4-40 and service use self-efficacy from 5-50. Good reliability was demonstrated for the CSES in a previous study.²⁸

The Dutch version of *the Center for Epidemiological Studies Depression Scale (CES-D)*³⁶ consists of 20 items that rate the frequency of depressive symptoms during the past week, with higher total scores indicating greater depressive symptoms. Scores range from 0 (rarely or none of the time [less than 1 day]) to 3 (most or all of the time [5 to 7 days]). The total score ranges from 0 to 60. Items represent depressed mood, feelings of guilt and worthlessness, feelings of helplessness and hopelessness, psychomotor retardation, loss of appetite, and sleep disturbance. The CES-D is sensitive to changes in caregiver depressive symptoms after intervention.³⁷

TIMEPOINT**	STUDY PERIOD						
	Enrolment	Baseline	Post-allocation				
	-T ₁	T ₀	T ₁	T ₂	T ₃	T ₄	T ₅
ENROLMENT:							
Eligibility screen	X						
Informed consent	X						
Allocation		X					
Demographics		X					
INTERVENTION:							
<i>Partner in Balance</i>		X	X		X	X	X
<i>Waiting-list</i>		X	X		X	X	X
<i>Waiting-list + Partner in Balance</i>
ASSESSMENTS:							
CSES		X	X	X	X	X	X
CES-D		X	X	X	X	X	X
GAS		X	X	X			
PMS		X	X	X	X	X	X
PSS		X	X	X	X	X	X
HADS-A		X	X	X	X	X	X
ICECAP-O		X	X	X	X	X	X
Relationship quality		X	X	X	X	X	X
NEO-FFI		X	X	X	X	X	X
Semi-structured interview			X	X			
RUD-lite		X	X	X	X	X	X

Figure 2. Schedule of enrolment and assessments per condition

Secondary outcomes

*Goal attainment scaling (GAS)*³⁸ is a measure of treatment-induced change. GAS enables comparisons of individuals' relative success in achieving goals that are individually determined. Scores range from -2 (much less than expected) to +2 (much better than expected), with 0 indicating that the goal is attained. Raw scores are transformed into T-scores.³⁹ T-scores include attainment level and a potential weight assigned to the goal(s). T-scores of ≥ 50 indicate effective goal attainment. GAS demonstrated reliable monitoring of progress over time.⁴⁰

*The Pearlin Mastery Scale (PMS)*⁴¹ measures perceived control, otherwise known as mastery. The scale includes 7 items, with scores ranging from 1 (completely agree) to 5 (completely disagree). The sum score (range 0-35) indicates the extent of perceived control or mastery, with higher scores indicating greater perceived control. The psychometric properties of the Dutch version of the Mastery Scale have found to be good in previous studies.⁴²

*The Perceived Stress Scale (PSS)*⁴³ measures overall appraisals of stress in the past month. Ten items on unpredictability, control and overload are rated on a 5-point scale from 0 (never) to 4 (very often), with higher total scores indicating higher levels of stress. The scale showed good reliability.⁴⁴

*The Hospital and Anxiety Depression Scale (HADS-A)*⁴⁵ is used to generate scores for generalized anxiety. The anxiety subscale consists of 7 items rated from 0 (not at all) to 3 (a great deal of the time). Total scores range from 0 to 21, with higher scores indicating more anxiety. Good reliability was found.⁴⁶

*The Investigating Choice Experiments for the Preferences of Older People CAPability measure for Older people (ICECAP-O)*⁴⁷ measures five important attributes of quality of life. The value system for the 1024 states defined by the instrument was derived from a survey of older people in England, using a best-worst scaling valuation method. The value system provides a single summary score, anchored at zero ('no capability') and 1.0 ('full capability'), for each state described in terms of the five attributes. The ICECAP-O may have the potential to measure broader outcomes and be more sensitive to differences between intervention and comparators than the EQ-5D, which is often used in cost-effect evaluations.⁴⁸

Additional measures

Quality of the relationship is rated with four items of *the University of Southern California Longitudinal Study of Three-Generation Families measures of positive affect*.⁴⁹ The items indicate a) general closeness, b) communication, c) similarity of views about life and d) degree of getting along. Scores range from 1 (not at all) to 4 (very). The value system for the 1024 states uses a best-worst scaling valuation method, providing a single summary score, anchored at zero ('no capability') and 1.0 ('full capability'). Good reliability was found in a previous study.⁵⁰

*The NEO Five-Factor Inventory (NEO-FFI)*⁵¹ measures personality. The 12-item Neuroticism domain will be used to identify individuals who are prone to psychological distress. This domain assesses 6 traits: anxiety, angry hostility, depression, self-consciousness, impulsiveness and vulnerability.⁵² The reliability of the Dutch version of the NEO-FFI is good.⁵¹

Semi-structured interview

After the intervention is completed, a semi-structured interview will be conducted to qualitatively evaluate the effect of the program on participants' self-efficacy. The interview will take place face-to-face in the caregiver's home or at the participating institution and will be audiotaped with the participants' permission. Topics include the application of the intervention in daily life and the intervention's impact on knowledge about the disease, caregiver functioning, and self-esteem.

Process outcomes

Prior to the analysis of effects, the internal and external validity of the intervention will be evaluated using data on sampling quality (recruitment, randomization, and reach) and intervention quality (relevance, feasibility, and performance according to protocol) to provide essential information on the program's credibility and generalizability.²⁹ A description of the recruitment and randomization procedure, the informed consent and allocation procedure, and the barriers and facilitators to recruiting caregivers will be provided. Reach will be determined by the proportion of caregivers participating in the study and the number of institutions involved in the intervention. Intervention quality will be determined on two levels, (1) coach and (2) participant. Data will be collected from the research database, and during focus group interviews with coaches and individual semi-structured interviews with participants post-intervention. Coaches will be asked to complete a questionnaire about clearness, relevance, and usability of the intervention. Delivery of the intervention according to protocol will be evaluated with a structured registration form (Appendix I). For an overview of the specific methods used for each aspect of validity, see Table 1.

Table 1. Methods used to assess process of the intervention

Process Aspects	Methods used
<i>Sampling quality</i>	Procedure of recruitment, informed consent, and allocation; recruitment barriers and facilitators; reach (proportion participants/institutions)
<i>Intervention quality (rated by coach)</i>	
Protocol deviations; amount/intensity contact with participant	Registration form (Appendix I)
Relevance for caregivers + professional coaches; usability in daily practice	5-point rating scale ^a
Advantages of the program; disadvantages/suggestions for improvement; recommendation to other professionals	Open ended questions
<i>Intervention quality (rated by participant)</i>	
Number of online visits and time spent per module	Online system usage data ^b
Compliance to the program	Ratio number of modules chosen/completed
Clarity of the content; website ease of use; satisfaction with online aspect combined with face-to-face contact; satisfaction with personal coach and feedback; advantages of the program; disadvantages/suggestions for improvement; impact on understanding and knowledge; impact on caregiver self-esteem; recommendation to other caregivers	Semi-structured interview

^a 1 = totally disagree to 5 = totally agree

^b Online system usage data include frequency of logging in to the system, length of visit (per module feature), and time and date of visit.

Intervention costs

To provide a comprehensive presentation of the value of Partner in Balance, a cost-consequence analysis will be conducted. This is a listing of all the relevant costs and consequences (outcomes) of the intervention. Costs will be based on the Dutch guidelines for cost calculations in health care.⁵³ Formal and informal resources used by the caregiver and care recipient will be mapped by means of The Resource Utilization in Dementia – shortened version (RUD-lite),⁵⁴ which includes information on hospital costs, contacts with the GP or other health care professionals, home care, day care, admissions to a nursing home or elderly home, medication and acquisition of goods/aids. Costs are calculated by multiplying the volume of resource use by the cost price per resource unit and include the period from the baseline assessment up to the last follow-up measurement (12 months). Intervention costs

include time spent on the intake and evaluation session, e-mail contact, the coach training sessions, materials, and coach supervision. The coaches will register the amount of time spent on the intake, evaluation session and e-mail contact on a structured registration form. All costs are expressed in Euros and are adopted from Hakkaart.⁵³

Sample size

We determined our sample size based on previous online intervention studies on caregivers of people with dementia using the Caregiver Self-efficacy Scale (CSES) as outcome measure, the use of repeated measures, within-between interaction with a mean effect size of 0.2,⁵⁵ the following assumptions: alpha 0.05, power 85% and 25% loss to follow-up. In accordance with these criteria, we aim to enroll 80 participants (40 participants per group).

Statistical analyses

Quantitative measures

Prior to the analysis, data will be checked for missing values, outliers, and normality. Possible differences between the study groups' baseline characteristics will be tested with t-tests for continuous variables and χ^2 -tests for categorical variables. In case of missing data, we intend to test if data is missing completely at random (MCAR) based on a comparison of the baseline characteristics of study completers and participants with missing values. If $p < .05$ for (one of) the variables in the model, the missing values are non-random. In case of data MCAR, the specification of a missing value or dropout model is not necessary and list wise deletion will be applied. In case of missing data not at random, we will apply a multiple imputation-based strategy.⁵⁶

To examine differences in the outcomes of the intervention and the waiting-list control groups during the intervention period, an analysis of covariance (ANCOVA) will be conducted with outcome at post-intervention as the dependent variable, intervention (Partner in Balance, waiting-list control group) as the between-subjects variable and the pre-intervention outcome, emotional instability, quality of the relationship, educational level and relationship to the care recipient as covariates. Each outcome will be assessed as a dependent variable. Group differences in the post-intervention outcome adjusted for its baseline value will be examined to test the primary hypothesis. If differences are found, the inter-group effect size will be calculated according to Cohen's d .

To analyze changes in the primary and secondary outcomes during the total study period, the data from the intervention-only group and the waiting-list group receiving the intervention after 8 weeks will be combined using a linear mixed model (LMM). The LMM will estimate fixed effects (regression slopes) for the change during the waiting-list interval (T0-T1 as measured in the waiting-list group only) and fixed effects for change in the intervals during (T1-T2) and after (T2-T3, T3-T4, T4-T5) the intervention period (measured in the waiting list group after the first 8 weeks and in the intervention group). This will allow us to compare the rate of change in those receiving no intervention (T0-T1) with those receiving the intervention (T1-T5) while accounting for the fact that data are nested in individuals and, therefore, correlated. Intervals will be entered as a categorical variable (5 levels) using dummies. Model fit of models with random intercepts (at the participant level) and models with random intercepts and random slopes (at the interval level) will be compared using likelihood ratio tests.

Emotional instability and quality of the relationship will be included as covariates because they are expected to influence the difference between groups. Coach will be introduced into the analysis as a random factor to estimate the variability attributable to the coach. For goal attainment, descriptive statistics will be used to calculate the total number of goals set per domain. Mean goal attainment scaling scores (T-scores) will be calculated with a standard formula³⁸ for each measurement time point.

All analyses will be carried out according to the intention to treat principle using IBM SPSS statistics 22.0 for Macintosh. All tests of significance will report mean change and will be two tailed, with α set at 0.05.

Semi-structured questionnaire and process evaluation

The qualitatively obtained data from the semi-structured interview will be transcribed verbatim. Two independent researchers will perform deductive content analysis of the transcribed text using ATLAS.ti. Conceptual labels will be assigned to textual fragments and organized into categories. Categories will be merged into common themes in a consensus meeting. Disagreements will be solved through discussion. The quantitative items scored by coaches will be calculated by means of descriptive statistics.

Monitoring and participant safety

Monitoring of the recruitment and execution of the study will be conducted by the trial monitoring committee of the MUMC+ (Clinical Trial Center Maastricht). Adverse events (AEs) and serious adverse events (SAEs) are not anticipated but cannot be ignored. If participants drop out, they will be asked if they had experienced an adverse or harmful event during the study period that could be attributed to 'Partner in Balance'. Included participants will be asked the same question during the post-intervention assessment and at the 3-, 6- and 12-month follow-ups. All AEs and SAEs will be recorded. SAEs will be reported to the accredited MEC that approved the protocol. AEs will be followed until they have abated or until a stable situation has been reached. Depending on the event, follow-up may involve additional tests or medical procedures, as indicated, and/or referral to the general physician or a medical specialist. If participants do not agree to this procedure, they cannot participate in the study.

DISCUSSION

In this paper, we described the design of a randomized waiting-list controlled trial to evaluate the effectiveness and process of a blended self-management program to improve caregiver self-efficacy and psychological well-being. As recommended by the MRC Framework,²⁷ this study was preceded by an iterative development and feasibility study.²⁸ There are several unique aspects of the current study. To our knowledge, this is the first blended care intervention for early-stage dementia caregivers developed with potential users and tailored to the individual user. Furthermore, the MRC Framework suggests that implementation should be considered during the first phases of intervention development and evaluation.²⁷ Implementation is expected to be successful because this intervention was developed with potential professional users and will be evaluated in multiple institutions and with coaches from different backgrounds. The program will be delivered in daily practice and can be integrated in the present care provided. Furthermore, tailoring to individual caregiver needs is expected to increase program effectiveness¹⁷ and facilitate implementation.⁵⁷ Additionally, GAS enables identification of individual benefits that caregivers experience beyond the generalized measures.⁵⁸ The process evaluation facilitates our understanding of the quantity and quality of intervention delivered and evaluates the generalizability of the research based on an understanding of the context.⁵⁹ The mixed methods approach enables

better understanding of whether and how the intervention works, and facilitates replication of the intervention through greater knowledge of the active component(s) and potential barriers to implementation.⁶⁰ Because all the resources used, costs and outcomes are transparently listed in the cost-consequence analysis, decision makers can select the information that is of most interest to them. Finally, the waiting-list controlled design of the study allows all potentially interested participants to participate in the intervention program. It may increase caregivers' motivation to participate given that usual care for (very) mild dementia caregivers often either does not include counseling or includes only very infrequent counseling.⁶¹

In conclusion, the results of this study will be a valuable contribution to the growing knowledge on e-health for dementia caregivers. Partner in Balance is expected to be effective in increasing caregiver self-efficacy and reducing depressive symptoms in early-stage dementia caregivers. The study will also provide insight into program delivery and program costs related to the program consequences. The results will be used to inform clinicians and researchers of the delivery, costs and effects of Partner in Balance as a tool to support dementia caregivers.

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Appendix 1. Registration form coaches Partner in Balance

Participant number: _____

	Date	Time spent	(if applicable) On whose initiative?	Topics discussed	Other remarks
Action undertaken Preparation <ul style="list-style-type: none"> - Attending coach training - Reading protocol - Attending coach intervention meetings 					
Intake session <ul style="list-style-type: none"> - Getting acquainted - Needs assessment - Setting GAS goals - Choosing modules + adding modules to account - Explaining online procedure - Contact moment agreements - Providing login information 					
Online period <ul style="list-style-type: none"> - Responding to online assignments (email) - Other online help (support requests, reminders) - Telephone contacts (if applicable) 					
Evaluation session <ul style="list-style-type: none"> - General evaluation of modules and experience with the program - Evaluating GAS goals - Identify need for additional modules or types of aid 					

CHAPTER 7

Validity and implementation of the blended care self-management program 'Partner in Balance' for caregivers of people with early-stage dementia: a process evaluation

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ABSTRACT

Background: The blended care self-management program 'Partner in Balance' (PiB) for family caregivers was executed in Dutch dementia care organizations.

Objective: A process evaluation was performed to determine internal and external validity assessing PiB credibility and generalizability of the results.

Methods: Implementation, sampling, and intervention quality were evaluated with quantitative and qualitative data from (1) coach questionnaires (N=13), (2) interviews with coaches (N=10) and participants (N=49), and (3) logistical research data. Goal attainment scaling (GAS) was used to measure treatment-induced change. Analyses were performed with descriptive statistics and deductive content analysis.

Results: The participation rate of caregivers was 52%. Recruitment barriers were no computer and no need for support. Recruitment facilitators were young age and being employed. Caregivers were recruited by clinicians (N=122); the Dutch Alzheimer Association (N=26); family members (N=4), or magazines and newspapers (N=11). Coaches (N=13) had a professional background as psychologist (N=7) or psychiatric nurse (N=6). All coaches received training and supervision in blended care self-management. Coaches reported that PiB deepened the contact with the caregiver. Caregivers appreciated the personalization and confirmation. The blended structure increased their openness. The program's primary focus on the caregiver and the discussion forum were appreciated less. Overall, goals were attained after the program (T>50). Performance according to protocol was substantial (77%). Deviations were reported on intervention time, structure and feedback. Implementation barriers were lack of financing, time and deviating target population.

Conclusion: Caregivers and coaches were satisfied with the intervention, but the content should be adapted to younger caregivers. It could be considered to take age of the caregiver and background of the coach into account in the effect analysis. Awareness of benefits of blended care self-management and training is required for sufficient program implementation.

INTRODUCTION

Caring for a family member with dementia puts one at risk for depression, anxiety and other health problems.¹ The benefits of e-health support for dementia caregivers are increasingly recognized in dementia care practice. Multicomponent, tailored, interventions are particularly promising for increasing caregiver confidence and self-efficacy, and decreasing caregiver stress and depression.² Blending online and face-to-face support increases caregiver-therapist relations and adherence.³ Dementia caregiver support is well-established,⁴ although supporting caregivers early in the dementia process is not commonplace but could prevent high levels of burden and psychological problems in the later stages.⁵ Early stage interventions should not be problematizing, but should meet the challenges and needs of the early phases. Existing programs are mostly aimed at problem-behaviors that occur in the advanced stages of dementia.⁶⁻¹¹ To this end, the blended care program 'Partner in Balance' for caregivers in the early stages was developed, aimed at the enhancement of the positive, intact experiences, tailored to the individual caregiver.¹² To evaluate the program's effectiveness on caregiver self-efficacy, mastery, and psychological complaints, a randomized controlled trial (RCT) was performed. Many caregiver e-health support studies lack methodological rigor,² and RCTs are considered proper designs for convincing evidence. But even with a prudent study design, evaluation of sampling quality and intervention quality is essential for the interpretation and generalizability of results.¹³ Furthermore, knowledge on implementation barriers and facilitators in an effect study can aid future adoption of a new intervention in care practice. Generalization and applicability of findings (external validity) is especially of interest for clinicians and policymakers. A newly developed program can be very effective, but difficult to implement in care practice if health professionals or policy makers do not accept it. Implementation can be complicated in the complex and heterogeneous structure and culture of dementia care organizations.¹⁴ Therefore, process evaluations should focus on internal validity and implementation knowledge to increase credibility.¹³ Different frameworks for process evaluations have been proposed, but there is no consensus on elements that process evaluations should cover.¹³ In this study we describe first order (sampling and intervention quality) and second order process data (implementation knowledge), based on the model of Leontjevas et al.,¹³ to assess the internal and external validity of the PiB trial and its implementation.

METHODS

The process evaluation was conducted alongside the effectiveness study. Detailed information on the methods are presented in Chapter 6.¹⁵ A short description is provided below.

Study design

A randomized waiting-list controlled trial was conducted in the south of the Netherlands. Family caregivers were recruited within memory clinics, mental health care organizations and caregiver support services. The intervention was delivered and evaluated within these organizations. A waiting-list controlled design was chosen to increase acceptability and adherence to the research protocol in the control group, and decrease attrition effects.¹⁶ Data were collected pre- and post-intervention and at 3, 6 and 12 months follow-up.

Intervention

Detailed information about the program components and development is presented in Chapter 5¹² and program results will be presented in Chapter 8. In short, the blended care self-management program 'Partner in Balance' (PiB) consists of (1) a face-to-face intake session with the personal coach to familiarize with the coach and program, set goals with the Goal Attainment Scaling method¹⁷ and select relevant modules, (2) engagement in four out of nine available online thematic modules including psycho-education, behavioral modeling, reflective assignments, change plans and e-mail feedback from the coach during 8 weeks, and (3) a face-to-face evaluation session with the coach in which previously set goals are assessed. Furthermore, participants can exchange information with other participants via the discussion forum. Module themes are Acceptance, Balance in activities, Communication with family member and environment, Coping with stress, Focusing on the positive, Insecurities and rumination, Self-understanding, The changing family member, and Social relations and support. Two weeks were allocated per module, but participants were allowed to complete the modules at their own pace in accordance with the self-management approach.¹⁸ The personal page and modules remained accessible for participants after the intervention period. Participants in the control group were on a waiting list for 8 weeks, while receiving usual care (non-frequent counseling). After the post-test assessment they were given the opportunity to follow PiB.

The personal coach

The personal coaches were trained, experienced professionals (psychologist or psychiatric nurse) from one of the participating organizations. They received a 2-hour training in self-management techniques, goal setting and online help, and regular supervision meetings. Their tasks were familiarizing participants with the online program, supporting them in module choice and goal setting, and giving feedback on online self-reflective assignments.

Process evaluation

First-order process data were evaluated prior to the effect analysis. Second-order process data are presented together with the first order data for a complete overview of the implementation and trial quality.¹⁴ The framework for this process evaluation was based on earlier research.^{13,14}

First order process data

The sampling quality was determined by a description of the procedures of recruitment, informed consent, allocation, recruitment barriers and facilitators, and reach. Data were extracted from the research database and 2 focus group interviews with 5 coaches per group (See Box 1 for topics). The intervention quality (relevance, feasibility, and performance according to protocol) was determined on two levels; (1) *coaches*, and (2) *participants*.

First-level data collection (*coaches*) involved registration of protocol deviations and amount and intensity of contact with caregivers on a structured registration form (see Appendix I of the previous Chapter 6), an 8-item questionnaire rating the overall usability of PiB and its relevance for caregivers and coaches with 4 multiple-choice items rated on a 5-point scale (1=completely disagree to 5=completely agree) (see Appendix I of the current Chapter), and 4 open-ended items on the advantages, disadvantages, recommendation to other organizations or colleagues, and general appreciation of the program.

Second-level data (*participants*) were collected post-intervention by a semi-structured interview with participants regarding their experiences with PiB (Box 1). Furthermore, Goal attainment scaling (GAS)¹⁷ was used to measure treatment-induced change and to compare relative success of previously set personal goals. GAS is a suitable measure to translate goals into achievement ratings. The scores range from -2 (much less than expected) to +2 (much better than expected), with a

score of 0 meaning that the goal was attained. Usage of the website (clickstream per intervention component) was tracked. Clickstream data are information-trails users leave behind while visiting the website captured in a log file. Clicks represent the number of times a page has been viewed.¹⁹

Box 1. Topic list for interviews with participants and coaches

TOPIC LIST	
INDIVIDUAL INTERVIEW PARTICIPANTS	FOCUS GROUP INTERVIEW COACHES
<ul style="list-style-type: none"> • Clarity of content • Website ease of use • Satisfaction blended care (online and face-to-face) • Satisfaction personal coach and feedback • Advantages and disadvantages of the program • Recommendations 	<ul style="list-style-type: none"> • Feasibility: recruitment, instructions, time investment, collaboration researchers • Value for participating caregivers • Barriers and facilitators for program implementation

Second-order process data

Knowledge on implementation of the program (components delivered and received, and barriers and facilitators to implementing) was investigated with additional items in the questionnaire for coaches described above (2 open-ended items on barriers and facilitators for program implementation, see Appendix I), and the data obtained from the focus group interviews (Box 1).

Analysis

Descriptive statistics (SPSS version 22.0) were used for the quantitative data analysis. Interviews were audiotaped and transcribed verbatim. Deductive content analysis was used for the qualitative data analysis (open-ended questions and transcripts) by authors LMMB and CMJS, using the qualitative analysis software ATLAS.ti (Version 1.0.14 for Macintosh). Topics that were mentioned frequently and explicitly served as the basis for the categorization. Categories were merged into common themes in a consensus meeting (LMMB and CMJS). Raw GAS scores were transformed into an individual mean GAS score (T-score) to determine goal attainment.¹⁷ T-scores included attainment level and a potential weight assigned to the goal(s). T-scores of ≥ 50 indicate effective goal achievement.

RESULTS

First-order process data

Sampling quality

Recruitment and randomization

Family caregivers (N=163) were recruited from memory clinics (MUMC+, Elkerliek Hospital Helmond, Catharina Hospital Eindhoven), ambulatory mental health clinics (Virenze-RIAGG Maastricht, MET ggz Roermond), caregiver support services in the southern regions of the Netherlands, and the Dutch Alzheimer Association. If interested, family caregivers (N=138) received the detailed information letter. Reasons for declining more information were not meeting the inclusion criteria at double check (N=9), no need for support (N=6), no computer/experience (N=5), too busy (N=2), care recipient does not agree with caregiver participation (N=1), family emergency (N=1), or unknown (N=1). Of the information recipients, informed consent (IC) was signed by 58% (80/138). Reasons for not signing the IC after more detailed information were, no need for support (N=8), no computer/experience (N=8), too busy (N=12), health problems (N=6), care recipient does not agree with caregiver participation (N=4), personal contact preferred over e-health (N=8), participation feels like a burden (N=9), or unknown (N=3). Of the 163 caregivers 154 were eligible. The participation rate of eligible caregivers was 52% (80/154).

Following the baseline assessment, 80 participants were randomly allocated to either Partner in Balance or the waiting-list control group. The researcher (LMMB) not involved in the assessments performed the allocation. A research assistant blind to allocation conducted the assessments, and recorded blinding success and reason for possible unmasking on the Case Record Form. At T1, 68 participants had completed the post-intervention or post-waiting list assessment and blinding was intact for 46% (31/68), unsuccessful for 49% (33/68), and for 7% (5/68) a conjecture of allocation was expressed.

Barriers and facilitators for recruitment

The interviewed coaches (N=10) reported that their caseload comprised many people with dementia living alone without a registered primary caregiver. This was listed as a primary recruitment barrier, next to “caregiver does not own computer” and “caseload only comprises caregivers of people with moderate to severe dementia”. Other barriers included concerns of burden for caregivers, high staff workload, and involvement in other caregiver support approaches. Coaches reported

that younger caregiver age and being employed were facilitators for program recruitment, as e-health suits a busy schedule and work-related computer literacy.

Reach

Caregivers were invited to participate by the clinician who treated their family member (N=122); informed about the program's existence by the Dutch Alzheimer Association (N=26); or knew caregivers/family members already involved in the program (N=4). Others (N=11) requested information based on editorials in health magazines, local newspapers and information stands in the south of the Netherlands. The Dutch Alzheimer Association disseminated information about the program via (1) monthly meeting spots for people with dementia and their caregivers, (2) newsletters, (3) their website and social media platforms Facebook and Twitter.

Intervention quality

Relevance and feasibility

Coaches. All coaches (N=13) completed the questionnaire and rated 'Partner in Balance' as adequately feasible in daily practice (M 4.5, SD 0.5) and fairly easy to integrate in their work-related activities (M 4.4, SD 0.5). The program was rated as a useful addition for family caregivers (M 4.5, SD 0.5), and for the coach as a professional caregiver (M 4.2, SD 0.8). The mean time spent per participant was 6.2 hours (SD 1.5) spread over 8 weeks: intake session 1.9 hours (SD 0.5), online feedback 2.5 hours (SD 1.0), evaluation session 1.4 hours (SD 0.7). Categories emerged from the open-ended questions in the questionnaire and the focus group interviews were divided into two themes: advantages for coaches and caregivers and experienced difficulties and suggestions for improvement. Themes are described below and illustrated with quotations. Each quotation is assigned a code indicating the coach number in the trial.

Advantages for coaches and caregivers

The detailed situations described by participants enabled coaches to empathize with them and focus their feedback. They reported a more profound relationship with the participant after the intervention. The flexibility to provide feedback whenever and wherever was considered very positive; it fitted their busy schedule and offered them the time to reflect on their words. The face-to-face contact during the intake session was necessary to create a personal connection with the participant. Coaches

stressed that the examples offered recognition for participants, and the assignments increased awareness about behaviors and feelings. The switch from thinking in problems to thinking in quantifiable goals was considered very valuable. The availability of the information, assignments and feedback after the intervention was seen as an advantage over merely face-to-face support.

“Analyzing problems makes them easier to solve. With the focus on a particular problem, other issues are raised that normally would not be addressed. It really breaks the normal routine for both client and coach. I noticed it deepens the relationship you have with people.” [C1]

Experienced difficulties and suggestions for improvement

Some coaches struggled with their level of direction in the self-management approach, as they were accustomed to a pro-active care role and felt the urge to assist more than instructed for this PiB program. Goal setting during the intake session was considered difficult by the coaches. However, they stressed the importance of goal setting and quantifying possible outcomes of program participation to make them tangible.

Several suggestions for improvement were mentioned. The user-friendliness of the instant messaging could be increased. Furthermore, a possible alarm function for crisis situations and follow-up care options were desired. To avoid confusion in module structure, it was suggested to make modules available to caregivers one by one, not all at once.

Participants. Participants who completed the intervention (N=49) most often selected the available themes *communication with family member and environment* (44x) and *self-understanding* (44x), followed by *the changing family member* (39x), *acceptance* (36x), *coping with stress* (30x), *balance in activities* (24x), *insecurities and rumination* (21x), *focusing on the positive* (20x), and *social relations and support* (20x). Emerged categories from the semi-structured interviews were divided into four themes: Program content, program structure, role of the personal coach, and target audience. Each quotation is assigned a code indicating the participant number in the trial.

Program content

Most participants were satisfied with the content, as it suited their current concerns. Specifically the personalized assignments and challenges were appreciated. It was often mentioned that the content was not innovative, but a confirmation of participants' conjectures. Some participants struggled with the primary focus on the caregiver, as they felt the care recipient should change.

"I think it's odd that the caregiver has to make changes, and my wife [person with dementia] doesn't have to learn or change anything" [P25]

Suggestions for content improvement were also made. Including links to more disease-specific information was desired. Adding subtitles to the movie clips to watch them on mute was preferred when the care recipient was not aware of the caregiver's participation.

Program structure

The program structure of blending face-to-face contacts with online modules was experienced positively. Participants mentioned that the face-to-face contact personalized the program and increased their openness during the online assignments.

"You need to see who is going to ask you these intimate questions. In my opinion that is a prerequisite for sending such personal information." [P68]

It was stressed that the module structure facilitated the personal assignments; the examples fostered reflection and the tips were used as input. Others reported difficulties compartmentalizing their answers in the assignment structure. Participants mentioned using the website when they had time and often revisited the examples, their own answers or the feedback. A printed workbook and an autosave option were considered desirable additions.

Role of the personal coach

The feedback was considered supportive and critical at times, allowing participants to reflect on their answers. Participants emphasized that the coach was essential for

motivation and questions. Knowing that there was someone there to guide them, made them feel less alone.

“She [coach] made me think about things. You don’t expect the feedback to be like the philosopher’s stone, but it’s nice to get some confirmation and sometimes a critical note; you are saying this, but how are you going to live up to it? You’re not doing it alone” [P03]

Participants with a familiar coach reported an intensified relationship post-intervention, by being able to speak freely online and getting acquainted with the coach on a different level. Lastly, participants mentioned coaches should not participate on the discussion forum, as this was a safe zone for caregivers’ opinions.

Target audience

Younger participants felt that the program should be specified to different subgroups. They could not identify with the older population in the examples, as they were still employed and dealt with other issues in daily life, such as (young) children living at home. Furthermore, caregivers of people with young-onset dementia missed the behavioral disturbances in the examples, as this was something they struggled with daily.

“As a younger and employed person I cannot identify with the older people and their struggles in the movie clips. It makes me feel alone.” [P67]

The forum was not used, as caregivers struggled with shame in the early stages and sharing their story felt like betrayal to the care recipient. Reading about other people’s misery was considered undesirable. Some participants mentioned that the course came too late for them. It was stressed that the program should be made available for all caregivers following diagnostic disclosure.

“I was exceptionally alert and active in my search for information, but it should be provided to anyone. Don’t wait until people ask for it. I considered it an ‘integration course’ for caregivers” [P54]

Goal attainment

Of the program completers in both groups (N=49), 42 participants set 93 goals in total. Five program completers were not able to set goals as they felt their care recipient should change and two completers had no goals due to coach turnover. The majority of participants (N=35) achieved ≥ 1 goal(s). Overall, seventy goals were attained (43 attained, 17 higher than expected, 10 much higher than expected), and 22 goals were not attained (17 lower than expected, 5 much lower than expected). The mean T-score at baseline (set at -2 level) was 25.2 (SD 3.4). The mean achieved T-score at post-intervention was 50.1 (SD 10.08). Table 1 shows the number of goals for each domain, with most goals set on communication with the care recipient, followed by planning time alone and not feeling guilty about it, decreasing or preventing tension and anxiety, and obtaining social support.

Table 1. Number of set goals, attainment scores and domains (N=42)

	<i>Mean (SD)</i>	<i>Range</i>
<i>Number of set goals per participant</i>	2.2 (1.1)	1.0 - 4.0
<i>GAS^a score at baseline</i>	25.5 (3.4)	21.0 - 30.0
<i>GAS^a score achieved</i>	50.1 (10.8)	30.0 - 77.4
<i>Number of set goals per domain (N)</i>		
- Communication with care recipient	21	
- Positive activities with care recipient	5	
- Social support and contacts	10	
- Time alone and feeling guilty	16	
- Tension and anxiety	13	
- Role and relationship changes	9	
- Feeling in control by gaining knowledge	8	
- Positive thoughts and rumination	11	

^aGAS = Goal Attainment Scaling

Performance according to protocol

Coaches. Intervention performance according to protocol comprised: face-to-face intake session, online modules during 8 weeks, individualized feedback via email per module, and a face-to-face evaluation session. Ten coaches reported performance according to protocol (77%), three reported deviations in intervention time, structure and feedback (23%). Intervention time was reported longer (N=2) or shorter (N=1) than 8 weeks, module structure was consumed differently than intended (N=2) or feedback was given by telephone (N=2) or face-to-face (N=1). Reasons to deviate

from the protocol were caregiver pace and understanding of the program structure, illness, holiday leave, changes in work load and hours, personal family emergencies, and struggling to verbalize feedback in an email.

Participants. With regard to dose delivered, of the program completers (N=49) 87.8% (43/49) completed all 4 modules, 6.1% (3/49) 3 modules, and 6.1% (3/49) 2 modules. The tracked usage data showed 21946 clicks per module, including scoping the website (2444 clicks), viewing the psycho-education (3922 clicks) completing the assignments and change plan (8748 clicks), contacting the personal coach (6489 clicks) and visiting the discussion forum (310 clicks). Total intervention time ranged from 4 to 32 weeks (M 13.9, SD 6.8). Reasons for intervention period variance were holiday, illness, busy schedules, and technical difficulties. Following the intervention period, 77.6% of the program completers (38/49) requested access to the additional modules, with (16/49) or without (33/49) the coach at their disposal for questions.

Second-order process data

Implementation components

Coaches (N=13) had a professional background as psychologist (N=7) or psychiatric nurse (N=6). During the regular supervision meetings coaches shared experiences and asked feedback. Support concerning the website and feedback content was requested outside the supervision meetings via e-mail (N=13) and telephone (N=6) during the trial.

Barriers and facilitators for implementation

Directors of 22 dementia care organizations in the southeast of the Netherlands were asked to participate in the trial. The response rate of organizations was 73% (16/22). Of the responders, 63% (10/16) expressed their interest to adopt the program. Refusal was based on upcoming reorganization (1/6), no suitable caregivers in caseload (4/6), or high workload of staff members (1/6). Of the interested organizations, 40% (4/10) choose to implement 'Partner in Balance' and train staff members (psychologists or psychiatric nurses) to act as personal coaches. Six organizations (60%) choose to refer caregivers to the coordinating center, due to high staff workload. Emerged categories regarding implementation barriers and facilitators from the open-ended questions and focus groups were divided into three themes: organizational aspects and financing, time and practical aspects, and

organization's target population. Themes are described below and illustrated with quotations followed by a code indicating the coach number in the trial.

Organizational aspects and financing

Coaches mentioned that elderly care organizations in the Netherlands often file caregiver support under patient care, which could create problems for implementation of caregiver support programs when the person with dementia is not registered. Also, financial cutbacks hampered professionals in adopting new support tools. Mentioned facilitators were separate registration of caregiver support, insurance compensation, and integration of online support in already provided caregiver support.

"If we cannot register caregiver support, we cannot make time for it. Managers need to be convinced that caregiver support also benefits the person with dementia" [C3]

Time and practical aspects

It was mentioned that unfamiliarity with the program could create a barrier for future implementation. The training and self-study was considered a substantial personal time investment. Coaches suggested training all staff members as coach and applying the program as regular care to facilitate implementation.

"We don't get a lot of time per client so taking too much time for training feels wrong." [C9]

"The program could easily be implemented as regular care if all staff members or a constant group of staff members were trained as coach." [C4]

Organization's target population

Professionals mentioned that many health care organizations only treat people with moderate to severe dementia with severe comorbidity, or they expect the family caregivers to not be computer literate due to their high age, which hampers implementation of this type of caregiver support.

DISCUSSION

This study described the process of Partner in Balance (PiB) to explore its credibility and generalizability. First-order and second-order process data were evaluated from the perspective of both family caregivers (participants) and professionals delivering the intervention (coaches), increasing the understanding of the mode of delivery.²⁰

Sampling and randomization

Data on sampling quality showed that the participation rate of caregivers was 52%. Considering an average response rate of 27% for caregiver research, our participation rate can be considered substantial.²¹ However, the 52% only considered eligible caregivers who were already familiar with the care parties involved in recruitment and may have been more motivated and open to support.²² Recruitment barriers were e.g. no computer, no need for intervention or additional support, which were also reasons to decline participation. During the early stages, caregivers may struggle with a fear of stigma, shame and low acceptance.²³ This might explain why participants were not ready to openly discuss their situation on the discussion forum and why some participants struggled with acceptance of the situation, as was illustrated by stating that their care recipient should change. Young age and being employed were considered recruitment facilitators. However, caregivers of people with young-onset dementia and children had difficulties identifying with the older caregivers in the examples. Previous research confirmed that younger caregivers struggle with different aspects in daily life, when compared to older caregivers²⁴. It is essential that to match program content and specific needs of the target audience to maximize the benefit of a supportive intervention.^{2,25-27} The thematic structure of the program allows for add-on of specific themes for subgroups, such as caregivers of people with young-onset dementia.

At post-intervention assessment (N=68), blinding of allocation was intact for only 46% (31/68) of the participants, which can potentially bias the estimation of effectiveness. However, blinding in psychosocial research can be challenging and it is rarely reported if blinding is maintained.²⁸ This item from the Consolidated Standards of Reporting Trials (CONSORT) may have been developed with studies of medical treatments in mind, but blinding or masking may be unfeasible for certain aspects of psychosocial treatment studies.²⁹ Some other important aspects of psychosocial RCTs need to be considered and reported but are not addressed in the CONSORT statement, e.g. adequate reporting of treatment integrity (whether

therapists were consistent in providing the specified intervention). Verification of treatment integrity, or fidelity, in outcome studies is essential to ensure that valid comparisons of replicable treatments can be made.³⁰

Intervention quality

Professionals were satisfied with the intervention fitting their busy schedule, giving them time to focus their feedback. They reported a more profound relationship with the caregiver, as the program allowed them to empathize with the caregiver. However, the low level of professional involvement in the self-management approach was considered a challenge. This issue deserves further exploration, as the performance of the self-management health care provider is very important for the participant's performance of self-management tasks and overall intervention effectiveness.³¹ It was previously argued that health care providers do not always support self-management education, as this is not part of their attitudes, beliefs or regular care practice.¹⁸ To maximize the effects of self-management programs, it is recommended to increase the essential clinical competences of healthcare providers to provide tailored self-management support,²⁷ and that the health care system increases its awareness of the benefits of evidence-based self-management programs for their target population.¹⁸ For one, the present study showed that both participants and coaches mentioned that their relationship with each other had deepened, which was also demonstrated in a previous blended-care intervention for depression.³² Previous research confirmed that the opportunity to reflect on one's feelings anonymously in one's personal safe environment is easier than face-to-face, but the face-to-face contact increased caregiver openness, and therefore coach empathy with their situation.³ Participant compliance to all 4 modules was high (87.8%), which could be explained by motivational aspect of having a coach, also mentioned in previous studies.³ The varying intervention period and dose may influence the effectiveness of the intervention.³⁰ However, reasons for protocol deviations were diverse and not uncommon for informal caregivers and elderly participants (e.g. caregiver pace, time constraints, illness).²¹ In self-management interventions the participant is in control and should therefore be allowed to complete the modules at his own pace.^{18,33} Furthermore, complex interventions such as PiB are often designed to be implemented with some flexibility, in order to accommodate differences across participants.³⁴

Implementation

Pib was evaluated within multiple organizations with coaches from different backgrounds, who received training and supervision in self-management and blended care. A relatively high response rate of organizations was found (73%), which could be attributed to the current demand of health care insurances for care organizations to provide e-health.³⁵ However, a lack of financing and time could hamper the implementation. The MRC Framework suggests that implementation should be considered during the first phases of intervention development and evaluation.³⁶ As complex interventions are influenced by context, many psychosocial interventions show different results in different settings or countries.²⁹ Additional information about the process of the implementation is crucial to understanding why an intervention is effective in one setting and not in another.³⁴ PiB was evaluated within different settings with coaches of different backgrounds delivering the intervention. To evaluate if coach background has any influence on the intervention outcome, this variable will be considered in the effect analysis.

Limitations and recommendations for future research

In our study, protocol deviations were measured with the self-report questionnaire for coaches. Previous research measuring protocol deviations with self-report questionnaires and ratings based on tape-recordings found large discrepancies between the two measurements, indicating that professionals may not always be aware of their level of treatment fidelity.³⁷ Furthermore, tracked usage data were measured in clicks. Clicks represent page views, but this clickstream method has a large disadvantage; many people who click on a page do not necessarily read it. Even one in three visitors spend less than 15 seconds reading the page, so a measured click does not automatically mean the attention of the visitor is directed to the information on the page that is being viewed.¹⁹ Nevertheless, the results showed that the participants spent most of their time on the assignments and change plans and the e-mail contact with their coach, which represent the essential elements of a blended-care program.^{3,32}

Goal attainment scaling (GAS) was used to rate goal attainment. Goal setting and rating is considered a therapeutic task and was therefore performed by the coaches during the face-to-face sessions. Future research could consider setting and rating goals by an independent research assistant in all treatment arms to consider GAS as an outcome measure. However, GAS is a challenging evaluation method

when not all participants set or evaluate goals, goals change along the way, or participants lack insight, communicational skills or the capacity to specify goals. Therefore, previous research recommends using GAS as a complementary scale, not as a replacement of other outcome instruments.³⁸

Conclusion

Participants and professionals were satisfied with the intervention, but the content should be adapted to specific subgroups such as younger caregivers. It could be considered to take age of the caregiver and background of the coach into account in the effect analysis. Implementation of the program requires more awareness of the benefits of blended care self-management programs and training in tailored self-management skills for the healthcare provider. Overall, Partner in Balance can be considered a valuable addition to the already provided caregiver support, as it is tailored to the needs of the target audience and deepened the coach-caregiver relationship. GAS enables a clinical evaluation of individual participants that benefit from the program.

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Appendix 1. Partner in Balance – Coach Questionnaire

	Completely disagree	Disagree	Neutral	Agree	Completely agree
1. The program is feasible for coaches	1	2	3	4	5
2. I can combine the coach responsibilities with my usual activities	1	2	3	4	5
3. The program is a valuable contribution for caregivers	1	2	3	4	5
4. The program is a valuable contribution for coaches/professionals	1	2	3	4	5
5. Was the program delivered according to protocol (in +/- 8 weeks, feedback after each module, face-to-face intake and evaluation session). If not, what was performed inconsistent with the protocol and why?					
6. How much time, on average, did you spent coaching one participant? (Based on the structured registration form)					
7. What are the advantages of the program?					
8. What are the disadvantages of the program? Points for improvement?					

Implementation

9. What are the barriers for implementation of the program in your organization?
10. What could be possible facilitators for future implementation of the program within your organization?

CHAPTER 8

Effectiveness of the blended care self-management program
'Partner in Balance' for early-stage dementia caregivers: results
of a randomized controlled trial

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ABSTRACT

Background: The benefits of e-health support for dementia caregivers are increasingly recognized. Reaching early-stage dementia caregivers could prevent high levels of burden and psychological problems in the later stages. The current study evaluates the effectiveness of the blended care self-management program 'Partner in Balance' compared to a control group.

Methods/design: A mixed method single-blind, randomized controlled trial with 80 family caregivers of community-dwelling people with (very) mild dementia was conducted. Participants were randomly assigned to either the 8-week blended care self-management program 'Partner in Balance' or a waiting-list control group receiving usual care. Semi-structured interviews were conducted post-intervention. Primary proximal outcome included self-efficacy, primary distal outcome symptoms of depression. Secondary outcomes included mastery, psychological complaints (anxiety and perceived stress), and quality of life. Possible modifying effects of variables (quality of the relationship, neurotic personality, coach background) on the intervention effect were also evaluated.

Results: A significant increase in self-efficacy, mastery, and quality of life were demonstrated in the intervention group, compared with the control group. No significant differences were found between the groups on depressive symptoms, anxiety and perceived stress.

Discussion: The program could provide accessible care to future generations of early-stage dementia caregivers and strengthen the primary caregivers.

INTRODUCTION

Family caregivers are important as the main source of care for people with dementia,¹ but caregiving puts them at risk for feeling burdened, which may result in depression, anxiety and other health problems.² Many caregiver support interventions have been developed to ameliorate negative caregiver consequences with promising results.³ Early intervention and support for caregivers could prevent high levels of burden and psychological problems in the later stages of dementia.^{4,5} However, early-stage interventions may not be effective, and even do more harm than good if they do not fit the personal situation of the caregiver.⁶ Negative and stigmatizing information can hamper acceptance, while enhancing the positive, intact experiences may be effective in increasing caregiver self-efficacy. By increasing caregiver resilience through self-efficacy, an increase of psychological problems in a later stage may be prevented.⁷ A self-management approach focused on learning to positively manage life with dementia could facilitate the adaptation process to the new caregiving role in the early stages.⁸

With the growing gap between the number of people in need of support and available care professionals⁹, e-health interventions could serve as cost-effective alternatives for dementia caregiver support¹⁰, with increased access and extended reach.¹¹⁻¹⁴ Blending face-to-face guidance with online support increases client-therapist connection and adherence.^{15,16} E-health interventions for caregivers are being developed and evaluated, but are mainly aimed at dementia related problems in an advanced stage of the caregiver career^{17,18} and their overall quality of evidence is low.¹⁹ An iterative step-wise approach was employed to develop the blended care self-management internet-based program 'Partner in Balance' for early-stage dementia caregivers. The current study evaluated if 'Partner in Balance' is superior to a waiting-list control condition as evidenced by improved subjective self-confidence (self-efficacy and mastery), and lower levels of psychological complaints (symptoms of depression, anxiety and stress) post-intervention.

METHODS

This randomized controlled trial was carried out between 2014 and 2016 in the Netherlands. The 'Partner in Balance' program was compared to a waiting-list control group receiving usual care. The Medical Ethics Committee of the Maastricht University Medical Center+ (MUMC+) approved this study (#12-4-059) and the study

was registered in the Dutch trial register (NTR4748). The study protocol and supporting SPIRIT checklist are available.²⁰

From September 2014 to December 2015, family caregivers of people with (very) mild dementia of all subtypes (Clinical Dementia Rating (CDR) score 0.5-1) [28] were recruited from memory clinics (MUMC+, Elkerliek Hospital Helmond, Catharina Hospital Eindhoven) and ambulatory mental health clinics (Virenze-RIAGG Maastricht, MET ggz Roermond) in the south of the Netherlands, via caregiver support services, and via the website of the Dutch Alzheimer Association (www.alzheimernederland.nl). Caregivers were included if they had access to the Internet at home, basic skills in the use of computers, and provided written informed consent. Potential participants with insufficient cognitive abilities to engage in the online self-management program; overburdened or with severe health problems as determined by study staff; or who cared for people with dementia caused by human immunodeficiency virus (HIV), acquired brain impairment, Down syndrome, chorea associated with Huntington's disease or alcohol abuse were excluded from participation. Both spouses and other caregivers could be included, e.g., children, as long as they met the criteria above and were >18 years. Details on the recruitment procedure are described in Chapter 7.

Randomization and masking

Following the baseline assessment, participants were randomly assigned to either 'Partner in Balance' or the waiting-list control group receiving usual care, using a computerized random-number generator for block randomization with variable sizes of 4, 6 and 8. An independent research assistant who was blinded to the allocation of the treatment conducted the post-intervention assessments.

Intervention and control

Experimental group: Partner in Balance (PiB). The 8-week blended intervention PiB consists of a face-to-face intake session with a personal coach, an online period, and a closing-out face-to-face evaluation session with the personal coach. The intervention is described in detail in Chapter 5.²¹ In short, in the face-to-face intake session with the personal coach participants were familiarized with the program, selected four out of nine available modules, and set goals that they wished to accomplish. Module themes were Acceptance, Balance in activities, Communication with family member and environment, Coping with stress, Focusing on the positive,

Insecurities and rumination, Self-understanding, The changing family member, and Social relations and support. Following the intake, participants completed their chosen modules online during an 8-week period. Two weeks were allocated per module, but participants were allowed to complete the modules at their own pace in accordance with the self-management approach.²² After the online period, a face-to-face evaluation session was conducted with the personal coach to discuss their ability to accomplish goals and to cope with future difficulties. Participants maintained access to their personal page and modules after the intervention period and were given the opportunity to follow additional modules without a time limit. The personal coaches were experienced psychologists (N=7) and psychiatric nurses (N=6) from memory clinics, ambulatory mental health clinics or caregiver support services in the south of the Netherlands. Coaches received a 2-hour training in self-management techniques, goal setting and online help, and regular supervision meetings where they could share experiences and ask feedback. Coaches supported participants in choosing modules, identifying feasible goals, and providing feedback on their assignments.

Control group: waiting-list. The waiting-list group received usual care consisting of non-frequent counseling during 8 weeks. They received the same pre-test and post-test attention from the research team as the experimental group. After they completed the post-test assessment, they were given the opportunity to follow PiB.

Procedures

For this study data from baseline visit (T_0) and after 8 weeks (T_1) were compared. Data was collected with a mixed-methods approach; effectiveness was evaluated quantitatively (self-report) and qualitatively (semi-structured interview). The primary proximal outcome was caregiver self-efficacy and primary distal outcome was depressive symptoms. Caregiver self-efficacy was measured with *The Caregiver Self-efficacy Scale (CSES)*,²³ measuring care management self-efficacy (4 items) and service use self-efficacy (5 items). Care management self-efficacy scores range from 4-40 and service use self-efficacy from 5-50. The 20-item *Centre for Epidemiological Studies Depression Scale (CES-D)*²⁴ was used to measure depressive symptoms. Total scores range from 0-60. Secondary outcomes were mastery, psychological complaints (anxiety and perceived stress), and quality of life. Raw scores are transformed in individual mean GAS scores (T-scores). T-scores of

≥50 indicate effective goal attainment.²⁵ Mastery was measured with the 7-item *Pearlin Mastery Scale (PMS)*.²⁶ The total score ranges from 0-35. The 7-item *Hospital and Anxiety Depression Scale anxiety subscale (HADS-A)*²⁷ rates symptoms of anxiety, with scores ranging from 0-21. Quality of life was measured on five attributes with the *Investigating Choice Experiments for the Preferences of Older People CAPability measure for Older people (ICECAP-O)*.²⁸ The value system for the 1024 states uses a best-worst scaling valuation method, providing a single summary score, anchored at zero ('no capability') and 1.0 ('full capability').²⁹

Demographics were obtained (sex, age, relationship to care recipient, level of education, sharing household, and care intensity in years). The Global Deterioration Scale (GDS)³⁰ measured dementia severity with the caregiver as informant. *Quality of the relationship* was measured using 4 self-rating items of the University of Southern California Longitudinal Study of Three-Generation Families measures of positive affect.³¹ The 12-item Neuroticism domain of the *NEO Five Factor Inventory (NEO-FFI)*³², was used to identifying individuals who are prone to psychological distress, by assessing 6 traits: anxiety, angry hostility, depression, self-consciousness, impulsiveness and vulnerability. Scores ranged from 0-24.

Following the waiting-list period participants were offered the opportunity to follow the program. Qualitative data on the effect of PiB were obtained using a *semi-structured interview* after completion of the intervention in both groups. The interviews were audiotaped with the participants' permission. Topics included the application of the intervention in daily life, and intervention impact on knowledge about the disease, caregiver functioning, and self-esteem.

Data analysis

Prior to the analysis, data was checked for missing values, outliers, and normality. Possible differences between the study groups' baseline characteristics were tested with t-tests for continuous variables and χ^2 -tests for categorical variables. Non-parametric tests were used when necessary in case of non-normality.

To examine differences between outcomes for the intervention and the waiting-list control group during the intervention period, an analysis of covariance (ANCOVA) was conducted with outcome at post intervention as the dependent variable, intervention (Partner in Balance, waiting-list control group) as the between-subjects variable and per outcome its baseline value, age, sex, emotional instability, quality of the relationship, educational level and relationship to the care recipient as

covariates. If significant, the inter-group effect size was calculated according to Cohen's *d*. Effect sizes of 0.2 are considered small, 0.5 is considered medium and 0.8 high.³³ IBM SPSS statistics 22.0 for Macintosh was used and all tests of significance reported mean change and were two-tailed with α set at 0.05.

The qualitatively obtained data from the semi-structured interview was transcribed verbatim. Two independent researchers performed deductive content analysis of the transcribed text using ATLAS.ti (Version 1.0.14 for Macintosh). Conceptual labels were assigned to textual fragments and organized into categories. Categories were merged into common themes in a consensus meeting. Disagreements were solved through discussion.

RESULTS

Participants

A total of 163 caregivers expressed an interest to participate. See Figure 1 for the study flowchart. Details are described in Chapter 7. Table 1 lists the baseline data for the included caregivers (N=80).

Between-group comparisons revealed no significant differences in demographics and main outcome measures at baseline. Care recipients of the included caregivers were 73.9 years old (SD 8.2), diagnosed with MCI (12; 15%), AD (32; 40%), or other dementias (36; 45%). Dementia severity was rated as preclinical memory decline (55; 68.8%), mild dementia (23; 28.7%), or moderate dementia (2; 2.5%) on the GDS. At T1, 13 caregivers were lost to follow-up. The completers did not differ from non-completers at baseline in terms of age ($t=0.19$, $p=0.851$), relationship to the care recipient ($X^2=1.39$, $p=0.238$), same household as care recipient ($X^2=0.82$, $p=0.665$), care intensity in years ($U=377.5$, $p=0.781$), sex ($X^2=2.80$, $p=0.094$), education ($X^2=1.20$, $p=0.550$), self-efficacy service use ($t=0.53$, $p=0.599$) care management ($t=1.36$, $p=0.177$), depression ($U=280.0$, $p=0.266$), stress ($t=0.25$, $p=0.806$), anxiety ($U=372.0$, $p=0.497$), mastery ($t=-1.18$, $p=0.253$), and quality of life ($U=775.0$, $p=0.956$).

Figure 1. Study flowchart

Intervention effects

The effects were compared between groups (intervention and waiting-list control) after 8 weeks. Table 2 shows the results of the ANCOVA at T₁ on self-efficacy (care management and service use), depression, mastery, perceived stress, anxiety, and quality of life. Examination of relationships between covariates and intervention outcomes showed a positive association between a higher quality of the relationship at baseline and improved self-efficacy care management ($B=1.18$, $p=0.019$) and mastery ($B=0.72$, $p=0.007$) post-intervention. Improvements on post-intervention quality of life were significantly related to lower scores on neurotic personality traits at baseline ($B=-0.01$, $p=0.037$). Relationship to the care recipient, caregiver level of

Table 1. Descriptive data caregivers for both groups at baseline

	<i>Intervention</i> (N=41)	<i>Waiting-list</i> (N=39)	<i>Test value</i>	<i>P</i>
Socio-demographics				
<i>Age, mean (SD)</i>	67.8 (10.2)	70.2 (10.1)	T = 1.0	0.302
<i>Spouse, mean (%)</i>	37 (90.2)	37 (94.9)	X ² = 0.6	0.432
<i>Same household as PwD, N (%)</i>	39 (95.1)	37 (94.9)	X ² = 1.3	0.513
<i>Care intensity in years, mean (SD)</i>	1.8 (1.8)	1.9 (1.8)	U = 674.5	0.929
<i>Female, N (%)</i>	29 (70.7)	24 (61.5)	X ² = 0.8	0.385
<i>Education (N,%)</i>				
High school	8 (19.5)	4 (10.3)	X ² = 2.3	0.321
College	17 (41.5)	15 (38.5)		
Graduate school	15 (36.6)	20 (51.3)		
Primary outcomes				
<i>Self-efficacy (CSES)</i>				
Care management	34.7 (7.8)	33.0 (9.4)	T=-0.9	0.395
Service use	25.8 (6.3)	23.7 (6.2)	T=-1.5	0.141
<i>Depression (CES-D)</i>	13.1 (8.7)	13.1 (9.0)	U = 732.0	0.927
Secondary outcomes				
<i>Stress (PSS)</i>	11.8 (6.0)	13.5 (6.2)	T=1.2	0.223
<i>Anxiety (HADS-A)</i>	6.0 (3.7)	6.7 (4.7)	U = 717.5	0.666
<i>Mastery (PMS)</i>	23.7 (4.1)	22.9 (4.4)	T=-0.8	0.430
<i>Quality of life (ICECAP-O)</i>	0.8 (0.1)	0.8 (0.1)	U=755.0	0.956

education, and coach background were not significantly related to improvement on any of the outcomes. After controlling for age, sex, emotional instability, and quality of the relationship, significant effects in favor of the intervention group were found for self-efficacy care management ($F(1,60)= 10.37, p=0.002, d=0.85$), and self-efficacy service use ($F(1,60)= 11.47, p=0.001, d=0.93$), but not for depression ($F(1,60)=1.13, p=0.293$). Significant effects in favor of the intervention group were also demonstrated for mastery ($F(1,60)= 12.66, p=0.001, d=0.94$), and quality of life ($F(1,60)= 4.83, p= 0.032, d=0.58$), but not for perceived stress ($F(1,60)= 3.40, p=0.071$), and anxiety ($F(1,60)= 0.80, p=0.374$).

Table 2. Analysis of covariance comparing intervention and control group at post-test

	Control (N=37)		Intervention (N=31)				
Outcome	Mean (SD/SE)		Mean (SD/SE)		Mean difference ² (95% CI)	F	d
	Crude ¹	Adjusted ²	Crude ¹	Adjusted ²			
Primary outcomes							
CSES							
Care management	31.38 (8.71)	31.65 (1.05)	37.03 (6.33)	36.73 (1.12)	-5.07 (-8.23, -1.92)	10.37**	0.85
Service use	21.88 (6.33)	22.48 (0.83)	27.43 (5.11)	26.76 (0.89)	-4.274 (-6.80, -1.75)	11.47**	0.93
CES-D	13.27 (9.21)	12.87 (1.08)	10.73 (8.20)	11.17 (1.14)	1.70 (-1.51, 4.91)	1.13	0.28
Secondary outcomes							
PMS	21.15 (4.49)	21.32 (0.63)	24.87 (4.09)	24.68 (0.67)	-3.36 (-5.26, -1.47)	12.66**	0.94
PSS	13.76 (6.84)	12.92 (0.69)	10.03 (6.35)	10.99 (0.74)	1.94 (-0.17, 4.04)	3.40	0.50
HADS-A	5.94 (4.59)	5.91 (0.61)	6.70 (4.65)	6.73 (0.63)	-0.81 (-2.63, 1.00)	0.80	0.24
ICECAP-O	0.76 (0.15)	0.76 (0.02)	0.82 (0.10)	0.83 (0.02)	-0.06 (0.01)	-0.12, -4.83*	0.58

CSES: Caregiver Self-efficacy Scale; CES-D: Center for Epidemiological Studies Depression Scale; PMS: Pearlin Mastery Scale, PSS: Perceived Stress Scale, HADS-A: Hospital Anxiety and Depression Scale-Anxiety; ICECAP-O: Investigating Choice Experiments for the Preferences of Older People

* p < 0.05

** p < 0.01

¹Group means

²Adjusted for outcome measure at baseline, age, sex, education, quality of the relationship at baseline, neurotic personality traits, and coach background

Qualitative findings

Semi-structured interviews (N=49) were held in both the intervention and waiting-list group post-intervention. Saturation occurred after coding of 40 semi-structured interviews. Coding and categorization resulted in 4 themes: Insight in behavior, increased acceptance and adjusted expectations, active coping, and positive emotions. Categories per theme are listed in Box 1. The themes are described below and illustrated with quotations to elucidate the results.

Box 1. Overview of categories and major themes

THEMES	CATEGORIES
Insight in behavior	Awareness of own behavior Confronting
Increased acceptance and adjusted expectations	Acceptance of new situation Adjusting expectations Increased understanding
Active coping	Taking control Openness in communication with environment Setting personal boundaries Armed with tools for the future
Positive emotions	Confirmation of propriety of own actions Mistakes are normal Supportive and reassuring Feel less lonely Increased positive encounters with care recipient

Insight in behavior

Participants reported that the program made them more aware of their own behavior and its impact on the care recipient. Putting your emotions into words in the assignments increased their insight into their own feelings regarding the new situation. Some participants labeled the experience as confronting at first, but insightful when they reviewed their responses afterwards. Participants felt taken seriously because the difficulty of their task as caregivers was recognized.

Active coping

The awareness that many situations are within their own control gave participants hope for the future and the urge to think about what they would like to change. An active role decreased anxiety about possible future scenarios. Participants felt that they were challenged to explore their problems, uncover the causes, and actively seek solutions. This led to setting clear limits for themselves and protecting their own energy level.

“I feel that I did a lot myself, not just got offered advice. I’m kind of proud of that”
[P72]

“You’re forced to analyze your problems, but you don’t linger in them, you have to look for possible solutions. Don’t reach for the stars, but try realistic things. That helped me to put my situation and feelings into perspective.” [P28]

Increased acceptance and adjusted expectations

Some participants were frustrated that not every situation has a solution, while others experienced a more accepting attitude towards these situations. Knowledge that certain behaviors of the care recipient were disease-related and the realization that their own behavior accounted for a great deal of their perception of the situation, led participants to adjust their expectations about the future and live one day at a time. The acceptance of the situation as it is made participants more open about their situation to their social network, which decreased feelings of shame for the disease of their family member or for taking time for themselves.

Positive emotions

Recognition of their daily encounters and possible ‘mistakes’ one may experience in the examples in the program and the feedback of the coach decreased their feelings of loneliness and increased feelings of reassurance. Participants reported a shift from focus on loss to possibilities in day-to-day activities, which resulted in more positive encounters with the care recipient. As tension and worrying was seen as part of normal life, anxiety about the future was replaced with a feeling of being ‘armed’ for the future.

“Everything is about him (care recipient), so the fact that someone takes me seriously and tries to support me really helps, because you feel alone a lot of the time” [P03]

DISCUSSION

This controlled study evaluated the first blended care intervention for caregivers of people with early-stage dementia and demonstrated a significant improvement in care management self-efficacy, service use self-efficacy, mastery and quality of life after receiving the ‘Partner in Balance’ intervention, compared to a waiting-list control group receiving care as usual. Effect sizes were moderate (>0.5) for quality of life to substantial (>0.8) for self-efficacy and mastery. No differences between groups were demonstrated on caregiver depression, anxiety, and perceived stress.

Results on caregiver self-efficacy, mastery, and quality of life are in line with previous results in an uncontrolled smaller sample²¹ and results of previous e-health interventions for dementia caregivers.¹⁹ Furthermore, the results fit the Stress and Coping paradigm by Lazarus and Folkman³⁴ and the Social Learning theory by Bandura⁷, suggesting that taking charge of the changes in one's life increases self-efficacy and general wellbeing. Learning to positively manage life with dementia instead of managing the dementia itself in a self-management program may have facilitated caregivers' adaptation to their new caregiving role. The program's focus on enhancing positive, intact experiences that are tailored to the individual caregiver's situation could explain the positive effects on caregiver self-efficacy.⁸ However, it was expected that a decrease in stress resulted in the demonstrated higher levels of wellbeing or quality of life^{7,34}, which the present study could not demonstrate. It is conceivable that interventions aimed at the early stages may not be capable of decreasing burden and stress, as these are relatively low during the early stages⁶. Previous caregiver interventions demonstrating positive effects on burden and stress were not specifically aimed at early-stages of dementia.^{17,35-39} Future follow up of PiB effects could clarify if an increase in self-efficacy results in a decrease or prevention of increased stress and depression in the long term. Measures of self-efficacy are preferred over measures of sense of competence and distress for caregiver interventions in the early stages.⁴⁰

Strengths and limitations

The mixed method evaluation approach enabled better understanding of the active intervention ingredients and qualitative data helped clarify the quantitative results.

High face validity was demonstrated as the program was evaluated in multiple institutions with multiple coaches of different backgrounds. Development together with the potential users and a pilot evaluation following the MRC Framework may have increased its effectiveness.

The waiting-list period may have affected the differences in outcomes between both groups. However, this design allowed all potentially interested participants to participate in the intervention program, which may have increased their motivation to participate given that usual care for (very) mild dementia caregivers often either does not include counseling or includes only very infrequent counseling.⁴¹ Furthermore, the waiting-list group was not deprived of usual care. An alternative would be a pseudo-intervention in which only psycho-education or only attention of the coach is

provided, but the aim of this study was not to evaluate the online aspect of the intervention only, but the effect of the blended-care intervention of which psycho-education and face-to-face contacts are integral parts.

Intention-to-treat analyses was not fully possible, as intervention non-completers refused to participate in further assessments. However, we did include participants that were not completely compliant (completed only 2, 3 or no modules at all) in the analyses.⁴² Drop-out was higher in the intervention group compared to the control group, but selective drop-out was not demonstrated as completers did not differ from non-completers. Often mentioned reasons for drop-out were no need for help or refusal by the care recipient, which was demonstrated previously as reasons of non-use of formal services.^{43,44} Furthermore, a higher rate of drop-out in the intervention group has previously been reported and previous RCT's even controlled for this phenomenon beforehand by increasing the sample of the intervention group. Although the power of our group was not jeopardized based on our previous power calculation, future studies could consider controlling for a higher rate of drop-out in the intervention group to prevent loss of power.

Our sample was not limited to memory clinics only, but the included participants may represent a subgroup of all dementia caregivers in the early stages. Caregivers in the early stages often decline formal care and it is conceivable that many were not familiar with the care parties involved in recruitment and were therefore overlooked in this study.^{43,44} This could have resulted in a highly motivated sample more open to support.⁴⁰ Furthermore, only computer-literate caregivers could be included, which represents only 59.1% of dementia caregivers.⁴⁵ However, seniors' use of Internet is expected to rise in the near future⁴⁶, increasing the accessibility of PiB.

Future research and clinical implications

Future research could consider combining all resources used during the intervention period with the intervention costs and outcomes in a cost-consequence analysis to aid decision makers. Furthermore, sustainability of improvements will be evaluated at long-term follow-up.

Conclusion

In conclusion, this study showed that a blended care self-management program for dementia caregivers in the early stages is effective in increasing caregiver self-efficacy, mastery and quality of life. The program could provide accessible care to future generations of early-stage dementia caregivers and strengthen the primary caregivers.

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CHAPTER 9

General Discussion

INTRODUCTION

People with Mild Cognitive Impairment or early-stage dementia are often left with a diagnosis but no support. Research indicates that although interference in daily life is still low, people with cognitive problems and their family members do struggle with the changes that occur and the uncertainty about their future.^{1,2} Efficacious pharmacotherapies are not yet available to cure cognitive disorders, but an early diagnosis offers opportunities to improve early adaptation to the caregiver role. In turn, this may prevent high levels of burden and institutionalization of the person with the dementia in the later stages.^{3,4} However, the evidence for early-stage caregiver support was not yet conclusive.⁵ E-health self-management interventions could suit the caring role transition caregivers face during the early stages.⁶ The main aim of this thesis was to develop and evaluate an e-health self-management intervention for caregivers of people with early-stage dementia. In this thesis we explored the state of the art with respect to the evidence of e-health interventions for caregivers of people with dementia (Chapter 2), the problems of caregivers of people with early-stage dementia and their needs for care and support (Chapter 3 and 4), the content and feasibility of the newly developed program 'Partner in Balance' (Chapter 5) and its process and effects on self-efficacy, mastery, and psychological complaints (Chapter 7 and 8).

This chapter starts with an overview of the main findings of this thesis and discusses their scientific interpretation and implications. Next, some methodological considerations are discussed, together with the implications for clinical practice and future research.

Main findings and implications

E-health interventions for caregivers of people with dementia

Internet interventions to support dementia caregivers are relatively new but show promising results on caregiver confidence, self-efficacy, stress, burden, and depression (Chapter 2). Although quality of the evidence is still low, several successful elements could be identified, such as combining tailored information with the help of a coach and offering possibilities to interaction with other caregivers. These results are in line with the conclusions of previous studies emphasizing the importance of guidance by a coach and caregiver interaction.^{7,8} Furthermore,

previous reviews have shown that caregiver interventions are more effective if they are tailor made and fit the needs of the caregiver.^{9,10}

Problems and needs of caregivers of people with early-stage dementia

A further qualitative exploration of these needs showed that there is a mismatch between supply and demand of informal support. Barriers to supply support were partly similar to those identified in earlier research, such as a fear of stigma,¹¹ negative attitudes towards accepting support, for example a sense of responsibility, and unwillingness to relinquish support to others¹². The identified mismatch was strengthened by an observed cognitive bias. Both the spousal caregivers and the social network members tended to think for others and exhibited unverified and sometimes incorrect thoughts concerning each other's intentions, resulting in not explicitly communicating support wishes and opportunities. According to Beck's cognitive theory, people can become susceptible to interpreting the intentions of others in a distorted or biased way because meanings are derived from personal experiences and the way people structure the world^{13,14}. Open communication in formal and informal care systems might repair this mismatch (Chapter 3). This finding underscores the importance of early education and social network interventions to facilitate positive interactions. Early caregiver interventions^{15 16,17} might effectively improve support and open communication to prevent these cognitive biases. However, it was not clear whether and which early-stage interventions are desired. To tailor interventions accordingly and maximize the benefit of an early-stage intervention, the problems and needs for care of caregivers of people with early-stage dementia were explored (Chapter 4). Results showed that early-stage caregivers found it difficult to acknowledge care needs in an early phase of the disease due to fear of stigma and low acceptance. Fear is linked with an urge to escape¹⁸, which could explain why caregivers often postpone services utilization until care becomes an acute necessity.¹⁹ Previous research showed that next to stigma,²⁰ a lack of awareness, no perceived need of such services, or fear of care recipients' reactions²¹ might explain non-use of services. Better understanding of the disease, increasing personal time, structuring ones day and using appropriate humor can reduce negative communication. In turn, this may increase positive encounters and caregiver-confidence, contributing to positive interaction with the care recipient and an increase in well-being. This focus on adaptation and positive aspects of caregiving fits the broaden and build theory of positive emotions, stating that certain positive

emotions, such as joy, interest, contentment, pride, and love all share the ability to broaden people's momentary thought-action possibilities.²² This broadened mindset has indirect and long-term adaptive benefits, as it builds enduring personal resources, which can be used to manage future threats. For instance, Chapter 3 discussed that caregivers do not want to ask their social network members for help, but do want to strengthen positive experiences and emotions within the social network, which can result in a lowered threshold to ask for help when it is inevitable. Consistent with this finding, caregiver intervention research might focus on strengthening aspects of health. As ageing with chronic illnesses has become more 'normal' than divergent, the current WHO definition of health is counterproductive, declaring that people with chronic diseases and disabilities are by definition ill. A newly developed concept of health emphasizes people's capacity to fulfill their potential and obligations, manage their life with some degree of independence and engage in social activities, despite their medical condition or that of their loved one²³. From this perspective, health is a dynamic balance between opportunities and limitations. If people are able to successfully cope with a difficult situation by enhancing its comprehensibility, manageability and meaningfulness, the perceived quality of life does not have to deteriorate.²⁴ Our data confirmed that participation in social activities are highly valued and that a positive focus on opportunities, rather than limitations, might facilitate positive social interactions and supportive behavior. Furthermore, the meaningfulness of caregiving can be found in the positive aspects of caregiving. Next to the negative consequences of caregiving, caring can also be rewarding and provide a sense of self-efficacy and feelings of accomplishment.²⁵ Support interventions may include cognitive behavioral techniques that address maladaptive thoughts regarding caregiver support. For example, cognitive restructuring and positive reappraisal techniques may shed a more positive light on seeking informal support, such as the realization that providing or asking for support does not only impose a burden or stigma but, in contrast, might lead to a reciprocal enrichment of relationships and increased social functioning.

Content and feasibility of an e-health self-management program

Fitting the new concept of Health emphasizing people's capacity and use of resources, the Stress and Coping paradigm by Lazarus and Folkman²⁶ and the Social Learning theory by Bandura²⁷ propose that taking charge of the changes in one's life promotes healthier behavior, increases self-efficacy, and can therefore

reduce caregiver stress and its impact on general wellbeing.²⁸ Following these theories and the findings discussed above, a support program for caregivers in the early stages of their caregiving role could be aimed at positively managing life with dementia rather than managing the dementia itself.²⁹ Self-management programs suit the caring role transition and have previously been used to support informal caregivers of several chronic diseases with promising results.³⁰⁻³²

To this end, we developed the blended care self-management program 'Partner in Balance' and evaluated its feasibility and preliminary effects (Chapter 5). This tailored intervention approach appeared to be feasible for informal EDC and supported them in the difficulties of caregiving. The convenience of completing the program at home, the tailored content, and the guidance (face-to-face and online) were appraised positively. Previous self-management studies confirm that personal caregiver needs should be used as a starting point.³³ As guidance from a 'real life' person was often desired, a blended care format was chosen. The value of this format has been supported by previous studies; participants have felt connected to the coach or therapist delivering the intervention³⁴ and have been more motivated to persist with web-based interventions.³⁵ Preliminary effects on caregiver self-efficacy were promising. This finding is in line with Bandura's theory; when equipped with the tools needed to make a change towards a more desired situation, caregivers' objective understanding of the situation and their beliefs about their ability to manage the situation, e.g., their self-efficacy level, may increase.²⁷ Furthermore, the finding is congruent with previous research on online support for dementia caregivers.^{7,36,37} Confirming the feasibility and preliminary effectiveness is a valuable step towards examining the effectiveness of a newly developed intervention.^{38,39}

Process and effects of 'Partner in Balance'

Feedback from the feasibility study was used to adapt the program to increase user-friendliness. Next, we aimed to evaluate the process characteristics and effectiveness of 'Partner in Balance'. The process evaluation (Chapter 7) showed that the participation rate of recruited caregivers was 52%. Considering an average response rate of 27% for caregiver research, our participation rate can be considered substantial.⁴⁰ However, the 52% only considered eligible caregivers who were already familiar with the care parties involved in recruitment and may have been more motivated and open to support⁴¹. Recruitment barriers reported by coaches were e.g. no computer, no need for intervention or additional support, which were

also reasons to decline participation. As mentioned in Chapter 4, caregivers found it difficult to acknowledge care needs in an early phase of the disease due to fear of stigma, shame and low acceptance, which could explain this finding. Young age and being employed were considered recruitment facilitators. However, caregivers of people with young-onset dementia and children had difficulties identifying with examples about older caregivers. Previous research confirmed that younger caregivers struggle with different aspects in daily life, when compared to older caregivers ⁴². It is essential that to match program content and specific needs of the target audience to maximize the benefit of a supportive intervention ^{9,16,43,44}. The thematic structure of the program allows for add-on of specific themes for subgroups, such as caregivers of people with young-onset dementia.

Both participants and coaches mentioned that their relationship with each other had deepened, which was also demonstrated in a previous blended-care intervention for depression ³⁴. Previous research confirmed that the opportunity to reflect on one's feelings anonymously in one's personal safe environment is easier than face-to-face, but the face-to-face contact increased caregiver openness, and therefore coach empathy with their situation ³⁵. Participant compliance to all 4 modules was high (87.8%), which could be explained by the motivational aspect of having a coach, also mentioned in previous studies ³⁵. The varying intervention period and dose may influence the effectiveness of the intervention ⁴⁵. However, reasons for protocol deviations were diverse and not uncommon for informal caregivers and elderly participants (e.g. caregiver pace, time constraints, illness) ⁴⁰. In self-management interventions the participant is in control and should therefore be allowed to complete the modules at his own pace ^{46,47}. Furthermore, complex interventions such as Partner in Balance are often designed to be implemented with some flexibility, in order to accommodate differences across participants ⁴⁸.

The low level of professional involvement in the self-management approach was considered a challenge. The performance of the coach in self-management care is very important for the participant's performance of self-management tasks and overall intervention effectiveness ⁴⁹. It was previously argued that health care providers do not always support self-management education, as this is not part of their attitudes, beliefs or regular care practice ⁴⁷. Therefore, it can be recommended to increase the essential clinical competences of healthcare providers to provide tailored self-management support ⁴⁴, and their awareness of the benefits of evidence-based self-management programs for their target population ⁴⁷. Partner in Balance

was evaluated within multiple organizations with coaches from different backgrounds, who received training and supervision in self-management and blended care. A relatively high response rate of organizations to adopt the program was found (73%), which could be attributed to the current demand of health care insurances for care organizations to provide e-health⁵⁰. However, a lack of financing and time could hamper the implementation. It is important to consider the context and level of implementation during the first phases of intervention development and evaluation, as many psychosocial interventions show different results in different settings or countries^{38,51}

A randomized controlled trial was executed to demonstrate the effects of Partner in Balance (Chapter 8). The controlled study demonstrated a significant increase in self-efficacy, mastery, and quality of life in the intervention group (Partner in Balance), compared to a waiting-list control group receiving usual care. No significant differences were found between the groups on depressive symptoms, general distress and perceived stress. These results are in line with previous results in the pilot study (Chapter 7) and other e-health interventions for dementia caregivers.¹⁶ The program focused on enhancing positive, intact experiences that are tailored to the individual caregiver's situation, with a positive outcome on self-efficacy and quality of life. This suggests that positive emotions should not just be considered as a result of support, but could also be adopted as a mean to achieve psychological growth and improved well-being over time. For instance, the distinct positive emotion that follows personal achievements, pride, broadens the mind by creating an urge to share achievements with others and envision greater achievements in the future. In Chapter 8, participants reported more openness with their environment following the intervention, which could be attributed to the positive emotion pride experienced by attaining their goals.⁵² However, it was expected that a decrease in stress caused the demonstrated higher levels of wellbeing or quality of life^{26,27}, which the effect study could not demonstrate. It is conceivable that interventions aimed at the early stages may not be capable of decreasing burden and stress, as these are relatively low during the early stages.⁶ Previous caregiver interventions demonstrating positive effects on burden and stress were not specifically aimed at early-stages of dementia.⁵³⁻⁵⁸ Follow-up of effects could clarify if an increase in self-efficacy post-intervention is maintained in the long term and results in a decrease or prevention of increased stress and depression.

Methodological considerations

Each chapter in this thesis has its methodological strengths and weaknesses, which we discuss below.

Strengths

In this thesis we made use of an iterative process recommended by the new Medical Research Council (MRC) framework³⁸ by exploring the existing evidence, theoretical frameworks and user- and professional input, which led to the development of a program based on scientific knowledge, clinical experience and needs of the target audience. The mixed method methodology facilitated replication through greater knowledge of the active component(s) and potential barriers to implementation.⁵⁹ The evaluation of the process and effects of Partner in Balance in different contexts increased the generalizability of the results.⁶⁰ These type of pragmatic trials are recommended by the MRC Framework, as they may prevent different intervention outcomes in different settings and countries.³⁸

Limitations

First, the systematic review used two different quality appraisals to rate and categorize the investigated studies, which may have led to exceedingly negative evaluations. Also, the methodological quality was rated with a set of criteria based on the Consolidated Standards of Reporting Trials (CONSORT) criteria, which can be difficult for psychosocial research to comply to.⁶¹

Second, the waiting-list period may have affected the differences in outcomes between both groups. The effects of waiting are highly variable and depend on the characteristics of the sample and of the trial.⁶² However, this design allowed all potentially interested participants to participate in the intervention program, which may have increased their motivation to participate given that usual care for (very) mild dementia caregivers often either does not include counseling or includes only very infrequent counseling.⁶³ Furthermore, the waiting-list group was not deprived of usual care. An alternative would be a pseudo-intervention in which only psycho-education or only attention of the coach is provided, but the aim of this study was not to evaluate merely the online aspect of the intervention, but the effect of the blended-care intervention of which psycho-education and face-to-face contacts are integral parts.

Third, intention-to-treat analysis was not fully possible, as intervention non-completers refused to participate in further assessments. However, we did include participants that were not completely compliant (completed only 2, 3 or no modules at all) in the analyses.⁶⁴ Drop-out was higher in the intervention group compared to the control group, but selective drop-out was not demonstrated as completers did not differ from non-completers. Often mentioned reasons for drop-out were no need for help or refusal by the care recipient, which was demonstrated previously as reasons of non-use of formal services.^{21,41}

Finally, our participants may represent a subgroup of all dementia caregivers in the early stages. Caregivers in the early stages often decline formal care and it is conceivable that many were not familiar with the care parties involved in recruitment and were therefore overlooked in this study.^{21,41} This could have resulted in a highly motivated sample more open to support.⁵ The studies in this thesis also encompassed a high percentage of spousal caregivers compared to other family caregivers. Previous research indicated that especially people with dementia with spousal caregivers could benefit from early diagnosis and intervention⁶⁵, which the present study was not able to demonstrate, as the power for subgroup analyses was not sufficient. Furthermore, only computer-literate caregivers could be included, which represents only 59.1% of dementia caregivers.⁶⁶ However, seniors' use of Internet is expected to rise in the near future⁶⁷, increasing the accessibility of e-health programs such as Partner in Balance. Younger generations are familiar with new technology and more and more elderly seem to get acquainted with a computer or tablet.⁶⁷

Clinical implications

A dementia diagnosis might be stigmatizing and put people with dementia and their caregivers outside of society.²⁰ The research conducted in this thesis aimed to support the caregivers of people that received the widely advocated early diagnosis of dementia.

First, this thesis showed that reaching and effectively supporting caregivers in the early stages is inconsistent with the negative view on dementia as a horrifying disease with merely adverse consequences. The current focus on dementia as a terrible disease might lead to fear of stigma in caregivers and should therefore be adapted to a more positive view in which people with dementia and their caregivers can focus on their capacity to fulfill their potential and obligations, manage their life

with some degree of independence and engage in social activities, despite the diagnosis.²³

Second, the thesis showed that an active support approach aimed at self-management like the Partner in Balance program successfully supports caregivers in the early stages of dementia. The program could therefore be a valuable support option for dementia caregivers in the early stages. Involving caregivers in their choice of support is important, as previous research showed that actively involving caregivers in treatment decision-making sets aside effective from ineffective support programs,⁶⁸ and offering choices may result in a greater sense of personal control, better connection with personal needs, more satisfaction with treatment, higher adherence and consequently better outcomes.⁶ However, it can be argued that early-stage support should not be offered when people do not express a specific need for support, to avoid stigmatization. Stigma in dementia is still persistent and can be defined as a process of exclusion whereby a 'normal' person is reduced to a person with whom something is wrong.⁶ Moreover, as Zarit and Femia⁶⁹ put it: "A trial that enrolls caregivers who don't need help in a specific area provides treatment for a problem that doesn't exist". However, even in an early stage caregivers experience distress and depressive symptoms, which may be related to changes in family roles and relationships^{2,70} and common neuropsychiatric symptoms like apathy that undermine relationship reciprocity.^{1,6} Furthermore, the early-stage needs paradox described in Chapter 3 showed that caregivers in later stages desired receiving support earlier-on, but caregivers in the early stages struggled with acknowledging care needs. This was also demonstrated in Chapter 7 where reasons for declining participation and inability to set goals were, amongst others, not needing support or an intervention. It was argued that this paradox could be attributed to low levels of acceptance in the early stages. However, it should not be disregarded that this program is not suitable for all caregivers. The higher rate of drop-out in the intervention group showed that this program can be considered as burdensome and e-health interventions in general are not appropriate for caregivers that are not computer-literate or have more practical care needs. Nonetheless, a relatively high response and participation rate was found, indicating that there is a need for at least having the option to choose for this type of caregiver support. An active role of health care professionals in outlining care and support options early in the dementia process is recommended to increase the possibility that caregivers receive the support that fits their needs, which can consequently help caregivers involve the

person with dementia in making medical, financial, legal and care decisions.⁷¹

Finally, the effectiveness of the program may be particularly attributed to the blended aspect, as was argued in Chapter 7. Previous research also suggests that blended care clients feel connected to the coach or therapist delivering the intervention and are more motivated to persist with Internet-based interventions.³⁵ Furthermore, blending online modules with face-to-face care offers the opportunity to enhance self-management and cost-effectiveness of an intervention, while still providing the support caregivers need.³⁴ It is recommended that Partner in Balance is adopted in its current blended care format to optimize its effectiveness. If clinicians choose to implement Partner in Balance, it can be recommended to use an instrument like Goal Attainment Scaling to assess caregiver needs, as goal attainment may have a positive effect on feelings of control and self-efficacy. Self-management studies also stress that personal caregiver needs should be taken as a starting point of support.³³

We can conclude that people need to be informed about support possibilities following diagnosis, their need for support should be assessed and shared decision making should be adopted when it comes to decisions about caregiver support. Positive aspects of caregiving should be promoted to protect caregivers against negative health outcomes.

Future research directions

Our thesis showed that psychosocial research for dementia caregiver support lacked methodological rigor. First, it can be recommended that more high quality studies (randomized controlled trials; RCTs) are needed to make stronger statements about the effects of supportive Internet interventions and their most promising elements. However, while an RCT is the golden standard for determining the effectiveness of an intervention, the use of an RCT design in complex psychosocial interventions can be difficult because of their often unblinded and multi-component character.^{38,61} Furthermore, an RCT is not the only rigorous method for evaluating interventions; many alternatives exist when RCTs are not possible or appropriate due to scientific, practical, and ethical concerns, such as observational, quasi-experimental, and qualitative studies. Also, pragmatic trials (trials designed to evaluate the effectiveness of interventions in real-life routine practice conditions) are becoming increasingly important, as they yield results that can be generalized and applied in routine practice settings, whereas more standard explanatory trials (to evaluate

whether an intervention works under optimal situations) often fail to be broadly generalizable.⁷² However, many of the issues faced in reporting RCTs also relate to other evaluation designs.⁷³ Determining the effectiveness of interventions is very important for policy and practice decision-making, but poor reporting limits the ability to replicate findings, combine evidence in systematic reviews and utilize findings in policy and practice. Therefore, psychosocial intervention studies could consider adhering to the extension of the CONSORT criteria, the CONSORT for Social and Psychological Interventions (CONSORT-SPI).⁷³ These criteria could improve the accuracy, comprehensiveness, and transparency of study reports.

Second, some important aspects of psychosocial RCTs are not addressed in the CONSORT statement, e.g. adequate reporting of treatment integrity. It is important to understand how psychosocial interventions are actually delivered and received. Performing a process evaluation alongside an effectiveness trial can improve clarity of possible sources of bias, which allows readers to better assess and interpret treatment effects and generalizability of results and explain why an intervention is effective in one setting and not in another.⁵¹

Third, RCTs investigating caregiver support often struggle with demonstrating quantitative results, while qualitative results show very positive intervention experiences.⁵ This suggests that there is some room for improvement when it comes to appropriate outcome measures for this type of research. Outcome measures for interventions are often used based on their psychometric properties or familiarity in the field, but the results of this thesis may argue that outcome measures tailored to the intervention content and the personal situation of the target audience could yield more positive results. For example instruments like Goal Attainment Scaling enable identification of individual benefits beyond the generalized measures.⁷⁴ However, this recommendation can be debated, as the ultimate aim of interventions is to improve the overall quality of life, which can be demonstrated with more generic instruments. Furthermore, statistically significant benefits on retrospective self-report measures may be marginal in clinical practice. Therefore, measures like the Experience Sampling Method (ESM) could be a useful addition to measure variations in intervention outcomes in every-day-life situations, possibly mapping individualized evidence of intervention benefit more accurately than retrospective self-report measures only administered pre- and post-intervention.^{75,76}

Last, future research could consider tailoring the content of support interventions like Partner in Balance to specific subgroups of caregivers, such as

caregivers of people with young-onset dementia and children to further optimize the program's effectiveness. Also, caregiver needs may depend on the relationship with the person with dementia, thus intervention effects may vary between for example spouses and adult children. Future research should consider including larger samples to make valid statements about the benefits for these subgroups of caregivers. Furthermore, sustainability of long-term intervention effects should be evaluated and a cost-consequence or cost-effectiveness analysis should be conducted to inform decision makers on the value of Partner in Balance.

In conclusion, the research presented in this thesis provides a valuable contribution to the growing knowledge on e-health for dementia caregivers and showed that a tailored support intervention for dementia caregivers in the early stages is effective in increasing caregiver self-efficacy. Results can be used to inform clinicians and researchers of the delivery and effects of Partner in Balance as a tool to support dementia caregivers. It can be concluded that it is important to take both the benefits and the costs of caregiving into account in intervention development and research.

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SUMMARY

SUMMARY

Dementia is a generic term for deterioration in memory and other cognitive functions that facilitate a person's ability to function in everyday life. The majority of people with dementia are living at home and cared for by one or more family members, often referred to as the informal caregivers. Caregiving generally puts a large strain on family members, increasing their risk for depression and anxiety. Many caregiver support interventions have been developed to ameliorate negative caregiver consequences. Timing of these interventions might be crucial in maximizing their effects. Early support could help caregivers to adapt to the changes of early dementia and to feel more competent towards care. However, the current contrast between highly advanced tools with respect to the timely diagnosis of dementia and the lack of available support to match this early diagnosis is challenging. Nonetheless, the scientific evidence for early-stage caregiver interventions is not yet conclusive. Next to intervention timing, intervention delivery can also be essential to maximize intervention effects. E-health technology offers an opportunity for accessible tailored interventions. However, existing e-health programs for dementia caregivers are mainly aimed at dealing with dementia related problems in the later stages of dementia, which may not benefit caregivers in the early stages. Therefore, the main aim of this thesis was to develop and evaluate an e-health self-management intervention for caregivers of people with early-stage dementia.

Chapter 1 provides a general introduction to the theme and aims of this thesis. Information on dementia, informal caregiving, and the relevance of caregiver interventions is provided, as well as the research questions and outline of the thesis.

In **Chapter 2** a systematic review of the effectiveness, feasibility, and quality of Internet interventions for informal caregivers of people with dementia is presented. Intervention types, dosage and duration differed widely, as did the methodological quality of the 12 included studies. The overall level of evidence was low. However, the results demonstrated that Internet interventions for informal dementia caregivers can improve various aspects of caregiver well-being, e.g., confidence, self-efficacy, stress, burden and depression, provided they comprise multiple components and are tailored to the individual. Furthermore, caregivers could benefit from guidance by a coach or contact with other caregivers.

Chapter 3 describes an exploration of the needs, perceptions and experiences with informal support from the perspective of the primary caregiver and his/her social network members. Results revealed that there is a mismatch between supply and demand of informal support, strengthened by a cognitive bias; primary

caregivers reported to think for other social network members and vice versa. Both presented unverified and sometimes incorrect thoughts concerning each other's intentions, resulting in not explicitly communicating support wishes and opportunities. Openness in communication might repair this mismatch.

In **Chapter 4** an in-depth analysis of the problems, needs and wishes of caregivers of people with early-stage dementia and their perspectives on need for care during these early stages is presented. The results showed that early-stage caregivers struggled with acknowledging needs due to fear of stigma and low acceptance. They stressed the importance of acceptance as a prerequisite for adequate adaptation, but were hindered by lack of knowledge, difficulty acknowledging changes and focus on loss. In contrast, better understanding of the disease, increasing personal time, structuring one's day and using appropriate humor can reduce negative communication. In turn, this may increase positive encounters and caregiver-confidence, contributing to positive interaction with the care recipient and an increase in well-being.

Chapter 5 describes the development of the blended care self-management program 'Partner in Balance' and an evaluation of its feasibility and preliminary effects on self-efficacy and goal attainment. 'Partner in Balance' is a self-management intervention, which means that participants are motivated to reflect on their situation, create personal goals and search for possible solutions. The intervention is presented in a 'blended care' format; it combines *online* modules with *face-to-face* contact moments. In the intake session participants and coaches set goals and choose 4 out of 9 available modules or themes that fit their personal situation. Modules consist of information, examples, and personal assignments. Participants follow the modules online at their own convenience, guided by the personal coach. A discussion forum was added to allow caregivers to exchange information and tips. Following the online period the modules and goals are evaluated in a closing-out session with the coach. The tailored intervention approach appeared to be feasible for caregivers in the early stages and supported them in the difficulties of caregiving. The convenience of completing the program at home, the tailored content, and the guidance (both face-to-face and online) were appraised positively. Feedback of the participants was used to increase the program's user-friendliness. Preliminary effects on caregiver self-efficacy and goal attainment were promising.

Chapter 6 describes the design of a randomized controlled trial evaluating the process characteristics and effects of 'Partner in Balance' on self-efficacy, mastery, quality of life and psychological complaints (depression, anxiety, and stress) compared to a waiting-list control condition receiving usual care.

Chapter 7 assesses the internal and external validity of the 'Partner in Balance' intervention and its implementation in a process evaluation. Data were evaluated from the perspective of both family caregivers (participants) and professionals delivering the intervention (coaches) with the objective to increase the understanding of the mode of delivery. Participation rate of recruited caregivers was 52%. Recruitment barriers reported by coaches were e.g. no computer, no need for intervention or additional support, which were also reasons to decline participation. Younger age and being employed were considered recruitment facilitators. However, caregivers of people with young-onset dementia and children had difficulties identifying with examples about older caregivers. Both participants and coaches mentioned that their relationship with each other had deepened. Participant compliance to all 4 modules was high (87.8%) and performance according to protocol as rated by the coaches was substantial (77%). The varying intervention period and different dose (i.e. time spent on the intervention) may influence the effectiveness of the intervention. Participants appreciated the personal touch and the confirmation of existing thoughts they experienced during the program. Overall, caregivers attained their previously set goals at the end of the program. Participants reported that the blended structure increased their openness during the online modules. The program's primary focus on the caregiver (and not on the caregiver-patient dyad) was appreciated less. The discussion forum was hardly used. Partner in Balance was evaluated within multiple organizations with coaches from different backgrounds, who received training and supervision in self-management and blended care. A relatively high response rate of organizations to adopt the program was found (73%). However, a lack of financing and time could hamper the implementation.

Chapter 8 investigates whether 'Partner in Balance' is superior to the waiting-list control condition as evidenced by improved self-efficacy, mastery, quality of life, and lower levels of psychological complaints (depression, anxiety, and stress). The results demonstrated a significant increase in self-efficacy, mastery, and quality of life in the intervention group (Partner in Balance), compared with the control group. No significant differences were found between the groups with respect to depressive symptoms, general distress and perceived stress.

In **Chapter 9** the main results and their scientific interpretation are discussed, together with a reflection on methodological issues and the implications for clinical practice and future research.

SAMENVATTING

Dementie is een algemene term voor achteruitgang van het geheugen en andere cognitieve functies die men nodig heeft om te functioneren in het dagelijks leven. De meerderheid van de mensen met dementie woont thuis en wordt verzorgd door een of meerdere familieleden, ook wel mantelzorgers genoemd. Zorgen voor iemand met dementie legt een grote druk op mantelzorgers en verhoogt hun risico op depressie en angstklachten. Om deze negatieve gevolgen te verminderen zijn er ondersteuningsmogelijkheden of interventies voor mantelzorgers ontwikkeld. De timing waarop deze interventies worden ingezet kan cruciaal zijn om hun effect te vergroten. Wanneer familieleden in een vroeg stadium ondersteuning krijgen bij het aanpassen aan de veranderingen die dementie teweeg brengt, kan dit ervoor zorgen dat ze zich meer competent voelen als mantelzorger. Het is echter vreemd dat de nieuwe geavanceerde methoden om een vroegtijdige dementie diagnose te stellen niet samengaan met ondersteuningsmogelijkheden voor mensen die deze vroege diagnose te horen krijgen. Daarentegen is nut van zulke ondersteuningsmogelijkheden in een vroeg stadium nog niet eenduidig wetenschappelijk aangetoond.

Naast timing van een interventie kan de manier waarop een interventie wordt aangeboden ook van essentieel belang zijn om de effecten te vergroten. E-health technologie maakt het mogelijk om op een toegankelijke manier op maat gemaakte interventies aan te bieden. Reeds bestaande e-health interventies voor mantelzorgers van mensen met dementie zijn voornamelijk gericht op het omgaan met dementie-gerelateerde problemen die vaak kenmerkend zijn voor de latere stadia van dementie en mogelijk niet passen bij de situatie van mantelzorgers in een vroeg stadium. Daarom richtte het onderzoek in dit proefschrift zich op het ontwikkelen en evalueren van een e-health interventie voor mantelzorgers van mensen met dementie in een vroeg stadium.

Hoofdstuk 1 geeft een algemene inleiding op het thema en de doelstellingen van het proefschrift. In dit hoofdstuk komen dementie, mantelzorg en de relevantie van mantelzorginterventies aan bod. Ook worden de onderzoeksvragen en de opzet van dit proefschrift besproken.

In **Hoofdstuk 2** wordt een literatuurstudie gepresenteerd die zich richt op de effectiviteit, bruikbaarheid en kwaliteit van e-health interventies voor mantelzorgers van mensen met dementie. De invulling per interventie en de methodologische kwaliteit van de 12 besproken studies liepen sterk uiteen. Het bewijs van effectiviteit van de verschillende interventies bleek over het algemeen laag te zijn. De resultaten

suggereerden wel dat e-health interventies voor mantelzorgers van mensen met dementie een positief effect kunnen hebben op verschillende aspecten van hun welzijn (onder anderen hun zelfvertrouwen, zelf-effectiviteit, stress, belasting en depressie), mits deze interventies bestonden uit meerdere componenten en waren afgestemd op het individu. Daarnaast bleek dat contact (op afstand) met een coach en andere mantelzorgers een belangrijke toevoeging kan zijn.

Hoofdstuk 3 beschrijft een onderzoek naar de behoeften, percepties en ervaringen met informele steun vanuit het perspectief van de primaire mantelzorger en zijn of haar sociale netwerk. Uit de resultaten bleek dat er een slechte afstemming is tussen vraag en aanbod van informele steun, wat mogelijk wordt veroorzaakt door een bepaalde denkfout. Mantelzorgers vullen vaak gedachten in voor de leden uit hun sociale netwerk en andersom. Zowel mantelzorgers als hun netwerkleiden rapporteerden gedachten over elkaars bedoelingen die niet bij elkaar werden geverifieerd en soms onjuist waren. Dit resulteerde in een onduidelijke communicatie over de wensen en mogelijkheden op het gebied van wederzijdse ondersteuning. Meer openheid in de communicatie zou deze slechte afstemming of 'mismatch' kunnen herstellen.

In **hoofdstuk 4** worden de problemen, behoeften en wensen van mantelzorgers van mensen met dementie in een vroeg stadium onderzocht. Daarnaast wordt hun behoefte aan zorg in dit vroege stadium in kaart gebracht. De resultaten toonden aan dat mantelzorgers in een vroeg stadium moeite hebben met het erkennen van hun behoeften, mogelijk door een bepaalde angst voor stigmatisering en problemen met acceptatie. Mantelzorgers benadrukten het belang van acceptatie als voorwaarde om zich te kunnen aanpassen aan de nieuwe situatie, maar ze werden in hun acceptie beperkt door een gebrek aan kennis, moeite met het erkennen van veranderingen en een overheersende focus op verlies. Daarentegen kan meer begrip van de ziekte, meer tijd voor zichzelf, een bepaalde structuur in de dag en gepaste humor de negatieve communicatie tussen de mantelzorger en de persoon met dementie verminderen. Dit kan het aantal positieve momenten en het zelfvertrouwen van de mantelzorger verhogen. Uiteindelijk dan dit weer bijdragen aan een positievere interactie met de persoon met dementie en een betere kwaliteit van leven.

Hoofdstuk 5 beschrijft de ontwikkeling van de interventie 'Partner in Balans' en een evaluatie van de bruikbaarheid en de voorlopige effecten van het programma op zelf-effectiviteit (zelfvertrouwen) van de mantelzorger en het bereiken van doelen.

'Partner in Balans' is een zelfmanagementinterventie, wat betekent dat deelnemers worden aangezet om na te denken over persoonlijke doelen en actieplannen om deze doelen te bereiken. De interventie wordt gegeven in een zogenaamde 'blended' vorm, waarbij *online* modules worden gecombineerd met *face-to-face* gesprekken. In een eerste gesprek worden doelen gesteld en kiezen deelnemers samen met hun coach 4 uit de 9 beschikbare modules of thema's die bij hun situatie passen. Modules bestaan uit informatie, voorbeelden en persoonlijke opdrachten. Deelnemers kunnen de modules thuis in hun eigen tijd bekijken, waarbij ze op afstand worden ondersteund door de coach. Daarnaast is er een discussieforum beschikbaar waar deelnemers met andere mantelzorgers tips of ervaringen kunnen uitwisselen. Na de online periode worden de modules en doelen geëvalueerd in een afsluitend gesprek met de coach. De op maat gesneden interventie bleek bruikbaar voor mantelzorgers van mensen met dementie in een vroeg stadium en ondersteunde hen in het zorgen voor hun familielid. Het gemak om het programma thuis te kunnen volgen, de op maat gemaakte inhoud en de begeleiding van de coach (face-to-face en online) werden positief beoordeeld. De ervaringen van de mantelzorgers werden gebruikt om het programma gebruikersvriendelijker te maken. De studie toonde veelbelovende voorlopige effecten op zelf-effectiviteit en het bereiken van doelen.

Hoofdstuk 6 beschrijft de opzet van een gerandomiseerde gecontroleerde studie waarin zowel de proceskenmerken als de effecten van 'Partner in Balans' op zelf-effectiviteit, ervaren controle, kwaliteit van leven en psychische klachten (depressie, angst en stress) worden vergeleken met een wachtlijst controlegroep.

Hoofdstuk 7 beoordeelt de interne en externe validiteit van 'Partner in Balans' en de implementatie van het programma in een procesevaluatie. De gegevens werden geëvalueerd vanuit het perspectief van zowel de mantelzorgers (deelnemers) als de professionals (dat wil zeggen: de coaches die de interventie hebben aangeboden en begeleid). Van de mantelzorgers die gevraagd werden om deel te nemen heeft 52% daadwerkelijk deelgenomen. Factoren die de werving bemoeilijkten waren het niet in bezit zijn van een computer of het geen behoefte hebben aan een interventie of extra steun. Werving werd gemakkelijker wanneer mantelzorgers relatief jonge waren en/of nog werkzaam waren. Zowel partners als kinderen van mensen met dementie op jonge leeftijd hadden echter moeite om zich te identificeren met de gegeven voorbeelden van oudere mantelzorgers. De deelnemers en de coaches gaven aan dat hun onderlinge relatie was verdiept na

deelname aan 'Partner in Balans'. Het percentage van deelnemers die alle 4 de modules had afgerond was hoog (87,8%). Daarnaast werd het programma volgens de coaches grotendeels volgens protocol gegeven (77%). De variërende interventieperiode en dosering (aantal gevolgde modules en tijd die er aan werd besteed) kan de effectiviteit van de interventie hebben beïnvloed. Mantelzorgers waardeerden het persoonlijke aspect en de bevestiging die het programma ze gaf. Over het algemeen bereikten de mantelzorgers hun vooraf gestelde doelen na afloop van het programma. Mantelzorgers gaven aan dat de 'blended' aanpak hun openheid tijdens de online modules vergrootte. Ze waren minder enthousiast over het feit dat de interventie zich alleen op de partner richt en niet ook op de persoon met dementie. Het discussieforum werd amper gebruikt. Partner in Balans werd geëvalueerd binnen meerdere organisaties, met coaches van verschillende achtergronden. Alle coaches ontvingen scholing en begeleiding in zelfmanagement en het geven van 'blended' zorg.

Hoofdstuk 8 onderzoekt of 'Partner in Balans' beter is dan een wachtlijst controle conditie op het gebied van zelf-effectiviteit, ervaren controle, kwaliteit van leven en psychische klachten (depressie, angst en stress). De resultaten toonden een significante toename van zelf-effectiviteit, ervaren controle en kwaliteit van het leven in de interventiegroep (Partner in Balans), in vergelijking met de controlegroep. Er werden geen significante verschillen gevonden tussen de groepen voor wat betreft depressieve symptomen, angst en ervaren stress.

In **hoofdstuk 9** worden de belangrijkste resultaten en hun wetenschappelijke interpretatie besproken, naast een kritische reflectie op methodologische aspecten en de implicaties voor de klinische praktijk en toekomstig onderzoek.

KNOWLEDGE VALORIZATION

This thesis described the development and evaluation of the supportive e-health intervention 'Partner in Balance' for caregivers of people with early-stage dementia. In this valorization paragraph we aim to describe how the obtained knowledge from our research can be made valuable in social and economical contexts.

Relevance and innovation

The global cost of dementia was estimated at 604 billion dollars in the 2011 World Alzheimer Report.¹ Due to the rise of people with dementia in the near future, it is expected that the cost of care for dementia will increase by 85% in 2030, possibly making it the most expensive disease of our society.¹ Efficacious pharmacotherapies are not yet available to cure dementia, but previous studies showed that psychosocial interventions aimed at reducing caregiver burden and increasing their self-efficacy might reduce (indirect) dementia care costs, as they improve caregiver mood, caregiver quality of life and delay the institutionalization of the care recipient for up to 1.5 years.²⁻⁴ These results are noteworthy, considering that a single day at a nursing home costs approximately 200 Dollars in the US.⁵

Most caregiver interventions focus on the mild to moderate stages of dementia, but timing of these interventions might be crucial in maximizing the effects. Our results showed that early support could help caregivers adapt to the changes of early dementia and feel more competent to care. Next to intervention timing, intervention delivery can also be essential to maximize intervention effects. E-health technology offers an opportunity for easy accessible and tailored interventions and could be an efficient alternative to continue to provide education and support for the informal caregivers at reduced costs.⁶⁻⁸ Our literature review confirmed this by presenting the promising results Internet interventions for dementia caregivers have on caregiver confidence, self-efficacy, stress, burden, and depression. However, existing e-health programs for dementia caregivers are mainly aimed at dealing with dementia related problems in the later stages of dementia, and results of our needs assessment showed that support should fit the stage-specific needs of the caregiver. E-health self-management interventions could suit the caring role transition caregivers face during the early stages and help future informal caregivers cope with the challenges of caring for a person with dementia.⁹⁻¹⁰ The studies in this thesis confirmed this hypothesis, as the newly developed e-health self-management intervention for caregivers of people with early-stage dementia 'Partner in Balance' is effective in increasing dementia caregiver self-efficacy, mastery, and quality of life.

Target groups

The findings in this thesis are relevant for caregivers of people with early-stage dementia, dementia healthcare professionals, and policy makers.

Caregivers of people with early-stage dementia can profit from our research as the 'Partner in Balance' program effectively increased caregivers' self-efficacy, mastery and quality of life. Dementia healthcare professionals could consider online support for informal dementia caregivers in addition to the already provided care as usual. In their care considerations they could take the stage of the disease, individual characteristics and coping mechanism of the caregiver, and relationship with the care recipient prior to the disease into account and adapt the care accordingly to suit the situation and needs of the individual caregiver. Furthermore, the results show that many difficulties in the early stages can be attributed to difficulties accepting the changes in family roles and relationships, therefore targeting acceptance of these changes in early interventions such as the currently developed program 'Partner in Balance' might prove to be beneficial. During the feasibility and effectiveness study, 'Partner in Balance' was introduced in some institutions in the southern part of the Netherlands. If interested, the institutions could participate in the study, delivering the intervention in their care practice under regular supervision of the research team. The Academic Hospital Maastricht, the Riagg Maastricht, all 5 chains of 'Hulp bij Dementie' (Integrated Dementia Care in Limburg), Elkerliek Hospital Helmond, Catharina Hospital Eindhoven and Metgcz Roermond have agreed to participate and already use the program in their daily practice. Results showed that caregivers who followed the program reported an increase in self-efficacy, mastery, and quality of life. As the number of people with dementia will increase in the future, this finding could be of great interest to insurance companies and policy makers. When policy and practice in the formal care system invest in improving the capability of informal carers to help them continue to care for their family member with dementia with effective programs such as 'Partner in Balance', this could contribute to the sustainability of the healthcare for people with dementia and their carers. Furthermore, the policies of the formal care system are conceptualized in rational and general terms, whereas effective care should fit the expectations and experiences of informal family carers that emerge out of a unique set of personal circumstances. If insurance companies and policy makers take these personal circumstances into account this could increase the effectiveness of support for informal carers.

Activities and products

Based on the user- and professional input, evidence from previous research, and feasibility findings the online self-management program 'Partner in Balance' was developed. The program comprises of multiple components, is tailored to the individual and includes interaction with a coach and the possibility to interact with other caregivers. The program is tailored to individual differences in caregivers based on their needs, while stressing the positive aspects of caregiving and focusing on adjusting expectations to be able to facilitate acceptance during the early stages.

The different institutions who offered the program during the study period were updated of the study progress through a bi-annual newsletter. Furthermore, we visited Alzheimer Cafes, senior centers and mental health institutions in the southern part of the Netherlands to present our study and preliminary findings and to ask feedback from both caregivers and professionals.

Schedule and implementation

As the intervention proved to be effective on caregiver self-efficacy, mastery and quality of life, the institutions that offered the program during the study and followed the coach training will focus on implementing the program in their daily care. Currently, we are exploring the possibilities to implement the program on a larger scale, by focusing on municipalities within the scope of Dementia Friendly Communities. We are currently discussing the option of implementing 'Partner in Balance' within the EU Prevent project (www.euprevent.eu), in which German and French regions have also expressed their interest. We are currently investigating (financial) opportunities for translating and implementing 'Partner in Balance' on a European level. Furthermore, as spousal- and child caregivers of people with young-onset dementia may benefit from other topics and examples, financial means were obtained to develop additional modules to meet the needs of this specific group.

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DANKWOORD

DANKWOORD

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DANKWOORD

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CURRICULUM VITAE

Lizzy Boots was born on December 24 1988 in Roermond. After graduating from high school in 2007 she obtained a bachelor degree in Health Sciences at Maastricht University in 2010. She wrote her Master thesis on the role of self-disclosure and mimicry on likeability in social anxiety, under supervision of dr. Marisol Voncken. During her master she worked as a clinical intern at Daelzicht in Heel, where she gained experience in psychological assessment and intervention, acquiring her psychodiagnostics registration

(BAPD). After obtaining her Master degree in Mental Health at Maastricht University in 2011 (Cum Laude) she briefly worked as a care worker on outpatient basis and as a tutor at Maastricht University, before starting her PhD at the department of Psychiatry and Neuropsychology. Under the supervision of Prof. dr. Frans Verhey, Prof. dr. Ruud Kempen, and dr. Marjolein de Vugt she focused her research on the development, implementation, and evaluation of the innovate e-health program 'Partner in Balance' for caregivers of people with dementia. During her time as a PhD candidate she gained clinical experience in individualized and group therapy for people with mild cognitive impairment and their caregivers, was the PhD representative for the School of Mental Health and Neuroscience (MHeNS), organized several events in the community, and gave many lectures and talks for both scientific and lay-audiences in the Netherlands and abroad. In May of 2016, Lizzy continued her passion for supporting people with dementia and their significant others as a psychologist at Proteion in Horn.

PUBLICATIONS

PUBLICATIONS

Boots LMM, de Vugt ME, van Knippenberg RJ, Kempen GIJM, Verhey FRJ (2014). A systematic review of Internet-based supportive interventions for caregivers of patients with dementia. *International Journal of Geriatric Psychiatry*, 29(4):331-44

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Dam AEH, **Boots LMM**, van Boxtel MPJ, Verhey FRJ, de Vugt ME (2016). A mismatch between demand and supply in informal dementia care: a qualitative study on perspectives of spousal caregivers and their social network members. *Submitted*

Voncken, M., Dijk, C., Lange, WG., **Boots, LMM**, Roelofs, J. (2016) The role of self-disclosure and mimicry on the development of likeability in social anxiety. *Submitted*

Boots, LMM, de Vugt ME, Kempen GIJM and Verhey FRJ (2016). Process evaluation to explore internal and external validity of the blended-care self-management program 'Partner in Balance' for early-stage dementia caregivers. *Submitted*

Boots, LMM, de Vugt ME, Kempen GIJM and Verhey FRJ (2016). Effectiveness of the blended-care self-management program 'Partner in Balance' for early-stage dementia caregivers: results of a randomized controlled trial. *Submitted*

THESIS DEFENSES FROM MHENS

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2013

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Nicole Veldhorst-Janssen: **Intranasal delivery of rapid acting drugs.** Supervisors: Prof.dr. M. Marcus / Prof.dr. C. Neef; Co-Supervisor: Dr. P.H. van der Kuy.

Stéphanie Knippenberg: **Vitamin D and Multiple Sclerosis: immunological and clinical outcome.** Supervisor: Prof.dr. J. Cohen-Tervaert; Co-Supervisors: Dr. J. Damoiseaux / Dr. Y. Bols.

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Olga A.H. Reneerkens: **Can PDE inhibition improve cognition ? Translational insights.** Supervisor: Prof.dr. H.W.M. Steinbusch; Co-Supervisor: Dr. J. Prickaerts;.

Lyzel S. Elias-Sonnenschein: **Clinical and biomarker correlates of genetic risk factors for Alzheimer's disease.** Supervisor: Prof.dr. F.R.J. Verhey; Co-Supervisor: Dr. P.J. Visser.

Diego F. Mastroeni: **Epigenetic Dysregulation and the Pathophysiology of of Alzheimer's Disease.** Supervisors: Prof.dr. H.W.M. Steinbusch / Prof.dr. P.D. Coleman, Sun City, Arizona; Co-Supervisors: Dr. B.P.F. Rutten / Dr. D.L.A. van den Hove.

Leonidas Chouliaras: **Epigenetic Regulation in Aging and Alzheimer's disease: A translational perspective.** Supervisor: Prof.dr. H.W.M. Steinbusch; Co-Supervisors: Dr. B.P.F. Rutten / Dr. D.L.A. van den Hove.

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Marisela Martinez-Claros: **Hippocampal plasticity and corticosterone: From dendrites to behaviour.** Supervisor: Prof.dr. H.W.M. Steinbusch; Co-Supervisors: Dr. J.L. Pawluski / Dr. J. Prickaerts.

- Marcus D. Lancé: **A circle of improvement in bleeding management: from laboratory to clinic and back.** Supervisors: Prof.dr. M.A.E. Marcu / Prof.dr. J.W.M. Heemskerk; Co-Supervisor: Dr. Y.M.C. Henskens.
- Hilde Braakman: **Imaging the brain; neuronal correlates of cognitive impairment in children with frontal lobe epilepsy.** Supervisors: Prof.dr. A.P. Aldenkamp / Prof.dr. J.S.H. Vles; Co-Supervisors: Dr.ir. W.H. Backes / Dr. P.A.M. Hofman.
- Willem H. van Zwam: **Aneurysmal subarachnoid hemorrhage: imaging strategies and cost-effectiveness aspects in diagnostic work-up and post-therapeutic follow-up.** Supervisors: Prof.dr. J.T. Wilmink / Prof.dr. J.E. Wildberger; Co-Supervisor: Dr. P.A.M. Hofman.
- Klara De Cort: **The Pathogenesis of Panic Disorder.** Supervisors: Prof.dr. I. Myin-Germeys / Prof.dr. E.J.L. Griez; Co-Supervisors: Dr. K.R.J. Schruers / Dr. I. Van Diest, Leuven.
- Kim van Wijck: **Mind the Gap; experimental studies on splanchnic hyperfusion and gastrointestinal integrity loss in man.** Supervisors: Prof.dr. W.A. Buurman / Prof.dr. C.H.C. Dejong; Co-Supervisor: Dr. K. Lenaerts.
- Yvette Roke: **Antipsychotic-induced hyperprolactinemia in children and adolescents with mainly autism spectrum disorders. Prevalence, symptoms, clinical consequences and genetic risk factors.** Supervisors: Prof.dr. P.N. van Harten / Prof.dr. J.K. Buitelaar (RUN); Co-Supervisor: Dr. A. Boot (UMCG).
- Fleur Goezinne: **Retinal detachment surgery: pre and postoperative prognostic factors.** Supervisors: Prof.dr. F. Hendrikse / Prof.dr. C.A.B. Webers; Co-Supervisor: Dr. E.C. La Heij (Amsterdam).
- Ralph L.J.G. Maassen: **The Merits of Videolaryngoscopy during Glottic Visualisation for Endotracheal Intubation.** Supervisors: Prof.dr. M. Marcus / Prof.dr. A. van Zundert (University of Queensland).
- Maria J. de Sousa Guerreiro: **The role of sensory modality in age-related distraction.** Supervisor: Prof.dr. C.M. van Heugten; Co-Supervisor: Dr. P.W.M. van Gerven.
- Ine Rayen: **Effects of developmental fluoxetine exposure on neurobehavioral outcomes.** Supervisor: Prof.dr. H.W.M. Steinbusch; Co-Supervisors: Dr. J.L. Pawluski / Dr. T.D. Charlier (Ohio University, USA).
- Nynke M.G. Bodde: **Psychogenic non-epileptic seizures; a separate disorder or**

part of a continuum? Supervisors: Prof.dr. R. van Oostenbrugge / Prof.dr. K. Vonck (UZ Gent); Co-Supervisors: Dr. R. Lazeron / Dr. A. de Louw (Epilepsiecentrum Kempenhaeghe, Heeze).

Alejandro M. Gomez: **Novel strategies for making myasthenia less gravis: targeting plasma cells and the neuromuscular junction.** Supervisor: Prof.dr. M.H. De Baets; Co-Supervisors: Dr. M. Losen / Dr. P. Martinez-Martinez.

Mohammad S. Rahnama'i: **Prostaglandins and Phosphodiesterases in the Urinary Bladder Wall.** Supervisors: Prof.dr. Ph. Van Kerrebroeck / Prof.dr. S. de Wachter (Universiteit Antwerpen); Co-Supervisor: Dr. G. van Koeveeringe.

Mariken B. de Koning: **Studying biomarkers in populations at genetic and clinical high risk for psychosis.** Supervisors: Prof.dr. T. Amelsvoort / Prof.dr. J. Booij (AMC).

Fabien Boule: **Epigenetic regulation of BDNF/TrkB signaling in the pathophysiology and treatment of mood disorders.** Supervisors: Prof.dr. H.W.M. Steinbusch / Prof.dr. L. Lanfumey (Universiteit Parijs); Co-Supervisors: Dr. D. van den Hove / Dr. G. Kenis.

2014

Iris Nowak-Maes: **Tinnitus; assessment of quality of life & cost-effectiveness.** Supervisors: Prof.dr. M. Peters / Prof.dr. B. Kremer; Co-Supervisors: Dr. M. Joore / Dr. L. Anteunis.

Marjolein Huijts: **Cognitive function in patients with cerebral small vessel disease.** Supervisor: Prof.dr. R.J. van Oostenbrugge; Co-Supervisors: Dr. A.A. Duits / Dr. J. Staals.

Markus Gantert: **Fetal inflammatory injury as origin of long term disease: Lessons from animal models.** Supervisors: Prof.dr. B. Kramer / Prof.dr. L. Zimmermann; Co-Supervisor: Dr. A. Gavilanes.

Elke Kuypers: **Fetal development after antenatal exposures: Chorioamnionitis and maternal glucocorticoids.** Supervisors: Prof.dr. B.W. Kramer / Prof.dr. H.W. Steinbusch / Prof.dr. Suhas G. Kallapur (University of Cincinnati, Ohio, USA).

Pieter Kubben: **Ultra low-field strength intraoperative MRI for Glioblastoma Surgery.** Supervisor: Prof.dr. J.J. van Overbeeke; Co-Supervisor: Dr. H. van Santbrink.

- Laura Baijens: **Surface electrical stimulation of the neck for oropharyngeal dysphagia in Parkinson's disease: therapeutic aspects and reliability of measurement.** Supervisor: Prof.dr. B. Kremer; Co-Supervisor: Dr. R. Speyer, Townsville.
- Janneke Hoeijmakers: **Small fiber neuropathy and sodium channels; a paradigm shift.** Supervisor: Prof.dr. R.J. van Oostenbrugge; Co-Supervisors: Dr. C.G. Faber / Dr. I.S.J. Merkies.
- Stephanie Vos: **The Role of biomarkers in preclinical and prodromal Alzheimer's disease.** Supervisor: Prof.dr. F.R. Verhey; Co-Supervisor: Dr. P.J. Visser.
- Muriël Doors: **The Value of Optical Coherence Tomography in Anterior Segment Surgery.** Supervisors: Prof.dr. R.M. Nuijts / Prof.dr. C.A. Webers; Co-Supervisor: Dr. T.T.J.M. Berendschot.
- Anneke Maas: **Sleep problems in individuals with genetic disorders associated with intellectual disability.** Supervisors: Prof.dr. I. Curfs / Prof.dr. R. Didden.
- Sebastiaan van Gorp: **Translational research on spinal cord injury and cell-based therapies; a focus on pain and sensorimotor disturbances.** Supervisors: Prof.dr. B. Joosten / Prof.dr. M. van Kleef; Co-Supervisors: Dr. J. Patijn / Dr. R. Deumens, KU Leuven.
- Andrea Sannia: **High risk newborns and brain biochemical monitoring.** Supervisor: Prof.dr. J.S.H. Vles; Co-Supervisors: Dr. D. Gazzolo, Alessandria, Italy / Dr. A.W.D. Gavilanes.
- Julie A.D.A. Dela Cruz: **Dopamine mechanisms in learning and memory: Evidence from rodent studies.** Supervisors: Prof.dr. H.W.M. Steinbusch / Prof.dr. R.J. Bodnar, New York; Co-Supervisor: Dr. B.P.F. Rutten.
- René Besseling: **Brain wiring and neuronal dynamics; advances in MR imaging of focal epilepsy.** Supervisors: Prof.dr. A.P. Aldenkamp / Prof.dr.ir. W.H. Backes; Co-Supervisor: dr. J.F.A. Jansen.
- Maria Quint-Fens: **Long-term care after stroke; development and evaluation of a long-term intervention in primary care.** Supervisors: Prof.dr. J.F.M. Metsemakers / Prof.dr. C.M. van Heugten / Prof.dr. M. Limburg, Almere; Co-Supervisor: dr. G.H.M.I. Beusmans.
- Veronique Moolaert: **Life after survival of a cardiac arrest; the heart of the matter.** Supervisors: Prof.dr. J.A. Verbunt / Prof.dr. C.M. van Heugten / Prof.dr. D.T. Wade, Oxford, UK.
- Feikje Smeets: **The hallucinatory-delusional state: a crucial connection in the**

- psychosis symptom network.** Supervisor: Prof.dr. J. van Os; Co-Supervisor: Dr. T. Lataster.
- Lies Clerx: **Alzheimer's disease through the MR-eye; novel diagnostic markers and the road to clinical implementation".** Supervisor: Prof.dr. F. Verhey; Co-Supervisors: Dr. P.J. Visser / P. Aalten.
- Sonny Tan: **The subthalamic nucleus in Parkinson's disease.** Supervisors: Prof.dr. Y. Temel / Prof.dr. H.W.M. Steinbusch / Prof.dr. T. Sharp, Oxford, UK / Prof.dr. V. Visser-Vandewalle, Koln.
- Koen van Boxem: **The use of pulsed radiofrequency in the management of chronic lumbosacral radicular pain.** Supervisors: Prof.dr. M. van Kleef / Prof.dr. E.A.J. Joosten; Co-Supervisor: Assoc. Prof.dr. J. van Zundert.
- Jérôme Waterval: **Hyperostosis cranialis interna.** Supervisors: Prof.dr. J.J. Manni / Prof.dr. R.J. Stokroos.
- Sylvie Kolfschoten-van der Kruijs: **Psychogenic non-epileptic seizures; the identification of neurophysiological correlates.** Supervisors: Prof.dr. A.P. Aldenkamp / Prof.dr. K.E.J. Vonck, Universiteit Gent; Co-Supervisors: Dr. J.F.A. Jansen / Dr. R.H.C. Lazeron, Kempenhaeghe.
- Wouter Pluijms: **Spinal cord stimulation and pain relief in painful diabetic: polyneuropathy, a translational approach.** Supervisors: Prof.dr. M. van Kleef / Prof.dr. E.A. Joosten; Co-supervisor: Dr. C.G. Faber.
- Ron Handels: **Health technology assessment of diagnostic strategies for Alzheimer's disease.** Supervisors: Prof.dr. F.R.J. Verhey / Prof.dr. J.L. Severens (EUR); Co-Supervisor: Dr. M.A. Joore / Dr. C.A.G. Wolfs.
- Evelyn Peelen: **Regulatory T cells in the pathogenesis of Multiple Sclerosis: potential targets for vitamin D therapy.** Supervisors: Prof.dr. R.M.M. Hupperts / Prof.dr. J.W. Cohen Tervaert; Co-Supervisor: Dr. J.G.M.C. Damoiseaux / Dr. M.M.G.L. Thewissen, Diepenbeek.
- Reint Jellema: **Cell-based therapy for hypoxic-ischemic injury in the preterm brain.** Supervisors: Prof.dr. B.W.W. Kramer / Prof.dr. H.W.M. Steinbusch; Co-Supervisor: Dr. W.T.V. Germeraad / Dr. P. Andriessen, Veldhoven.
- Maria Wertli: **Prognosis of Chronic Clinical Pain Conditions: The Example of Complex Regional Pain Syndrome 1 and Low Back Pain.** Supervisors: Prof.dr. M. van Kleef; Co-Supervisor: Dr. F. Brunner, Zürich / Dr. R. Perez, VUmc.
- Dagmar Zeef: **An experimental model of Huntington's disease: Validation &**

- Stimulation.** Supervisors: Prof.dr. Y. Temel / Prof.dr. H.W.M. Steinbusch; Co-supervisor: Dr. A. Jahanshahi.
- Jeroen Decoster: **Breaking Down Schizophrenia into phenes, genes and environment.** Supervisors: Prof.dr. I. Myin-Germeys / Prof.dr. M. De Hert, KU Leuven; Co-Supervisor: Dr. R. van Winkel.
- Eaja Anindya Sekhar Mukherjee: **Fetal Alcohol Spectrum Disorders: exploring prevention and management.** Supervisor: Prof.dr. L.M.G. Curfs; Co-Supervisor: Prof. S. Hollins, St. George's University of London, UK.
- Catherine van Zelst: **Inside out; On stereotype awareness, childhood trauma and stigma in psychosis.** Supervisors: Prof.dr. Ph. Delespaul / Prof.dr. J. van Os.
- Ibrahim Tolga Binbay: **Extended Psychosis Phenotype in the Wider Social Environment.** Supervisor: Prof.dr. J. van Os; Co-Supervisor: Dr. M. Drukker.
- Frank Van Dael: **OCD matters in psychosis.** Supervisors: Prof.dr. J. van Os / Prof.dr. I. Myin-Germeys.
- Pamela Kleikers: **NOXious oxidative stress: from head toe too and back.** Supervisors: Prof.dr. H.H.H.W. Schmidt / Prof.dr. H.W.M. Steinbusch; Co-Supervisor: Dr. B. Janssen.
- José Luis Gerardo Nava: **In vitro assay systems in the development of therapeutic interventions strategies for neuroprotection and repair.** Supervisors: Prof.dr.med. J. Weis / Prof.dr. H.W.M. Steinbusch; Co-Supervisor: Dr. G.A. Brook, RWTH Aachen.
- Eva Bollen: **Cyclic nucleotide signaling and plasticity.** Supervisors: Prof.dr. H.W.M. Steinbusch / Prof.dr. R. D'Hooze, KU Leuven; Co-Supervisor: Dr. J. Prickaerts.

2015

- Jessica A. Hartmann: **A good laugh and a long sleep; Insights from prospective and ambulatory assessments about the importance of positive affect and sleep in mental health.** Supervisor: Prof.dr. J. van Os; Co-Supervisors: C.J.P. Simons / Dr. M. Wichers.
- Bart Ament: **Frailty in old age; conceptualization and care innovations.** Supervisors: Prof.dr. G.I.J.M. Kempen / Prof.dr. F.R.J. Verhey; Co-Supervisor: Dr. M.E. de Vugt.
- Mayke Janssens: **Exploring course and outcome across the psychosis-continuum.** Supervisor: Prof.dr. I. Myin-Germeys; Co-Supervisor: Dr. T.

Lataster

Dennis M.J. Hernau: **Dopayours is not dopamine: genetic, environmental and pathological variations in dopaminergic stress processing.** Supervisor:

Prof.dr. I. Myin-Germeys; Co-Supervisors: Prof.dr. F.M. Mottaghy / Dr. D. Collip.

Ingrid M.H. Brands: **The adaptation process after acquired brain injury Pieces of the puzzle.** Supervisors: Prof.dr. C.M. van Heugten / Prof.dr. D.T. Wade,

Oxford UK; Co-Supervisors: Dr. S.Z. Stapert / Dr. S. Köhler.

Francesco Riso: **Urinary and salivary S100B monitoring in high risk infants.**

Supervisor: Prof.dr. J.S.H. Vles; Co-Supervisors: Dr. D. Gazzolo, Genoa, Italy / Dr. A.W.D. Gavilanes.

Alessandro Borghesi: **Stem and Progenitor Cells in Preterm Infants: Role in the Pathogenesis and Potential for Therapy.** Supervisor: Prof.dr. L.

Zimmermann; Prof.dr. B. Kramer; Co-Supervisors: Dr. D. Gazzolo, Genoa, Italy / Dr. A.W.D. Gavilanes.

Claudia Menne-Lothmann: **Affect dynamics; A focus on genes, stress, and an opportunity for change.** Supervisor: Prof.dr. J. van Os; Co-Supervisors: Dr. M.

Wichers / Dr. N. Jacobs.

Martine van Nierop: **Surviving childhood new perspectives on the link between childhood trauma and psychosis.** Supervisors: Prof.dr. I. Myin-Germeys /

Prof.dr. J. van Os; Co-Supervisor: Dr. R. van Winkel.

Sylvia Klinkenberg: **VNS in children; more than just seizure reduction.**

Supervisors: Prof.dr. J. Vles / Prof.dr. A. Aldenkamp; Co-Supervisor: Dr. H. Majoie.

Anouk Linssen: **Considerations in designing an adult hearing screening programme.** Supervisor: Prof.dr. B. Kremer; Co-Supervisors: Dr. L. Anteunis /

Dr. M. Joore.

Janny Hof: **Hearing loss in young children; challenges in assessment and intervention.** Supervisors: Prof.dr. B. Kremer / Prof.dr. R. Stokroos / Prof.dr. P.

van Dijk, RUG;

Co-Supervisor: Dr. L. Antheunis.

Kimberly Cox-Limpens: **Mechanisms of endogenous brain protection; Clues from the transcriptome.** Supervisors: Prof.dr. J. Vles / Prof.dr. L.

Zimmermann; Co-Supervisor:

Dr. A. Gavilanes.

Els Vanhoutte: **Peripheral Neuropathy outcome measures; Standardisation**

- (PeriNomS) study part 2: Getting consensus.** Supervisors: Prof.dr. C. Faber / Prof.dr. P. van Doorn;
Co-Supervisor: Dr. I. Merkies, Spaarne ziekenhuis Hoofddorp.
- Mayienne Bakkers: **Small fibers, big troubles; diagnosis and implications of small fiber neuropathy.** Supervisors: Prof.dr. C. Faber / Prof.dr. M. de Baets;
Co-Supervisor: Dr. I. Merkies, Spaarne ziekenhuis Hoofddorp.
- Ingrid Kramer: **Zooming into the micro-level of experience: An approach for understanding and treating psychopathology.** Supervisor: Prof.dr. J. van Os; Co-Supervisors: Dr. M. Wichers, UMC Groningen / Dr. C. Simons.
- Esther Bouman: **Risks and Benefits of Regional Anesthesia in the Perioperative Setting.** Supervisors: Prof.dr. M. van Kleef / Prof.dr. M. Marcus, HMC, Qatar / Prof.dr. E. Joosten; Co-Supervisor: Dr. H. Gramke.
- Mark Janssen: **Selective stimulation of the subthalamic nucleus in Parkinson's disease; dream or near future.** Supervisors: Prof.dr. Y. Temel / Prof.dr. V. Visser-Vandewalle, Keulen / Prof.dr. A. Benazzouz, Bordeaux, France.
- Reina de Kinderen: **Health Technology Assessment in Epilepsy; economic evaluations and preference studies.** Supervisors: Prof.dr. S. Evers / Prof.dr. A. Aldenkamp; Co-Supervisor: Dr. H. Majoie / Dr. D. Postular, GGZ O-Brabant.
- Saskia Ebus: **Interictal epileptiform activity as a marker for clinical outcome.** Supervisors: Prof.dr. A. Aldenkamp / Prof.dr. J. Arends, TUE / Prof.dr. P. Boon, Universiteit Gent, België.
- Inge Knuts: **Experimental and clinical studies into determinants of panic severity.** Supervisor: Prof.dr. I. Myin-Germeys; Co-Supervisor: Dr. K. Schruers; Influencing panic.
- Nienke Tielemans: **Proactive coping post stroke: The Restored4Stroke Self-Management study.** Supervisors: Prof.dr. C. van Heugten / Prof.dr. J. Visser-Meily, UMC Utrecht;
Co-Supervisor: Dr. V. Schepers, UMC Utrecht.
- Tom van Zundert: **Improvements Towards Safer Extraglottic Airway Devices.** Supervisors: Prof.dr. A.E.M. Marcus / Prof.dr. W. Buhre / Prof.dr. J.R. Brimacombe, Queensland, Australia / Prof.dr. C.A. Hagberg.
- Tijmen van Assen: **Anterior Cutaneous Nerve Entrapment Syndrome Epidemiology and surgical management.** Supervisors: Prof.dr. G.L. Beets / Prof.dr. M. van Kleef / Dr. R.M.H. Roumen / Dr. M.R.M. Scheltinga, MMC Veldhoven.

- Rohit Shetty: **Understanding the Clinical, Immunological and Genetic Molecular Mechanisms of Keratoconus**. Supervisors: Prof.dr. R.M.M.A. Nuijts / Prof.dr. C.A.B. Webers.
- Christine van der Leeuw: **Blood, bones and brains; peripheral biological endophenotypes and their structural cerebral correlates in psychotic disorder**. Supervisor: Prof.dr. J. van Os; Co-supervisor: Dr. M. Marcelis.
- Sanne Peeters: **The Idle Mind Never Rests; functional brain connectivity across the psychosis continuum**. Supervisor: Prof.dr. J. van Os; Co-supervisor: dr. M. Marcelis.
- Nick van Goethem: **$\alpha 7$ nicotinic acetylcholine receptors and memory processes: mechanistic and behavioral studies**. Supervisor: Prof.dr. H.W.M. Steinbusch; Co-supervisor: Dr. J. Prickaerts.
- Nicole Leibold: **A Breath of fear; a translational approach into the mechanisms of panic**. Supervisor: Prof.dr. H.W.M. Steinbusch; Co-supervisors: Dr. K.R.J. Schruers / Dr. D.L.A. van den Hove.
- Renske Hamel: **The course of mild cognitive impairment and the role of comorbidity**. Supervisor: Prof.dr. F.R.J. Verhey; Co-supervisors: Dr. I.H.G.B. Ramakers / Dr. P.J. Visser.
- Lucia Speth: **Effects of botulinum toxin A injections and bimanual task-oriented therapy on hand functions and bimanual activities in unilateral Cerebral Palsy**. Supervisors: Prof.dr. J. Vles; Prof.dr. R. Smeets; Co-supervisor: Dr. Y. Janssen-Potten, Adelante Hoensbroek.
- Yuan Tian: **The effects of Lutein on the inflammatory pathways in age-related macular degeneration (AMD)**. Supervisors: Prof.dr. C. Webers; Prof.dr. A. Kijlstra, WUR; Co-supervisor: Dr. M. Spreeuwenberg; Dr. H. Tange.
- Peggy Spauwen: **Cognition and Type 2 diabetes; the interplay of risk factors**. Supervisors: Prof.dr. F. Verhey; Prof.dr. C. Stehouwer; Co-supervisor: Dr. M. van Boxtel
- Marc Hilhorst: **Crescentic glomerulonephritis in ANCA associated vasculitis**. Supervisors: Prof.dr. J. Cohen-Tervaert; Co-supervisor: Dr. P. van Paassen
- Martin Gevonden: **The odd one out: exploring the nature of the association between minority status and psychosis**. Supervisors: Prof.dr. J-P. Selten; Prof.dr. J. Booij, Uva; Prof.dr. I. Myin-Germeys
- Bart Biallostorski: **Structural and functional aspects of sensory-motor Interaction in the urinary bladder**. Supervisors: Prof.dr. Ph. Van Kerrebroeck; Prof.dr. S.

- De Wachter, UvAntwerpen; Co-supervisors: Dr. G. van Koeveringe; Dr. M. Rahnama'i.
- Alexandra König: **The use of information and communication technologies (ICT) for the assessment of patients with Alzheimer's Disease and related disorders.** Supervisors: prof.dr. F. Verhey; prof.dr. Ph. Robert, Nice, Fr; Co-supervisors: dr. P. Aalten; dr. R. David, Nice. Fr.
- Micheline Chenault: **Assessing Readiness for Hearing Rehabilitation.** Supervisors: prof.dr. M.P.F. Berger; prof.dr. B. Kremer; Co-supervisor: dr. L.J.C. Anteunis.
- Anand Vinekar: **Retinopathy of Prematurity. Recent advances in tele-medicine screening, risk factors and spectral domain optical coherence tomography imaging.** Supervisor: prof.dr. C.A.B. Webers; Co-supervisor: dr. N.J. Bauer
- Fleur van Dooren: **Diabetes and Depression: exploring the Interface between Pathophysiological and Psychological factors.** Supervisors: prof.dr. F.R.J. Verhey; prof.dr. J.K.L. Denollet, UvT; prof.dr. F. Pouwer, UvT; Co-supervisor: dr. M.T. Schram.
- Gabriëlla Pons van Dijk: **Taekwondo and physical fitness components in middle-aged healthy volunteers; the Sekwondo study.** Supervisors: prof.dr. J. Lodder; prof.dr. H. Kingma; Co-supervisor: dr. A.F. Lenssen.
- Yara Pujol López: **Development and psychoneuroimmunological mechanisms in depression.** Supervisor: prof.dr. H.W.M. Steinbusch; Co-supervisors: Dr. G. Kenis; Dr. D. van den Hove; Dr. Aye Mu Myint, München.
- Romina Gentier: **UBB⁺¹; an important switch in the onset of Alzheimer's disease.** Supervisors: Prof. H. Steinbusch; Prof. D. Hopkins; Co-supervisor: Dr. F. van Leeuwen.
- Sanne Smeets: **Insights into insight: studies on awareness of deficits after acquired brain injury.** Supervisor: Prof. C. van Heugten; Prof. R. Ponds; Co-supervisor: Dr. I. Winkens
- Kim Beerhorst: **Bone disease in chronic epilepsy: fit for a fracture.** Supervisor: Prof. A. Aldenkamp; Prof. R. van Oostenbrugge; Co-supervisor: Dr. P. Verschuure.
- Alex Zwanenburg: **Cerebral and cardiac signal monitoring in fetal sheep with hypoxic-ischemic encephalopathy.** Supervisor: Prof. T. Delhaas; Prof. B. Kramer; Co-supervisors: Dr. T. Wolfs; Dr. P. Andriessen, MMC.

Ismail Sinan Guloksuz: **Biological mechanisms of environmental stressors in psychiatry.** Supervisor: Prof. J. van Os; Co-supervisors: Dr. B. Rutten; Dr. M. Drukker.

Seyed Ehsan Pishva MD: **Environmental Epigenetics in mental health and illness.** Supervisor: Prof.dr. J. van Os; Co-supervisors: Dr. B.P.F. Rutten; Dr. G. Kenis.

Ankie Hamaekers: **Rescue ventilation using expiratory ventilation assistance; innovating while clutching at straws.** Supervisors: Prof.dr. W.F. Buhre; Prof.dr. M. van Kleef.

Rens Evers. **22q11.2 deletion syndrome: intelligence, psychopathology and neurochemistry at adult age.** Supervisors: Prof.dr. L.M.G. Curfs; Prof.dr. T. v. Amelsvoort.

Sarah-Anna Heschem. **Novel insights towards memory restoration.** Supervisor: Prof.dr.

Y. Temel; Co-supervisor: Dr. A. Blokland; Dr. A. Jahanshahi.

João P. da Costa Alvares Viegas Nunes. **Insulin receptor sensitization improves affective pathology in various mouse models.** Supervisor: Prof.dr. H.W.M. Steinbusch; Co-supervisors: Dr. K-P. Lesch; Dr. T. Strekalova; Dr.B.H. Cline, Oxford.

Yanny Ying-Yee Cheng. **Clinical Outcomes After Innovative Lamellar Corneal Transplantation Surgery.** Supervisor: Prof.dr. R.M.M.A. Nuijts; Co-supervisor: Dr. J.S.A.G. Schouten.

2016

Oliver Gerlach. **Parkinson's disease, deterioration during hospitalization.** Supervisor: Prof.dr. R. van Oostenbrugge; Co-supervisor: Dr. W. Weber.

Remo Arts. **Intracochlear electrical stimulation to suppress tinnitus.**

Supervisor: Prof.dr. R.J. Stokroos; Co-supervisor: Dr. E.L.J. Georg.

Mitchel van Eeden. **The €- Restore4stroke study: Economic evaluation of stroke care in the Netherlands.** Supervisors: Prof.dr.mr. S.M.A.A. Evers; Prof.dr. C.M. v. Heugten; Co-supervisor: dr. G.A.P. van Mastrigt.

Pim Klarenbeek. **Blood pressure and cerebral small vessel disease.** Supervisor: Prof.dr. R.J. van Oostenbrugge; Co-supervisor: Dr. J. Staals.

- Ramona Hohnen. **Peripheral pharmacological targets to modify bladder contractility.** Supervisor: Prof.dr. Ph.E.V. van Kerrebroeck; Co-supervisors: Dr. G.A. van Koeveringe; Dr. M.A. Sahnama'i; Dr. C. Meriaux.
- Ersoy Kocabicak. **Deep brain stimulation of the subthalamic nucleus: Clinical and scientific aspects.** Supervisors: Prof.dr. Y. Temel; Prof.dr. K. van Overbeeke; Co-supervisor: Dr. A. Jahanshahi.
- Sven Akkerman. **Temporal aspects of cyclic messenger signaling in object recognition memory; a pharmacological approach.** Supervisor: Prof.dr. H.W.M. Steinbusch; Co-supervisors: dr. J. Prickaerts; dr. A. Blokland.
- Anja Moonen. **Emotion and Cognition in Parkinson's disease; etiology and neurobiological mechanisms.** Supervisor: Prof.dr. F.R.J. Verhey; Co-supervisor: dr. A.F.G. Leentjens.
- Anna Schüth. **Three-dimensional bladder tissue morphology.** Supervisors: Prof.dr. G.A. van Koeveringe; Prof.dr. M. v. Zandvoort, Aachen; Prof.dr. Ph. V. Kerrebroeck.
- Elisabeth van der Ven. **Ethnic minority position as risk indicator for autism-Spectrum and psychotic disorders.** Supervisors: Prof.dr. J.P. Selten; Prof.dr. J. van Os.
- Zuzana Kasanova. **Environmental reactivity for better or worse; The impact of stress and reward on neurochemistry, affect and behavior across the psychosis continuum.** Supervisor: Prof.dr. I. Myin-Germeys, KU Leuven/UM; Co supervisor: dr. D. Collip.