TAKING CARE TOGETHER

Nurses' self-management support in dementia care

Judith Huis in het Veld

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The research presented in this thesis was conducted at:
The Netherlands Institute for Health Services Research (Nivel), Utrecht, the Netherlands
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TAKING CARE TOGETHER

Nurses' self-management support in dementia care

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door

Judith Gerriët Huis in het Veld

geboren te Sassenheim

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CONTENTS

CHAPTER 1

General introduction

LIVING WITH DEMENTIA AT HOME

Living with dementia is generally a major challenge for both clients and informal caregivers. Dementia is defined as “a syndrome – usually of a chronic or progressive nature – in which there is deterioration in cognitive function (i.e. the ability to process thought) beyond what might be expected from normal ageing” [1]. During the course of the condition, people with dementia face a range of complex challenges caused by the condition that affect their cognitive, physical, and psychological health. Managing these challenges in daily life is not straightforward and over time dementia leads in most cases to greater disability and dependency on informal caregivers. Informal care is provided across all stages of dementia [2], with most of the care being undertaken at home [3, 4]. Informal caregivers (also referred to as family caregivers in this thesis) play a significant role in providing "hands-on" care for the person with dementia or in organizing care delivered by others, sometimes from a distance [1, 5]. This care provided at home will be increasingly important as the prevalence of dementia will rise markedly in the coming decades [6, 7] while numbers of healthcare professionals are not expected to increase [2]. Today, there are approximately 270,000 people in the Netherlands with dementia and 300,000 people who care for a person with dementia at home [8]. It is important that both people living at home with dementia and their informal caregivers have opportunities to manage the consequences of dementia in their daily lives, with an optimum quality of life, despite the circumstances and challenges faced.

SELF-MANAGEMENT IN PEOPLE WITH DEMENTIA AND INFORMAL CAREGIVERS

‘Self-management’ refers to “individuals’ ability to manage with symptoms, treatment, physical and psychosocial consequences, and lifestyle inherent in living with a chronic condition” [9, 10]. The concept of self-management emerged together with growing complexity of healthcare and the needs of people facing the physical, psychological, and social demands of living with a chronic disease [11]. Ongoing self-management tasks are required by patients and informal caregivers to overcome the consequences of the disease in daily life [11]. Taking ownership in managing life and health issues is encouraged by current Dutch policy [12], and patients and their families often also want to choose and decide for themselves how to deal with a chronic disease in daily life [13].

The tasks that patients and families face are listed by Corbin and Strauss [14] as types of ‘work’ involved in managing and living with a chronic illness in daily life including illness work, every day work, and biographical work. Illness work refers to managing medical aspects of the disease. Everyday life work refers to dealing with a condition in daily life. Biographical work concerns such aspects as managing the emotions that emerge from dealing with a chronic disease [11]. These three types of work encompass physical, psychological, social, spiritual, and existential aspects that reflect a holistic picture of self-management [15] that applies to both the person with dementia and their informal caregivers in order to live as well as possible.

Specifically for people with dementia, Martin et al. [16] and Mountain [17], [18] conceptualized self-management as covering five targets: 1) maintaining the relationship with family, 2) maintaining an active lifestyle, 3) pursuing and maintaining psychological wellbeing, 4) coping with memory changes, and 5) information about dementia [16]. These targets are related to the 'work' of managing and living with a chronic diseases as described by Corbin and Strauss [14].

For people with dementia, self-management often involves their informal caregivers [19]. The nature of the condition means that the ability to carry out self-management tasks deteriorates strongly in the person with dementia. Accordingly, self-management in terms of the types of "work" shifts increasingly towards informal caregivers [4, 14]. This often leads to a significant burden for informal caregivers [4, 20], not only in relation to their physical health, but also on their emotional and social functioning. Informal caregivers need to provide assistance to the person with dementia but also have to deal with the consequences of dementia in their lives. Many informal caregivers are elderly and facing diseases or disabilities themselves [21]. This makes it extra challenging for them to deal with the consequences in their daily lives of the dementia of their relative.

BEHAVIORAL AND MOOD CHANGES

One of the most challenging aspects of caring for people with dementia is changes in behavior and mood [2, 22], such as depression, apathy, agitation, aggression and night-time disturbance. Nearly all people with dementia experience behavioral and mood changes in the course of their disease [22-24]. Development of these changes in dementia can be explained by a complex interplay of physical, psychological and social aspects, including caregiver factors [25, 26]. Lawlor [26] described how social and environmental factors, such as informal caregiver distress and poor interpersonal interactions, can trigger these behavioral changes. These environmental factors should therefore be supportive in order to prevent challenging behaviors or further escalation thereof [27]. However, it is not so easy for informal caregivers to create such supportive environments at home. Many informal caregivers do not know how to respond to behavioral changes and become increasingly distressed when faced with these changes over a long period of time [28, 29]. This leads to an increased risk of poor quality of life, a negative impact on the marital relationship [30], and it is eventually a common cause of nursing home admission [20, 31]. Not surprisingly, the needs of informal caregivers for support – additional professional support – most often concerns advice about how to deal with behavior problems in the person with dementia [32].

INTERVENTIONS TO SUPPORT PEOPLE IN SELF-MANAGEMENT

Supporting people in their decisions and actions that promote self-management is called self-management support [33]. Self-management support interventions should aim to equip people (in our case both patients with dementia and their informal caregivers) with the skills to actively participate and take responsibility in the management of the consequences of the chronic condition [34]. This can be achieved by encouraging people to acquire self-management skills that will let them identify their problems, take appropriate actions, and make choices about the care they need as they encounter changes in their circumstances or the disease [11, 35]. In optimal self-management support, healthcare professionals, the patient, and their informal caregiver(s) work together as partners in managing the consequences of the disease in daily life adequately. In this partnership, they are all experts from their individual perspectives, in which the perceived problems and concerns of patients and their informal caregivers are the basis for care [36]. Healthcare professionals are experts in healthcare and diseases, and patients and informal caregivers are experts about their own lives and needs [35]. This makes self-management support an essential part of personalized care, focusing on a satisfactory quality of life with a chronic condition rather than managing the disease itself.

Nurses in particular are considered to be eminently suited for supporting patients and informal caregivers in their self-management [37-39]. Nurses are well-positioned as they often have an intensive partnership with patients and families, provide education and foster the motivation to engage in self-management of their health [37, 38].

That does not mean, however, that supporting self-management of patients and family is a natural task for every nurse [37]. Self-management and self-management support are part of the changing views of healthcare provision [40]. Unlike their traditional caring role with a focus on relieving caring tasks, nurses now have to take on a supportive role where patients and informal caregivers are taught problem-solving skills and are being supported in managing their problems [35]. Self-management support is a key feature of the nursing profession, and it is therefore important that nurses have the knowledge and skills to provide self-management support, including a focus on dealing with the somatic, psychological, social, and existential consequences of living with a disease [41, 42].

ONLINE INTERVENTIONS TO SUPPORT PEOPLE IN SELF-MANAGEMENT

Self-management support can also be delivered in the form of online interventions (in this thesis often referred to as ''eHealth"). Inspired by a well-known definition from Eysenbach [43], eHealth is defined as dementia-related information and/or support delivered or enhanced through the Internet or related technologies. Previous research has shown promising results from online interventions on people with dementia and their caregivers [44, 45]. For example, Boots et al. [45] found beneficial effects of online multicomponent programs that combined information, tailored caregiving strategies, and contact with other caregivers on informal caregivers' confidence, stress, depression, and self-efficacy. Martinez-Alcala et al. [44] identified the opportunities that eHealth offers to patients with dementia and their families, such as easy information exchange, counseling, education, and psychological support [44]. In this regard, Martinez-Alcala et al. [44] stressed that it is necessary to specifically give attention to the online support of informal caregivers, as people with dementia increasingly become dependent from them. Online interventions can help informal caregivers understand the process of dementia and manage situations in a way that is beneficial for both [44]. Boots et al. [45] adds to this that online interactions (for example e-mail contacts with a professional) may increase informal caregivers' confidence in using the strategies learned [45, 46]. Other studies also found tailored online contacts useful because the responses came in good time, and there was an opportunity to reach immobile informal caregivers [47, 48]. As eHealth is often seen as an efficient way to provide support to growing target groups, figuring out how online self-management support can be offered to informal caregivers of people with dementia is relevant.

AIMS, RESEARCH QUESTIONS AND OUTLINE OF THE THESIS

Summarizing the background of this thesis: self-management activities of people with dementia and their informal caregivers should be supported in order to help them deal with the consequences of dementia in daily life. Insight is needed into how self-management can be supported and what the effects are of online and other self-management support. Nurses are well-positioned to provide self-management support. The overall aim of this thesis is therefore **to investigate how nurses can effectively contribute to self-management of people with dementia and their informal caregivers.**

In the various chapters of this thesis, several research questions related to this overall aim are addressed, namely:

1. What scientific evidence is there for the effectiveness of various types of professional self-management support interventions for (a) people with dementia, and (b) informal caregivers of people with dementia?

   This research question is addressed in **chapters 2 and 3** by presenting two systematic meta-reviews.

2. What are the opinions and experiences of nursing staff working in home care or residential elderly care regarding self-management support for people with dementia and their family caregivers?

   This question is addressed in **chapter 4**, based on a survey among nursing staff.

3. What are (a) the self-management strategies and (b) the self-management support needs of informal caregivers when managing behavioral and mood changes of their relative with dementia?

   Chapters 5 and 6 address this question, using data from online focus groups with family caregivers of people with dementia.

4. Does an online self-management support intervention consisting of personal e-mail contacts with a specialized dementia nurse have an effect and does it get positive evaluations compared with online interventions without personal e-mail contacts?

   This last question is addressed in **chapters 7, 8, and 9**, presenting a randomized controlled study and a parallel process evaluation.

   Finally, **chapter 10** covers reflections on the answers to the main research questions, as well as on implications for practice and recommendations for future research.

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CHAPTER 2

A systematic meta-review of self-management support for people with dementia

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Dementia, 2018. 0(0): p.1-17

ABSTRACT

Self-management support for people with dementia is important to help them and their family caregivers to cope with challenges in daily live. Insight into the effects of self-management support interventions on people with dementia is however lacking, despite existing relevant systematic reviews. We therefore conducted a meta-review of relevant systematic reviews, following the PRISMA statement. Systematic literature searches were conducted in PubMed, CINAHL, the Cochrane Library, Embase and PsycINFO. The searches were done in December 2015, and all relevant references until then were taken into consideration. No conclusions about the effects of self-management support interventions on people with dementia could be drawn.

Recommendations for future research and practice include that self-management support interventions and effect measurements should be wider in scope than psychological well-being.

INTRODUCTION

Living with dementia presents a huge challenge both to the person with dementia themselves and to their family caregivers. Dementia leads to severe cognitive problems, changes in mood and behavior, and changes in the relationship with the partner and members of their social network [1, 2]. The care is often a considerable burden on persons directly involved, not just physically but also emotionally and because it affects their social lives [3, 4].

Self-management is therefore important both for the person with dementia and for their family caregivers in dealing with dementia and the consequences for their daily lives. Following the definition of Barlow *et al.* [5], we define self-management as *“the individual’s ability to manage symptoms, treatment, physical and psychological consequences and life style changes inherent in living with a chronic condition.”*

However, self-management is far from being a matter of course for people with dementia. They may need support with their self-management, for example, from health care professionals or in the form of eHealth, in the sense of dementia-related information and/or support through internet or related technologies. Yet up till now there has not been an overview of the effectiveness of the available interventions for self-management support in people with dementia, despite of existing relevant systematic reviews. We have therefore conducted a meta-review of these existing systematic reviews. However, it became clear during the analysis for the meta-review that it is too soon to draw conclusions on the effects of self-management interventions on people with dementia. Nevertheless, the meta-review gives some interesting insights into the kind of interventions being used and provides recommendations for future research and practice. This brief research paper presents the results of the meta-review.

METHODS

We conducted a meta-review, in the sense of a systematic literature study of existing relevant systematic reviews. We followed the PRISMA Statement for systematic reviews [6] wherever possible, as incorporated in a protocol drawn up in advance. The reviews had to deal with self-management support in dementia, in which the effects were measured at the individual patient level. Table 1 summarizes the specific inclusion criteria.

Search strategy and sources

Systematic literature searches were conducted in PubMed, CINAHL, the Cochrane Library, Embase and PsycINFO in December 2015. First, a sensitive search strategy was developed for PubMed/Medline. This was then adapted for use in the other databases. All publications up to December 2015 were taken into consideration, regardless of the publication language.

Study selection

A two-step procedure was used to identify references for inclusion. First, the titles and abstracts of the references that resulted from the database searches were checked to see whether they satisfied the inclusion criteria. One reviewer (JGH) screened all the references. The second reviewer (ALF) then independently screened a 10% random selection. The first reviewer proceeded individually if the level of agreement (Kappa) was ≥0.60. If enough information could not be obtained from the title and abstract, those references were taken to the next step of the selection process. In this second step, the full texts of the references selected in the first step (including the references with insufficient information in the title and abstract) were independently screened by the two reviewers. A third reviewer (RV) was consulted if the first and second reviewer did not agree.

Methodological assessment

After the second selection step (see before), the methodological quality of the reviews was determined with the Quality Assessment Checklist for Reviews developed by Oxman and Guyatt [7]. Reviews with a score of 2 or less were considered to be of “low quality” and were subsequently excluded.

Table 1 *Inclusion criteria for the meta-review*

Eligibility criteria
Types of study. Systematic reviews that met the following criteria: (a) the review included a description of search terms, (b) searches were conducted in Medline or PubMed and at least one other international scientific database, and (c) the review included effect studies (RCT, CCT, or quasi experimental designs).
Types of participant. People with dementia, or dyads of primary caregivers and people with dementia, living in the community.
Types of intervention. The systematic reviews had to focus on professional self-management support interventions. These interventions had to explicitly be geared to helping the person with dementia cope with the dementia and its effects on their day-to-day lives. Additionally, there had to be personal contact between the person with dementia and the health care professional. The review had to describe and analyze the effects of self-management support interventions, and to draw an overall conclusion about the interventions’ effectiveness. Cognitive training was not deemed a self-management support intervention.
Types of outcome measure. Only systematic reviews discussing effects on persons with dementia were included.

RESULTS

The flow chart in Figure 1 shows the number of studies assessed, excluded, and included at each stage of the selection process.

In the end, seven reviews were found that satisfied all the inclusion criteria [8-14]. One review was identified to have "major flaws," based on a quality score of 3.0 [9]. Three reviews received a quality score of 4.0 [14], 5.0 [8], or 6.0 [13] reflecting "minor flaws." Three reviews received a quality score of 7.0 indicating that they met all quality requirements of the Quality Assessment Checklist for Reviews [10-12]. Tables 2 and 3 show the key features of these seven reviews.

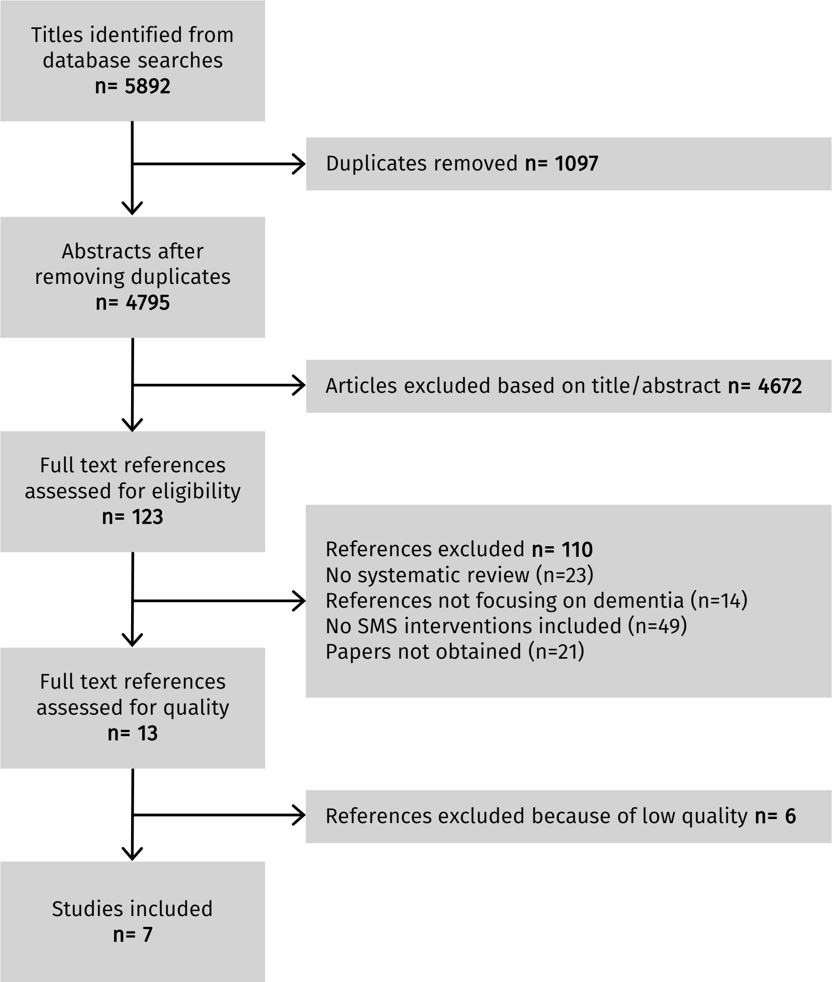

Figure 1 *Flow chart of the study selection.*

Table 2 *General and methodological characteristics of the reviews that were included*

The reviews that were included						Underlying studies in the reviews		
Reference, first author's country of origin	Review design	Review objective	Review's eligibility criteria	Information sources and search period	Score in methodological assessment	Number, design, and control conditions	Participants in underlying studies included in reviews	Number of sessions, intervention period, and professionals who delivered the self-management intervention
Cooper *et al.* (2012) United Kingdom	Systematic review	Give insight into the effectiveness of non-pharmacological interventions on quality of life or wellbeing of people with dementia.	Inclusion: • Primary research in people with dementia • Evaluating non-pharmacological interventions in randomized controlled trials (RCTs) • Which included quality of life or wellbeing as a quantitative outcome Exclusion: • studies not in English • single-case reports, dissertations, meeting abstracts, and studies that only used quality-of-life measure subscales, if reviewers judged that these did not measure overall quality of life.	PubMed, Web of Science, and Cochrane systematic reviews databases. Additional searches: searches of included papers and relevant systematic reviews. Asked experts in the field for papers meeting inclusion criteria. Search period: to January 2011.	**5**	20 studies included (20 RCTs). 3 studies included with self-management interventions including PwD (3 RCTs). Control conditions: usual care; waiting-list controls.	Dyads of persons with dementia and their informal caregivers.	Intervention duration ranged from 5 to 9 weeks Number of intervention sessions/modules ranged from 6 to 10 Professionals: occupational therapists; volunteer facilitators.
Corbett *et al.* (2012) United Kingdom	Systematic review with meta-analysis	To determine whether Dementia Adviser services confer significant benefit with respect to quality of life and neuropsychiatric symptoms in people with dementia and level of burden experienced by their carers.	Eligibility criteria: Only randomized controlled trials (RCT) were included in the review. Included studies were those focusing on a service intervention with information provision as a key service component and provided standardized outcome assessments for either people with dementia and their caregivers.	Cochrane, Embase, Medline and PsycInfo. Search period: Up to November 2009.	**3**	13 studies included (13 RCTs) 7 studies included with self-management interventions including PwD (7 RCTs).	Persons with dementia or their caregivers.	Reported intervention duration varied between 6 months and 3 years. Reported duration of sessions varied from 30 to 90 minutes. Professionals: not reported.

Table 2 *Continued*

The reviews that were included						Underlying studies in the reviews		
Reference, first author's country of origin	Review design	Review objective	Review's eligibility criteria	Information sources and search period	Score in methodological assessment	Number, design, and control conditions	Participants in underlying studies included in reviews	Number of sessions, intervention period, and professionals who delivered the self-management intervention
Orgeta *et al.* (2015) United Kingdom	Systematic review	To assess the effectiveness of psychological interventions in reducing anxiety and depression in people with dementia or mild cognitive impairment.	Inclusion criteria: Type of study: · randomized controlled trials including cluster randomized trials · including a control group · information about study design, results, and number of participants, · separate data on participants with dementia and MCI Participants: · diagnosed with dementia or MCI · any setting Type of intervention: · to reduce anxiety and depression or improve adaptive functioning or both · based on psychological theory · structured interaction between facilitator and participant · exclusion of treatments involving medication, exercise, reminiscence therapy, music therapy, art and drama therapy, befriending, or bibliotherapy. Type of outcome: · outcome measure of depression or anxiety.	The Cochrane Dementia and Cognitive Improvement Group (CDCIG) Specialized Register (including MEDLINE, EMBASE, CINAHL, PsychINFO, LILACS) Additional searches: reference lists of identified publications and all review papers. Contacted the corresponding authors of identified trials for additional references and unpublished data. Search period: to February 2013.	**7**	6 studies included (6 RCTs). 5 studies included with self-management interventions including PwD (5 RCTs). Control conditions: usual care; attention-control educational program.	Persons with dementia.	Intervention duration ranged from 6 weeks to 12 months. Intensity varied between 30-minute telephone calls, 60-minute therapeutic sessions and 90-minute group conversations or a combination of these provided weekly or biweekly. Professionals: social workers, psychotherapists, psychologists, master graduate students.

Table 2 *Continued*

The reviews that were included						Underlying studies in the reviews		
Reference, first author's country of origin	Review design	Review objective	Review's eligibility criteria	Information sources and search period	Score in methodological assessment	Number, design, and control conditions	Participants in underlying studies included in reviews	Number of sessions, intervention period, and professionals who delivered the self-management intervention
Reilly *et al.* (2015) United Kingdom	Systematic review with meta-analysis	To evaluate the effectiveness of case management approaches in home support for people with dementia from the perspective of the different people involved (patients, carers, and staff).	Inclusion criteria: Types of studies: randomized controlled trials (RCTs) and economic evaluations conducted alongside the RCTs. RCTs were sufficient in number and had enough participants to allow meta-analysis Types of participants: People with dementia of any type who live in the community and their carers. Studies that focused exclusively on carers were excluded. Types of interventions: Any case management intervention delivered in the community that predominantly focused on the planning and co-ordination of care required to meet the identified needs of the person with dementia. This may or may not have been part of multi-component interventions.	ALOIS, Specialized Register of the Cochrane Dementia and Cognitive Improvement Group, The Cochrane Library, MEDLINE, EMBASE, PsycINFO, CINAHL, LILACS, Web of Science (including Science Citation Index Expanded (SCI-EXPANDED) and Social Science Citation Index), Campbell Collaboration/SORO database and the Specialized Register of the Cochrane Effective Practice and Organization of Care Group. Search period: up to 31 December 2013.	**7**	13 studies included (13 RCTs). 13 studies included with self-management interventions including PwD (13 RCTs). Control conditions: Waiting list control; usual care; augmented usual care.	Persons with dementia.	Duration of the intervention ranged from four months to two years. Frequency of contacts with case managers ranged from one contact per month to two or more contacts per month. Professionals: registered nurses, district nurses, advanced practice nurses, social workers, occupational therapists and social workers, a psychiatrist, health care advisors without a professional qualification.
Spijker *et al.* (2008) The Netherlands	Systematic review with meta-analysis	To estimate the overall effectiveness of nonpharmacological support programs for caregivers and patients with dementia that are intended to delay institutionalization.	Inclusion criteria: · A study population of patients with dementia and their informal caregivers · Community-dwelling patients with dementia and informal caregivers · An outcome measure of institutionalization · A single-study design (not a review or a meta-analysis) · A controlled clinical study · A nonpharmacological study · A study written in English.	PubMed (including Medline), Web of Knowledge, and PsycInfo. Additional searches: searches of included papers. Search period: from 1990 to March 2006.	**7**	13 studies included (10 RCTs, 2 pretest/posttest, 1 quasi-experimental design). 13 studies included with self-management interventions including PwD. Control conditions: memory training for persons with dementia, respite care for caregivers; psychogeriatric day care; usual care; informal support upon request.	Dyads of persons with dementia and their informal caregivers.	Intervention duration ranged from 3 months to 8.5 years. Professionals: counselors, case managers, unknown.

Table 2 *Continued*

The reviews that were included						Underlying studies in the reviews		
Reference, first author's country of origin	Review design	Review objective	Review's eligibility criteria	Information sources and search period	Score in methodological assessment	Number, design, and control conditions	Participants in underlying studies included in reviews	Number of sessions, intervention period, and professionals who delivered the self-management intervention
Van 't Leven *et al.* (2013) The Netherlands	Systematic review	To study the effects of dyadic psychosocial interventions focused on community-dwelling people with dementia and their family caregivers, and the relationship of the effects with intervention components of the programs.	Inclusion criteria: Types of studies: • Randomized controlled trials Types of participants: • People with dementia (≥ 65 years) and their informal caregivers living in the community Types of interventions: Dyadic psychosocial interventions Combined interventions Involving face-to-face contact between a care professional, the person with dementia and the caregiver Targeting improvement of mental health or wellbeing Exclusion criteria: • The reviewers excluded RCTs involving respite interventions, and technological devices, as well as cost-effectiveness studies, studies among nursing-home residents, and integrated studies where results could not be related to a specific intervention or program • Excluded: pooled data from combination of intervention studies.	PsychInfo, Embase, Medline, Cinahl, Cochrane Library for systematic reviews. Additional searches: reference lists of identified systematic reviews. Search period: 1991 to January 2012.	**6**	23 studies included (23 RCTs). 16 studies included with self-management interventions including PwD. (16 RCTs).	Dyads of persons with dementia and their informal caregivers.	Intervention duration ranged from 5 weeks to 3 years. Duration of sessions varied from 30 minutes to 2 hours. Number of sessions varied from 5 to 75. Professionals: occupational therapists; multi-disciplinary teams; nurses; case managers; home care advisors; psychiatrists; primary care physicians; nurse practitioners; psychologists.
Zabalegui *et al.* (2014) Spain	Systematic review	To identify effective interventions which improve quality of care for people with dementia living at home.	Inclusion criteria: • randomized controlled trial design • articles in English published between 1990 and 2012 in peer review journals • interventions that addressed people with dementia living at home and their caregivers • PwD in the trial were older than 65 years. Exclusion criteria: • Articles that focused only on pharmacological treatment of dementia.	MEDLINE (PubMed), CINAHL, PsycINFO and ISI Web of Science. Search period: 1990 to 2012.	**4**	23 studies included (23 RCTs). 17 studies included with self-management interventions including PwD (17 RCTs).	Persons with dementia.	Intervention duration varied from 3 weeks to 2 years. Duration of sessions varied from 30 minutes to 3 hours. Number of sessions varied from 2 to 10. Professionals: not reported.

Table 3 *Outcome and effects of the reviews that were included.*

Outcome and effects of the reviews that were included					
Reference	Types of self-management support interventions	Outcome variables	Results of intervention as reported in review	Results for specific participant or intervention characteristics	Overall conclusions in relation to self-management interventions
Cooper *et al.* (2012) United Kingdom	Interventions for dyads of people with dementia living in the community. · combined interventions: programs containing activity and coping interventions · discussion groups.	· QoL	Combined interventions: In the two high-quality studies, quality of life was higher in the groups receiving the combined activity and coping intervention than in the comparison groups. Discussion groups: In the lower-quality study, there was conflicting evidence about whether a discussion-based group program for people with dementia and their family carers improved quality of life. There were no significant differences on the SF-36 or on the patient-rated quality of life scores between groups post-intervention.	No effects for participant and intervention characteristics were reported.	No specific conclusions were drawn in relation to the interventions in which self-management was supported.
Corbett *et al.* (2012) United Kingdom	Interventions for people with dementia or care givers of people with dementia living in the community. Combined intervention programs containing e.g.: · education on communications skills · caregiver coping skills · exercises and video for patient · caregiver handbook · education on behavior management · maintaining residual functional abilities	· Qol · Neuropsychiatric symptoms · Caregiver burden	The results cannot be related to the 7 self-management interventions including PwD.	No effects for participant and intervention characteristics were reported.	No specific conclusions in relation to the interventions in which the PwD was included can be drawn.
Orgeta *et al.* (2015) United Kingdom	Interventions for people with dementia living in the community: · Combined interventions: programs containing e.g. CBT, information, activity and coping interventions, and telephone support · Psychotherapy	· Depression · Anxiety · QoL · ADL · Neuropsychiatric symptoms · Cognition	· depression: improvement (remark: also a non-self-management study was included) · Anxiety: clinician-rated anxiety = improvement; self-rated anxiety = no effect · Patient self-rated QoL = no effect · Carer rated QoL = no effect · ADL = no effect · Neuropsychiatric symptoms = no effect · Cognition = no effect · Other: behavioral problems: not reported	No effects for participant and intervention characteristics were reported based on an analysis. The review did not identify any trials of psychological treatment aimed at people with MCI that met the inclusion criteria.	Self-management interventions delivered in the form of psychological treatments reduce depressive symptoms in people with dementia. No effects were found on any of the secondary outcomes, activities of daily living, self-rated and carer-rated patient quality of life (QoL), neuropsychiatric symptoms, cognition.

Table 3 *Continued*

Outcome and effects of the reviews that were included

Reference	Types of self-management support interventions	Outcome variables	Results of intervention as reported in review	Results for specific participant or intervention characteristics	Overall conclusions in relation to self-management interventions
Reilly *et al.* (2015) United Kingdom	Interventions for people with dementia living in the community. Combined intervention programs (case management) containing e.g.: · participant information and education · participant advocacy · medications review · financial assistance · emotional support · counseling · carer education	Primary: · Time to institutionalization · Number of institutionalizations · Number of hospital admissions · Mean number of days in nursing home / hospital · Number of deaths · Costs Secondary: · Behavioral measures: · Depression · QoL · ADL · Neuropsychiatric symptoms · Cognition	· Number of institutionalizations: improvements at follow-up at 6 and 12 months · Short nursing-home stays / hospital admissions: improvements at follow-up at 6 and 12 months · Costs: improvements at follow-up at 12 months · Use of services: increased use of services · Neuropsychiatric symptoms: improvements at follow-up at 18 months	No effects for participant and intervention characteristics were reported based on an analysis.	There is some evidence that self-management support delivered in the form of case management is beneficial in improving some outcomes at certain time points, in the person with dementia. There was some evidence from good-quality studies to suggest that admissions to care homes and overall healthcare costs are reduced in the medium term; however, the results at follow-up after longer intervals were uncertain. There was not enough evidence to clearly assess whether case management could delay institutionalization in care homes. There were uncertain results in patient depression, functional abilities and cognition.
Spijker *et al.* (2008) The Netherlands	Interventions for dyads of people with dementia living in the community. Combined intervention programs containing e.g.: · psychoeducation · CBT · respite care · environmental modifications · skills training/problem solving · case management · memory training	· The odds of institutionalization · Time to institutionalization	· Patients involved in experimental interventions were significantly less likely to be institutionalized than patients in control groups · The mean change in mean time to institutionalization from baseline to follow-up was significantly greater in patients involved in the experimental interventions than in the control groups	Effective support programs include counseling and personal assistance with problem solving, and they offer caregivers a choice of various support strategies and support services. The caregiver and the patient with dementia are actively involved in seeking solutions together and can try out and choose the support strategies or services that are best tailored to their individual needs.	Support programs can significantly decrease the odds of institutionalization and significantly increase the time to institutionalization.

Table 3 *Continued*

Outcome and effects of the reviews that were included					
Reference	Types of self-management support interventions	Outcome variables	Results of intervention as reported in review	Results for specific participant or intervention characteristics	Overall conclusions in relation to self-management interventions
van 't Leven (2013) The Netherlands	Interventions for dyads of people with dementia living in the community. Combined intervention programs containing e.g.: PwD: · information · ADL training · walking or exercise · environmental adaptations CG: · information · psycho-education · skills training · coping strategies	· Behavioral problems · Cognitive functioning · Mood · Independence in daily activities · Sleep · QoL	The results cannot be related to the 16 self-management interventions.	No effects for participant and intervention characteristics were reported.	No specific conclusions in relation to the interventions in which self-management was supported can be drawn.
Zabalegui *et al.* (2014) Spain	Interventions for people with dementia or dyads of people with dementia living in the community. Combined intervention programs containing e.g.: cognitive rehabilitation · physiotherapy · education · individual support · counseling · training · neurologist advice · support group · occupational therapy · CBT · respite care · psychoeducational interventions	· QoL	The results cannot be related to the 17 self-management interventions including PwD.	No effects for participant and intervention characteristics were reported.	No specific conclusions in relation to the interventions in which the PwD was included can be drawn.

PwD= person(s) with dementia; RCTs= randomized controlled trials; MCI=mild cognitive impairment; QoL=quality of life; ADL=activities of daily living.

Description of the interventions

The term “self-management support” is rarely mentioned explicitly in the seven reviews that were included. However, if the above-mentioned definition based on Barlow *et al*. [5] is applied, the selected reviews do indeed consider interventions in which self-management was a central component. Table 3 shows the elements that comprised the self-management support interventions we identified. Self-management support was often aimed at dealing with problems affecting the psychological well-being of the person with dementia. The table also shows that self-management is often combined with cognitive behavioral therapy (CBT) or coping interventions.

Professionals and a focus on managing psychological problems

The interventions were primarily performed by psychologists, occupational therapists, and psychiatrists. Nursing staff were only explicitly mentioned as professionals providing self-management interventions in two of the seven reviews [11, 13]. The interventions focused primarily on managing psychological problems, for example, depression or anxiety. In addition, improvement of quality of life in general and/or postponing admission to a nursing home was often an important aim of the interventions.

Effects

The seven systematic reviews that were included show effects for a number of outcome variables in the person with dementia, for example, depression [10] and the time to admission to a nursing home [11]. However, it was not possible to draw conclusions from this about the effects of self-management support on people with dementia. There are two key reasons for this.

In the first place, self-management support interventions often include other components as well. A clear example of such a combined intervention can be seen in the study by Burgener *et al*. [15], included in the systematic review by Orgeta *et al*. [10]. Burgener *et al*. [15] studied the effects of a support group in which people with dementia learned how to resolve problems in their day-to-day lives, which can be considered as a self-management intervention. However, this was combined with tai chi exercises and CBT [15]. The combination of interventions meant that the individual effects of the self-management components could not be distinguished properly.

The second reason was that four of the seven systematic reviews included studies of self-management support interventions, but did not analyze them separately from studies of other kinds of interventions. The review by Cooper *et al*. [8] is one such example. It included a study by Logsdon *et al*. [16]. Logsdon *et al*. [16] researched the effects of a self-management support intervention in which discussion groups of people with dementia and their family caregivers talked together about how to deal with how dementia impacts social and family relationships and about making plans for the future. In this review, the effects of this self-management support intervention were analyzed together with those of cognitive stimulation therapies that did not include any self-management support components [17-19].

DISCUSSION

Despite the fact that the reviews we examined showed positive effects, it is not possible at this point to draw conclusions about the effectiveness of self-management support interventions on people with dementia. A main reason for this is that the self-management support interventions that were studied were often combined with other kinds of interventions such as CBT.

By excluding reviews with low methodological quality (score of 2 or less), we reduced the risk of biased conclusions. Seven of the eight reviews included received a quality score of 4 or more indicating either minor or no flaws, which is also important for providing unbiased, valid results.

However, a limitation was that the reviews did not label the interventions as "self-management support interventions." Guided by the explicit inclusion criterion that "*interventions had to explicitly be geared to helping the person with dementia cope with the dementia and its effects on their day-to-day lives and there had to be personal contact between the person with dementia and the healthcare professional,*" we decided whether interventions concerned self-management support. This decision implied subjective judgments.

This meta-review also teaches us that existing self-management support interventions (even if they are not always explicitly denoted as such) focus almost exclusively on the psychological well-being of the person with dementia. Self-management support interventions should however be wider in scope. In addition to psychological well-being, the "relationship with relatives," "maintaining an active lifestyle," "techniques to cope with memory change," and "information" are also important objectives for self-management support interventions [20]. Future interventions should include one or more of these objectives as well in order to provide the best possible support for self-management by people with dementia and those around them.

Accordingly, different outcome measures linked to the above-mentioned objectives should be used in future research on the effectiveness of self-management support interventions for people with dementia. Examples are outcome measures that indicate "the quality of the relationship with family caregivers," "the number of social contacts," or "knowledge about dementia."

Hence, future research is needed on the effects of self-management support interventions on patients. At the moment, more information is available regarding the effects on relatives. A previous meta-review [21] described effects of self-management support on informal caregivers of people with dementia, for example, an increase of well-being, stress relieve and more quality of life. However, in current health care in which patients themselves are also expected to execute self-management, it is important to further investigate which kinds of self-management support interventions are effective in particularly people with dementia and which are not.

The meta-review also revealed that self-management support is often provided by psychologists, occupational therapists, and other therapists. It is striking that nurses were only mentioned in two of the seven reviews, since self-management support fits with a core competency of nurses, namely acting as an information and education resource for clients seeking to improve life styles, and who have to cope with changes in health and disability and death [22]. Nurses are often in closer contact with the person with dementia than psychologists and occupational therapists, for example, and they accordingly see self-management support as part of their job [23]. Nursing professionals can incorporate self-management support in the regular care that they deliver to people with dementia.

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CHAPTER 3

The effectiveness of interventions in supporting self-management of informal caregivers of people with dementia; a systematic meta-review

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ABSTRACT

Background

Informal caregivers of people with dementia are challenged in managing the consequences of dementia in daily life. The objective of this meta-review was to synthesize evidence from previous systematic reviews about professional self-management support interventions for this group.

Methods

In March 2014, searches were conducted in PubMed, CINAHL, Cochrane Library, Embase and PsycINFO. The PRISMA Statement was followed. Interventions were grouped using Martin's targets of self-management, covering 5 targets: relationship with family, maintaining an active lifestyle, psychological wellbeing, techniques to cope with memory changes and information about dementia. Using an evidence synthesis, the outcomes from the included interventions were synthesized and conclusions were drawn about the level of evidence for the effectiveness of interventions within each target.

Results

Ten high-quality systematic reviews were selected. Evidence exists for the effectiveness of professional self-management support interventions targeting psychological wellbeing on stress and social outcomes of informal caregivers. In addition, evidence exists for the effectiveness of interventions targeting information on ability/knowledge. Limited evidence was found for the effectiveness of interventions targeting techniques to cope with memory change on coping skills and mood, and for interventions targeting information on the outcomes sense of competence and decision-making confidence of informal caregivers.

Conclusions

Scientific evidence exists for the effectiveness of a number of professional self-management support interventions targeting psychological wellbeing and information. Health care professionals could take account of the fact that psycho-education was integrated in most of the self-management support interventions that were found to be effective in this meta-review. Furthermore, longer and more intensive interventions were associated with greater effects.

BACKGROUND

Nowadays, self-management and self-management support are becoming more and more important. Besides the fact that health policies encourage people to self-manage for as long as possible [1], most people also prefer to keep control over their own life and health care. A commonly used definition of self-management in this context is *"the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition"* [2]. Self-management is not only a task for patients but also for informal caregivers. In people with dementia, self-management increasingly becomes the responsibility of the informal caregivers as the disease progresses. However, self-management often makes great demands on informal caregivers. Besides managing problems in the person with dementia, they also have to manage their own problems, such as concerns about the future and the daily burden of caregiving. This can have negative consequences for the psychological wellbeing of the informal caregiver [3] and may have an impact on the relationship with the person with dementia [4].

Managing well with the problems and consequences of dementia is challenging for informal caregivers, and professional support may be needed. Nurses, psychologists or other professionals can act as partners with the informal caregivers, by supporting them in their decisions and actions to manage the disease and its consequences in daily life [5]. What type of support or intervention should be provided by professionals to informal caregivers depends on how the informal caregivers are managing or where they feel the need for support. A logical way to distinguish different types of self-management support interventions is to categorize them according to the main target of the intervention. Martin *et al*. [6] distinguish five self-management targets for persons with dementia: *1) relationship with family, 2) maintaining an active lifestyle, 3) psychological wellbeing, 4) techniques to cope with memory changes, and 5) information* about dementia. Since self-management by informal caregivers focuses first and foremost on the patient, the patient targets are also applicable when categorizing self-management support interventions aimed at informal caregivers.

In recent decades, many interventions have been developed to provide self-management support to informal caregivers of persons with dementia. Most of the time however, these interventions were labeled not as such as the concept of self-management has emerged relatively recently. Self-management support interventions were labeled for example as 'psychosocial interventions', 'support interventions' or 'case management interventions'. Related to these wide variety of labels used for these interventions, until now there has been no insight into the level of evidence for the effectiveness of different types of self-management support interventions for informal caregivers of persons with dementia. Nevertheless, there were already a lot of relevant review papers. We therefore conducted a systematic meta-review, making use of the self-management support targets defined by Martin *et al*. [6]. Additionally, we aim to identify participant and intervention characteristics that are related to positive outcomes of self-management interventions.

The primary question of this systematic meta-review is:

> What scientific evidence exists for the effectiveness of various types of professional self-management support interventions for informal caregivers of persons with dementia?

The secondary question is:

> Which participant and intervention characteristics of self-management support interventions for informal caregivers of people with dementia are associated with larger effects?

METHODS

We conducted a meta-review, in the sense of a systematic review of systematic reviews, following, for as much as possible and applicable for this type of study, the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Statement [7].

Eligibility criteria

Types of study

Only systematic reviews were included. We considered a review to be systematic if the following criteria were met: (a) search terms must be described and (b) a search was conducted in PubMed and at least one other international scientific database. References were excluded if no effect studies (i.e. Randomized Controlled Trial (RCT), Controlled Clinical Trial (CCT) or quasi experimental designs) were included.

Types of participant

The systematic reviews to be included had to focus on informal caregivers of persons with dementia. No limitations concerning age were applied.

Types of intervention

The systematic reviews to be included had to focus on professional self-management support interventions. We considered an intervention, provided by the professional, to be a self-management support intervention if it explicitly focused on helping the informal caregiver to deal with the relative's dementia and its consequences in everyday life. There must also have been direct or indirect (by phone/email) contact between the informal caregiver and the health care professional providing the intervention. Effects of self-management support interventions must be described and analyzed, and an overall conclusion must be drawn about the effectiveness of these interventions.

Types of outcome measure

Only systematic reviews presenting effects on informal caregivers of persons with dementia were included. References were excluded if the systematic reviews were primarily intended to address effects regarding health professionals or if they only described effects on the person with dementia.

Search strategy and information sources

In March 2014, systematic literature searches were conducted in PubMed, CINAHL (Cumulative Index to Nursing and Allied Health Literature), Cochrane Library, Embase and PsycINFO to find relevant systematic reviews that met all the eligibility criteria. A sensitive search strategy was constructed first for PubMed/Medline, and subsequently adapted for the other databases used. The detailed search strategy for PubMed can be found in Additional file 1. All publications until March 2014 were taken into consideration. No language restrictions were imposed. References retrieved from the searches were entered into EndNote (version X7). After duplicates were eliminated, the selection of studies was carried out.

Study selection

The protocol for study selection was as follows. References were identified for inclusion in two steps. First, the explicit pre-defined inclusion criteria described were applied to titles and abstracts of references identified from the search strategies. One reviewer (JGH) screened all references and the second reviewer (RV) independently checked a 10 % random selection of the references. If the level of agreement between the two reviewers was substantial to good (Kappa 0.60–0.80) [8] for the 10 % random selection, the first reviewer could proceed individually. If title and/or abstract provided insufficient information to assess the relevance, these references proceeded to the second inclusion stage. Second, full texts of the references selected in the first stage were independently screened by the reviewers. When the first and second reviewer did not agree on inclusion or exclusion, a third reviewer was consulted.

Methodological assessment

After study selection, the methodological quality of the selected references was determined using the Quality Assessment Checklist for Reviews of Oxman and Guyatt [9]. Additional instructions by the authors of another meta-review [10], using the Quality Assessment Checklist for Reviews of Oxman and Guyatt, were applied to explicate the decisions for assessment. This checklist includes nine criteria for quality assessment of systematic reviews. The scientific quality is rated according to whether the review fulfilled, partially fulfilled or did not fulfill the following nine criteria by reporting or performing: (a) a search method, (b) a comprehensive search, (c) inclusion criteria, (d) selection bias, (e) validity of studies, (f) assessment criteria, (g) methods used to combine findings, (h) findings addressing the primary question of the review and (i) conclusions supported by data. Based on these nine criteria, the reviewer must give a rating score on a grading scale from one, reflecting extensive flaws, to seven, reflecting minimal flaws. The mean of the rating scores of the reviewers was calculated. If the scores differed by more than 1 point, the reviewers discussed their assessments and came to a new joint score. Reviews were considered to be of 'high quality' if the review was evaluated with a score between five and seven reflecting 'minor flaws' and 'minimal flaws' respectively. Only these high quality reviews were considered for inclusion since it is known that reviews judged as having critical flaws may be unsuitable for guiding health care decisions [11].

Data-collection process

To investigate different aspects of the interventions, data were extracted from the systematic reviews. Data extraction was executed by the first reviewer (JGH) and subsequently checked by a second reviewer (BM). Extracted data included information about the study aim, search strategy described, databases used, target population, type of interventions, intended outcomes, design of the studies included, characteristics of the interventions, characteristics of implementation strategies, professionals' characteristics, patient characteristics, environmental characteristics and overall conclusions.

Data-analysis and synthesis

The underlying interventions in the included reviews were grouped based on the categorization of five targets described by Martin *et al.* [6]. A self-management support intervention could have one or multiple intervention targets. Martin *et al.* [6] describes the following self-management targets:

Relationship with family/friends/"carer" focuses on the importance of the relationship and the challenges for both parties to ensure it is supportive.

Maintaining an active lifestyle addresses the perception that people with dementia should be encouraged to stay active or engage in meaningful or pleasurable activities.

Psychological wellbeing focuses on improving or maintaining psychological wellbeing to improve quality of life but also to aid adjustment and alleviate the negative impact of low mood on cognitive processes.

Techniques to cope with memory change involves tips and techniques for living with an impaired memory, to improve coping with memory loss.

Information covers a wide range of topics including what dementia is as a disease, features of disease progression, what losses in functioning to expect, what medical and psychological interventions exist, resources such as financial benefits.

Multi-component interventions consist of and integrate several of the aforementioned intervention targets of Martin *et al.* [6].

Furthermore, an evidence synthesis was conducted to indicate the level of evidence for the effectiveness of self-management support interventions on a specific outcome. This synthesis takes into account the reported evidence in the reviews and the number of underlying studies included in the reviews on which that evidence is based. The criteria used to indicate the level of evidence were inspired by the review of Steultjens *et al.* [12]. Since Steultjens *et al.* [12] included only RCTs, we adapted the criteria for this meta-review. Table 1 shows that at least one high quality systematic review (based on at least two underlying effect studies) should report consistently positive significant effects on a specific outcome to establish evidence for a self-management support intervention.

Table 1 *Principles of evidence synthesis of systematic reviews.*

Evidence	Consistent positive, significant effects on a specific outcome in at least one high quality systematic review (based on at least two underlying effect studies)
Limited evidence	Effects on a specific outcome in at least one high quality systematic review (based on one underlying effect study)
Inconclusive evidence	Inconsistent effects on a specific outcome, because at least one high quality systematic review (including at least two underlying studies) shows positive, significant effects, while other review(s) included did not find such effects.
No evidence	None of the included reviews found consistent positive, significant effects on a specific outcome.
No research found	None of the included reviews examined effects on a specific outcome.

RESULTS

Study selection

Four thousand nine hundred fifty-six references were identified from database searches. After merging the search results, all references were entered into EndNote, and 4093 references remained after duplicates were discarded. The first (JGH) and second reviewer (RV) reached substantial agreement on the 10 % random selection of the references (kappa coefficient of 0.71) [8] and therefore the remaining 90% of the references were checked by the first author (JGH). 166 references remained after selection based on title and abstract. Full texts were searched for the 166 references, of which 163 were actually obtained. Four reviewers independently screened the full texts; the first reviewer (JGH) screened all full texts articles, one reviewer (PM) half of the total number of full texts, and two reviewers (RV, ALF) a quarter of the total full texts. Disagreement was resolved by discussion until consensus was reached. In total, 36 references remained after full text screening and were selected for the next stage of the review—the methodological assessment. Reasons for exclusion of the 130 references are detailed in Additional file 2. Three reviewers independently determined the methodological quality of the 36 references, of whom the first reviewer (JGH) screened all reviews and two reviewers (ALF, RV) both performed selection on half of the total number of included reviews. Ten reviews were evaluated with a high quality score. These high scores were based on well-documented methodology and the assessment of validity of the included primary studies. Twenty-six reviews received a score between one and four, reflecting ‘extensive’ to ‘major’ flaws in respect of the checklist. The main reason for excluding these reviews was that they either did not take measures or did not report on measures to prevent selection bias. In conclusion, ten reviews were selected for data-extraction (see Fig. 1).

Characteristics of the reviews included

Additional file 3 shows general and methodological characteristics of the ten reviews included.

Publication date, origin of authors, journals and design of included reviews

Publication dates of the reviews included ranged from 2003 to 2013. The majority were published in the past 5 years. Three of the reviews were conducted in the Netherlands [13-15], and the remainder in Australia [16], Brazil [17], Canada [18], Germany [19], Taiwan [20] and the United Kingdom [21], while a review written in German had a correspondence address in Italy [22]. All reviews had a systematic review design, and five also contained a meta-analysis [16, 17, 19-21].

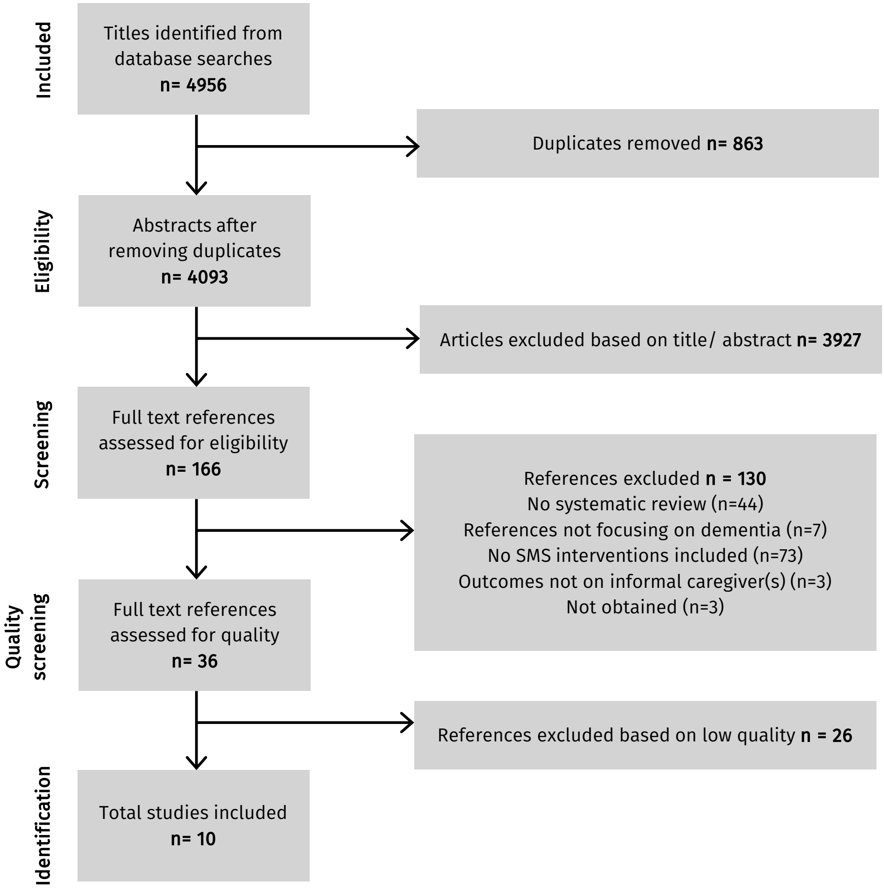

Figure 1 *Flowchart study selection flow for systematic reviews.*

Objectives of reviews included

All included reviews aimed to focus on the effectiveness of interventions. Half of the reviews focused on a specific type of intervention, e.g. internet-based interventions, support group interventions or case management interventions. Five reviews did not specify the type of intervention in advance and discussed a broader range of interventions. None of the included reviews explicitly used a definition of self-management or self-management support.

Eligibility criteria of reviews included

The target population in all reviews comprised informal caregivers of persons with dementia. The underlying studies in the reviews mainly evaluated the effectiveness of interventions (RCT, CCT, quasi-experimental design). Additional to the inclusion of these designs, two reviews also included systematic reviews [16, 22]. Reported outcomes of the intervention varied in the reviews; see Additional file 4. Restrictions in the reviews were mainly related to language: six reviews reported language restrictions [13, 14, 16, 19, 20, 22]; two reviews explicitly reported to have no language restrictions [17, 21].

Information sources and search periods of the reviews included

All included reviews performed a comprehensive search in at least three databases [range 3 to 15]. PubMed was used in all reviews and the Cochrane Library in most. In addition, almost all reviews carried out other searches such as manual searches or searches of references listed in the reviewed studies. In seven reviews [13, 15, 17-21], the search comprised an extensive publication period of 10 years or more; three reviews had a shorter search period [14, 16, 22]. However, two of these concerned an update of an earlier review and thus included earlier reviews or the related underlying studies.

Score of methodological assessment of the reviews included

Six reviews received a quality score of 5.0 or 5.5, reflecting ‘minor flaws’ [13, 14, 16, 18, 21, 22]. Four reviews were found to have ‘minimal flaws’ based on quality score of 6.0 or 7.0 [15, 17, 19, 20]. Three reviews [15, 17, 20] received a quality score of 7.0 indicating that they met all quality requirements of the Quality Assessment Checklist for Reviews.

Number, design and control conditions of underlying studies in the reviews included

In total, 313 underlying studies were included in the reviews (range 7–127). In these underlying studies, 292 interventions are considered to be self-management support interventions based on the inclusion criteria of this meta-review. Generally, almost all reviews included only RCTs. The control conditions mainly involved usual care or a limited version of the intervention.

Number of intervention sessions, intervention period and professional who delivered the intervention

The number of intervention sessions and/or intervention periods were often not described by the included reviews. Some reviews reported these characteristics for a number of the underlying studies; accordingly, a range for intervention sessions and intervention periods is given. Few studies contained information on the professional who delivered the intervention. In those reviews that contained this information, nurses and case managers were the most frequently reported professionals [see Additional file 3].

Results of underlying studies in reviews included

The underlying self-management support interventions of the included reviews and their reported outcome measures differed too much for their results to be pooled. Therefore, the interventions and results are categorized on the basis of the targets distinguished by Martin *et al*. [6]: *relationship with family/friends/"carer", maintaining an active lifestyle, psychological well-being, techniques to cope with memory change, information and multi-component interventions.* Within each category, first the different types of self-management support interventions are presented and the overall goal of each self-management support intervention is stated. Second, evidence for the self-management support interventions is presented based on the outcome. Additional file 4 presents the outcomes and effects of the reviews included. The most reported outcomes in the included reviews and the reported effectiveness of the self-management support interventions are shown in Additional file 5.

Self-management support interventions targeting relationship with family/friends/"carer"

Four reviews [16, 18, 19, 22], described self-management support interventions which target a supportive *relationship* between the person with dementia and the informal caregiver. Three reviews [18, 19, 22] described case management interventions; one review [16] included support interventions involving care planning and case management; and one review [18] described psychotherapy interventions.

Case management interventions under this target included advice and support by a health professional aimed at resolving personal problems that complicate informal care giving, to reduce conflict between caregivers and care recipients, and to improve family functioning.

Support interventions under this target consisted of supporting caregivers in their role involving care planning and case management.

Psychotherapy interventions consisted of individual and family counseling that focused on communication and problem-solving in relation to caregiving.

Using the described method for evidence synthesis, inconclusive evidence exists for the effectiveness of self-management support interventions, that focus on family relationships, for relieving caregiver burden [16, 19, 22] and enhancing coping skills [22]. All reviews that reported on caregiver depression presented no evidence [18, 19]. Other outcomes for which no evidence was found for the caregiver included subjective wellbeing and ability/knowledge [19]. None of the included reviews examined effects on self-efficacy, decision-making confidence, anxiety, stress, Revised Memory and Behavior Problem Checklist (RMBPC), quality of life, mood, health and sense of competence.

Self-management support interventions targeting the maintenance of an active lifestyle

None of the included reviews described self-management support interventions targeting the *maintenance of an active lifestyle* with effects on the informal caregiver.

Self-management support interventions targeting psychological wellbeing

Four of the reviews included described self-management support interventions targeting *psychological wellbeing* [15, 19, 20, 22]. In this category different types of interventions are categorized including caregiver support group interventions [20], psychotherapeutic interventions, support interventions [22], cognitive behavioral therapy, general support [19] and cognitive reframing interventions [15].

Support interventions, i.e. caregiver support groups and general support, under this target consisted of mutual emotional support for informal caregivers where they can share personal feelings, experiences and knowledge with other informal caregivers in order to relieve the pressure and burden of caregiving.

Therapeutic interventions, i.e. psychotherapy and cognitive behavior therapy, under this target involve dealing with difficult care situations and caregiving demands, and fostering activities that may promote subjective well-being.

Cognitive reframing interventions “focus on changing self-defeating or distressing cognitions into those cognitions that support adaptive behavior and reduce anxiety, depression and stress” [15].

Synthesizing these interventions under this target, evidence was found for self-management support interventions targeting psychological wellbeing for relieving stress or distress [15] and positive social outcomes [20]. Inconclusive evidence was found for the effectiveness of self-management support interventions targeting psychological wellbeing on relieving burden [15, 19, 20, 22], reduced depressive symptoms [15, 19, 20, 22], improving caregiver wellbeing [19, 20] and alleviating anxiety [15, 22].

No evidence was found for ability/knowledge [19], coping skills, self-efficacy and RMBPC [15]. None of the included reviews examined effects on the following outcomes reported in the included reviews: decision-making confidence, quality of life, mood, health and sense of competence.

Self-management support interventions targeting techniques to cope with memory change

Two of the reviews included described self-management support interventions targeting *techniques to cope with memory change* [19, 22].

Training programs under this target consisted of skills training for the informal caregivers, for example, to improve communication and problem solving skills. The person with dementia may possibly also be involved in the program, for example, in cognitive stimulation, ADL training and physical activity. Because physical and cognitive decline and behavior problems in the care recipient are associated with caregiver burden and depression, memory clinics and programs aimed at improving the competence of the care recipient may also have a positive effect on caregiver outcomes.

Limited evidence was found for the outcomes coping skills, mood and competence of the informal caregiver [22]. Inconclusive evidence was found for caregiver burden. No evidence was found for the effects of self-management support interventions targeting *techniques to cope with memory* change on caregiver depression, subjective wellbeing and ability/knowledge [19, 22]. None of the included reviews examined effects on self-efficacy, decision-making confidence, anxiety, stress/distress, RMBPC, quality of life, social outcomes and health.

Self-management support interventions targeting information

Seven of the reviews included described self-management support interventions targeting *information* [13, 16-19, 21, 22]. In this category, different types of interventions were categorized including (psycho-) educational interventions [16-19, 22], internet-based interventions [13], computer-networking interventions [18] and information and support interventions [21].

(Psycho-) Educational interventions under this target consisted of providing interdisciplinary education and knowledge about dementia, and teaching (coping) skills to support caregivers in their role. Pinquart and Sorensen [19] add that support may constitute part of psycho education, but is secondary to the educational content.

Internet-based computer-networking interventions under this target comprised education provision, decision-making support, communication and an opportunity for questions and answers for informal caregivers (through a computer network).

Evidence was found for the effectiveness of interventions targeting information on ability/knowledge [19, 22]. Limited evidence was found for caregiver stress [13], decision-making confidence [13, 18] and sense of competence [13]. One underlying study found a reverse effect on the outcomes anxiety, depression, well-being and quality of life. Anxiety and depression decreased significantly and well-being and quality of life increased in the control group whereas people in the online intervention group did not improve with respect to these outcomes [13]. Inconclusive evidence was found for improving caregiver burden, depression, well-being and self-efficacy [13, 16, 19, 22]. For coping skills and quality of life, two underlying studies had inconclusive findings. No evidence was found for caregiver health [16]. No research was found addressing RMBPC, social outcomes and mood.

Multi-component interventions

Four reviews [14, 16, 19, 22] included multi-component interventions. Multi-component interventions under this target consisted of a combination of various forms of interventions such as information, (psycho) education, support skills training and coping strategies for the caregiver and may also involve training for activities of daily life (ADL), walking or exercise and environmental adaptations for the person with dementia.

Inconclusive evidence was found for the effectiveness of multi-component interventions on caregiver burden, depression, quality of life, mood and sense of competence [14, 16, 19, 22]. No evidence was found for well-being and ability/knowledge [14, 16, 19, 22]. None of the included reviews examined effects on coping skills, self-efficacy, decision-making confidence, anxiety, stress/distress, RMBPC, social outcomes and health.

Intervention and participant characteristics

Two reviews additionally performed analyses on intervention and participant characteristics [19, 20]. The review of Chien *et al*. [20] conducted subgroup and regression analyses on intervention and participant characteristics, and their association with outcomes. Associations between these characteristics and effects were found in this review for the following characteristics: (psycho) educational groups, use of theoretical models, group size (6–10 people), group course (≥8 weeks) and intensity (≥16 h), follow up, leader background (interdisciplinary), female participation and age [20].

The review of Pinquart and Sorensen [19] also analyzed the association between intervention and participant characteristics. Associations for some outcomes were found for longer interventions (number of sessions, not further specified) and higher percentage of women [19].

DISCUSSION

This meta-review shows that scientific evidence exists for professional self-management support interventions targeting *psychological wellbeing* of informal caregivers of people with dementia. Effective interventions within this target were caregiver support group interventions, which were shown to relieve stress [15]; and cognitive reframing interventions that were shown to improve caregivers' social outcomes such as social support, relationship with the patient and life quality [20]. Evidence was also found for the effectiveness of professional self-management support interventions targeting *information* on increasing caregivers' knowledge. Examples of effective interventions in this target are psycho-educational interventions [19, 22].

Limited evidence was found for the effectiveness of self-management support interventions targeting *techniques to cope with memory change* on improving coping skills, mood and competence of informal caregivers [22]. Training programs are examples of these self-management support interventions. Further, limited evidence was also found for some interventions targeting *information* on improving decision-making confidence, stress and sense of competence [13, 18]. Examples for these interventions are internet-based support interventions and computer-networking interventions.

Inconclusive evidence was found for self-management support interventions targeting *relationship with family* and targeting *techniques to cope with memory change* on relieving caregiver burden. Self-management support interventions targeting *psychological wellbeing* were also found to have inconclusive findings on four caregiver outcomes including: burden, depression, wellbeing and anxiety. In the self-management support target *information*, inconclusive evidence was found on relieving burden and depression or improving wellbeing and self-efficacy in the informal caregiver. For multi-component interventions, inconclusive evidence was found on caregiver burden, depression, quality of life, mood and sense of competence.

Not much research was found on the informal caregiver outcomes self-efficacy, decision-making confidence, anxiety, stress or distress, RMBPC, quality of life, social outcomes, mood, health and sense of competence. Besides, none of the included reviews described effects of self-management support interventions targeting *maintaining an active lifestyle.*

We also aimed to identify specific intervention or participant characteristics that contributed to the effectiveness of these interventions. Two systematic reviews additionally performed analyses to investigate this. It is notable that both reviews found that in particular group course (≥8 weeks) and intensity (≥16 h) and longer interventions (number of sessions, not further specified) are associated with larger effects [19, 20]. These findings are in line with previous reviews, which also describe the importance for longer interventions or follow-up [23, 24].

The reviews in this meta-review studied different types of self-management support interventions. There was a considerable amount of variability between the underlying studies regarding, for example, content of the intervention, measurement tools used and implementation of the intervention. Despite this variability, it is noteworthy that psycho-education was integrated in most self-management support interventions that were found to be effective. For example, effective caregiver support group interventions consisted in most cases of a (psycho) educational group. Furthermore, it was shown that psycho-educational groups had a significantly higher effect on the outcome variables psychological well-being and depression [20]. The review of Pinquart and Sorensen [19] analyzed psycho-educational interventions with active participation of caregivers versus psycho-educational interventions that only provided information. Both interventions increased caregivers' knowledge, but psycho-educational interventions with active participation of the caregiver had the broadest effects. An example of a psycho-educational intervention included in the review of Pinquart and Sorensen [19] was a intervention described by Hebert *et al*. [25]. In this study, a group-intervention was tested consisting of fifteen two-hour weekly sessions and contained two components (cognitive appraisal and coping strategies). The intervention was aimed at primary caregivers of community-dwelling persons with dementia [25].

Looking at the main outcomes of the meta-review, the self-management support target of the successful interventions was directly related to the outcomes in informal caregivers. For example, self-management support interventions targeting *information* were found to be effective for improving the ability/knowledge of informal caregivers. This could also explain why we found no evidence for the effectiveness of interventions in the targets *maintaining an active lifestyle* on informal caregiver outcomes, since they were more focused on persons with dementia rather than on the informal caregiver.

Implications for research and practice

Evidence exists for self-management support interventions targeting p*sychological wellbeing* and *information* on specific caregiver outcomes; however more research is needed. To date, only limited research has been described in existent systematic reviews on, for example, the effect of self-management support interventions on quality of life or self-efficacy of the informal caregiver. This is remarkable because in many other studies on supporting self-management for people with long term conditions, it has been shown that self-management support can impact on these outcomes and that they are associated with each other [26]. Future research could focus on these outcomes for self-management support interventions for informal caregivers of persons with dementia.

Furthermore, more research is needed to investigate how effective interventions can be deployed and implemented. Although further investigation is needed, e-health was shown to be a promising extension to the currently offered care as usual [13]. Further research could take forward how self-management support interventions could be delivered by e-health.

Although self-evident, the results of this meta-review shows that it is important that the self-management support target is related to the main self-management need of the informal caregiver. For example, if health care providers want to improve caregivers' social outcomes, they should focus on interventions targeting *psychological well-being*. Therefore it seems more beneficial to tailor a self-management intervention to the needs of the informal caregiver by using interventions that target on these specific needs.

This meta-review also indicated that longer interventions were associated with greater effects [19, 20] on some caregiver outcomes. This finding suggests that self-management support interventions should be given over an extended period of time and with a certain intensity.

Another relevant finding of this meta-review is that most of the effective self-management support interventions involved psycho-education. We therefore recommend health care professionals to consider psycho-education when focusing on self-management support targets *information* and *psychological well-being*.

Strengths and limitations

To our knowledge, this is the first meta-review that gives insight into the level of evidence for the effectiveness of different types of self-management support interventions for informal caregivers of persons with dementia. Another important strength is the high methodological quality of the included reviews, indicating good reliability of the results which therefore may be appropriate for use in decision making [11].

Nonetheless, some limitations should be addressed. As mentioned earlier, none of the retrieved reviews labeled the interventions studies as 'self-management support interventions'. Therefore, our selection of the reviews for inclusion and allocation of the reviews to intervention targets could contain an element of subjective judgment. An explicit definition of 'self-management support' interventions was used by the reviewers in order to minimize this.

Another limitation concerns the heterogeneity of the self-management support interventions within specific intervention targets regarding, for example, the nature and intensity of the interventions. This should be taken into account when interpreting the results.

Furthermore, a limitation is that the reported evidence in the reviews is sometimes partially based on the same underlying intervention reviews. An example of this is the review of Mantovan *et al*. [22] that included, in addition to effect studies, systematic reviews (e.g. Thompson *et al*. [21] and Pinquart and Sorensen [19]). However, the fact that Mantovan *et al*. [22] included these two reviews did not change the conclusions of this meta-review.

CONCLUSIONS

Evidence exists for professional self-management support interventions targeting *psychological wellbeing* and *information*. Health care professionals could take into account that psycho-education was integrated in most of the self-management support interventions that were found to be effective. Furthermore, longer and more intensive interventions were associated with higher effects.

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ADDITIONAL FILES

Additional file 1. Detailed search strategy PubMed

(Dementia[MeSH Terms] OR Cerebral Autosomal Recessive Arteriopathy with Subcortical Infarcts and Leukoencephalopathy [Supplementary Concept] OR Korsakoff Syndrome[Mesh] OR dement*[tiab] OR alzheim*[tiab] OR binswanger*[tiab] OR CADASIL[tiab] OR CARASIL[tiab] OR cjd[tiab] OR Creutzfeld Jacob[tiab] OR Creutzfeld Jakob[tiab] OR Creutzfeldt Jacob[tiab] OR Creutzfeldt Jakob[tiab] OR Frontotemporal Degenerat*[tiab] OR hiv associated neurocognitive disorder*[tiab] OR Huntington*[tiab] OR Kluver-Bucy*[tiab] OR Korsakoff*[tiab] OR Lewy Body[tiab] OR Pick Disease*[tiab] OR Picks Disease*[tiab] OR Pick's Disease*[tiab] OR Primary Progressive Aphasia*[tiab] OR sundown syndrome[tiab] OR sundowning[tiab])

(self care[MeSH Terms] OR self efficacy[MeSH Terms] OR patient education as topic[MeSH Terms] OR caregiver[MeSH Terms] OR self care*[tiab] OR selfcare*[tiab] OR self mana*[tiab] OR selfmana*[tiab] OR self help*[tiab] OR selfhelp*[tiab] OR self efficacy*[tiab] OR selfefficacy*[tiab] OR patient educat*[tiab] OR supportive care*[tiab] OR carer*[tiab] OR caregiv*[tiab] OR chronic care model[tiab])

((((systematic review[ti] OR meta-analysis[pt] OR meta-analysis[ti] OR systematic literature review[ti] OR (systematic review[tiab] AND review[pt]) OR consensus development conference[pt] OR practice guideline[pt] OR cochrane database syst rev[ta] OR acp journal club[ta] OR health technol assess[ta] OR evid rep technol assess summ[ta] OR drug class reviews[ti]) OR (clinical guideline[tw] AND management[tw]) OR ((evidence based[ti] OR evidence-based medicine[mh] OR best practice*[ti] OR evidence synthesis[tiab]) AND (review[pt] OR diseases category[mh] OR behavior and behavior mechanisms[mh] OR therapeutics[mh] OR evaluation studies[pt] OR validation studies[pt] OR guideline[pt] OR pmcbook)) OR ((systematic[tw] OR systematically[tw] OR critical[tiab] OR (study selection[tw]) OR (predetermined[tw] OR inclusion[tw] AND criteri*[tw]) OR exclusion criteri*[tw] OR main outcome measures[tw] OR standard of care[tw] OR standards of care[tw]) AND (survey[tiab] OR surveys[tiab] OR overview*[tw] OR review[tiab] OR reviews[tiab] OR search*[tw] OR handsearch[tw] OR analysis[tiab] OR critique[tiab] OR appraisal[tw] OR (reduction[tw] AND (risk[mh] OR risk[tw]) AND (death OR recurrence))) AND literature[tiab] OR articles[tiab] OR publications[tiab] OR publication[tiab] OR bibliography[tiab] OR bibliographies[tiab] OR published[tiab] OR unpublished[tw] OR citation[tw] OR citations[tw] OR database[tiab] OR internet[tiab] OR textbooks[tiab] OR references[tw] OR scales[tw] OR papers[tw] OR datasets[tw] OR trials[tiab] OR meta-analy*[tw] OR (clinical[tiab] AND studies[tiab]) OR treatment outcome[mh] OR treatment outcome[tw] OR pmcbook)) NOT (letter[pt] OR newspaper article[pt] OR comment[pt]))

((Meta-Analysis[ptyp] OR Review[ptyp] OR systematic[sb])))

Additional file 2. Reason for exclusion of the excluded studies

Study	Reason for exclusion
Annerstedt 2011	Excluded based on criteria ‘type of participant’
Anonymous 2013	Excluded based on criteria ‘type of study’
Arbesman 2011	Excluded based on criteria ‘type of study’
Archer 2014	Excluded based on criteria ‘type of study’
Aung 2010	Excluded based on criteria ‘type of study’
Aung 2012	Excluded based on criteria ‘type of study’
Ayalon 2006	Excluded based on criteria ‘type of intervention’
Bahar-Fuchs 2013	Excluded based on criteria ‘type of intervention’
Baldwin 2010	Excluded based on criteria ‘type of study’
Bharucha 2009	Excluded based on criteria ‘type of intervention’
Biem 2003	Excluded based on criteria ‘type of intervention’
Brodaty 2012	Excluded based on criteria ‘type of intervention’
Brody 2013	Excluded based on criteria ‘type of participant’
Buettner 2010	Excluded based on criteria ‘type of intervention’
Caddell 2011	Excluded based on criteria ‘type of intervention’
Campbell 2012	Excluded based on criteria ‘type of intervention’
Carrion 2013	Excluded based on criteria ‘type of intervention’
Carswell 2009	Excluded based on criteria ‘type of intervention’
Cepoiu-Martin 2012	Excluded based on criteria ‘type of study’
Chatterton 2010	Excluded based on criteria ‘type of intervention’
Christofoletti 2007	Excluded based on criteria ‘type of study’
Clare 2003	Excluded based on criteria ‘type of intervention’
Cohen-Mansfield 2001	Excluded based on criteria ‘type of study’
Cooke 2001	Excluded based on criteria ‘type of intervention’
Coon 2009	Excluded based on criteria ‘type of study’
Cooper 2007	Excluded based on criteria ‘type of intervention’
Courtenay 2010	Excluded based on criteria ‘type of participant’
Croot 2009	Excluded based on criteria ‘type of study’
Cummings 2009	Excluded based on criteria ‘type of study’
Daly 1999	Excluded based on criteria ‘type of study’
DePalma 2007	Excluded based on criteria ‘type of study’
Doody 2001	Excluded based on criteria ‘type of intervention’
Drennan 2012	Excluded based on criteria ‘type of intervention’
Egan 2010	Excluded based on criteria ‘type of intervention’
Egan 2006.	Excluded based on criteria ‘type of study’
Eggenberger 2013	Excluded based on criteria ‘type of study’
Eggermont 2006	Excluded based on criteria ‘type of intervention’
Enmarker 2011	Excluded based on criteria ‘type of intervention’
Etters 2008	Excluded based on criteria ‘type of study’
Eustice 2000	Excluded based on criteria ‘type of participant’
Filan 2006	Excluded based on criteria ‘type of intervention’
Fischer-Terworth 2009	Excluded based on criteria ‘type of intervention’
Forbes 2008	Excluded based on criteria ‘type of intervention’

Study	Reason for exclusion
Forbes 2013	Excluded based on criteria ‘type of intervention’
Forbes 1998	Excluded based on criteria ‘type of intervention’
Gallagher 2011	Excluded based on criteria ‘type of study’
Gillespie Lesley 2012	Excluded based on criteria ‘type of intervention’
Gitlin 2012	Excluded based on criteria ‘type of study’
Gonzalez-Guillermo 2008	Excluded based on criteria ‘type of study’
Hall 2012	Excluded based on criteria ‘type of intervention’
Hautzinger 2002	Excluded based on criteria ‘type of study’
Herrmann 2007	Excluded based on criteria ‘type of intervention’
Hermann 2008	Excluded based on criteria ‘type of intervention’
Herrmann 2001	Excluded based on criteria ‘type of intervention’
Hodgkinson 2007	Excluded based on criteria ‘type of intervention’
Hort 2010	Excluded based on criteria ‘type of study’
Hulme 2010	Excluded based on criteria ‘type of study’
Innes 2011	Excluded based on criteria ‘type of intervention’
Jones 2012	Excluded based on criteria ‘type of intervention’
Kiepe 2012	Excluded based on criteria ‘type of study’
Kim 2012	Excluded based on criteria ‘type of intervention’
Koger 2000	Unobtainable
Kong 2009	Excluded based on criteria ‘type of intervention’
Konno 2013	Excluded based on criteria ‘type of intervention’
Kotronoulas 2013	Excluded based on criteria ‘type of intervention’
Kuske 2007	Excluded based on criteria ‘type of intervention’
Kverno. 2009	Excluded based on criteria ‘type of intervention’
Lawrence 2012	Excluded based on criteria ‘type of intervention’
LeClerc 1998	Excluded based on criteria ‘type of study’
Livingston 2005	Excluded based on criteria ‘type of study’
Lopez 2007	Excluded based on criteria ‘type of intervention’
Lorenz 2008	Excluded based on criteria ‘type of intervention’
Manckoundia 2008	Excluded based on criteria ‘type of study’
Marcus 1992	Excluded based on criteria ‘type of study’
McKeown 2006	Excluded based on criteria ‘type of intervention’
McLaren 2013	Excluded based on criteria ‘type of study’
Moniz Cook 2012	Excluded based on criteria ‘type of intervention’
Napoles 2010	Excluded based on criteria ‘type of intervention’
Neal 2003	Excluded based on criteria ‘type of intervention’
Nguyen 2008	Excluded based on criteria ‘type of intervention’
Nijhof 2009	Excluded based on criteria ‘type of study’
O'Connor 2011	Excluded based on criteria ‘type of study’
O'Connor 2009	Excluded based on criteria ‘type of participant’
Olazaran 2010	Excluded based on criteria ‘type of intervention’
O'Neil 2011	Excluded based on criteria ‘type of intervention’
Opie 1999	Excluded based on criteria ‘type of intervention’
Orgeta 2014	Excluded based on criteria ‘type of intervention’
Orgeta 2014	Excluded based on criteria ‘type of outcome measure’

Study	Reason for exclusion
Padilla 2011	Excluded based on criteria ‘type of intervention’
Paolino 2013	Excluded based on criteria ‘type of study’
Parks 2006	Excluded based on criteria ‘type of study’
Penrose 2005	Excluded based on criteria ‘type of intervention’
Perkins 2008	Excluded based on criteria ‘type of intervention’
Pimouguet 2010	Excluded based on criteria ‘type of intervention’
Powell 2008	Excluded based on criteria ‘type of intervention’
Preschl 2011	Excluded based on criteria ‘type of participant’
Price 2000	Excluded based on criteria ‘type of intervention’
Rae 2011	Excluded based on criteria ‘type of study’
Rice 2001	Excluded based on criteria ‘type of study’
Rigaud 2011	Excluded based on criteria ‘type of study’
Roberts 2000	Excluded based on criteria ‘type of intervention’
Robinson 2006	Excluded based on criteria ‘type of outcome measure’
Robinson 2007	Excluded based on criteria ‘type of intervention’
Santos 2011	Excluded based on criteria ‘type of intervention’
Schneider 1993	Excluded based on criteria ‘type of study’
Schoenmakers 2010	Excluded based on criteria ‘type of intervention’
Schulz 2002	Excluded based on criteria ‘type of intervention’
Seitz 2012	Excluded based on criteria ‘type of intervention’
Selwood 2007	Excluded based on criteria ‘type of study’
Sorbi 2012	Excluded based on criteria ‘type of study’
Souder 2003	Excluded based on criteria ‘type of study’
Spijker 2008	Excluded based on criteria ‘type of outcome measure’
Spira 2006	Excluded based on criteria ‘type of study’
Taft 1995	Excluded based on criteria ‘type of intervention’
Tam-Tham 2013	Excluded based on criteria ‘type of intervention’
Teri 2005	Excluded based on criteria ‘type of intervention’
Thirymoorthy 2013	Unobtainable
Topo 2009	Excluded based on criteria ‘type of study’
Torti 2004	Excluded based on criteria ‘type of study’
Toseland 1989	Excluded based on criteria ‘type of participant’
Ueda 2013	Excluded based on criteria ‘type of intervention’
van Ginneken 2013	Excluded based on criteria ‘type of intervention’
Vazquez 2009	Excluded based on criteria ‘type of intervention’
Verkaik 2005	Excluded based on criteria ‘type of intervention’
Wall 2010	Excluded based on criteria ‘type of intervention’
Warner 2008	Unobtainable
Woods 2012	Excluded based on criteria ‘type of intervention’
Woodward 2013	Excluded based on criteria ‘type of study’
Yu 2009	Excluded based on criteria ‘type of intervention’
Zetteler 2008	Excluded based on criteria ‘type of intervention’

Additional file 3. General and methodological characteristics of reviews included

General and methodological characteristics of reviews included						Underlying studies in the reviews		
Reference, first author's country of origin	Review design	Review objective	Review's eligibility criteria	Information sources and search periods	Score methodological assessment:	Number, design and control conditions	Participants in underlying studies included in reviews	Number of sessions, intervention period and professional who delivered the intervention
Boots et al. (2013) Netherlands	Systematic review	(1) To present an overview of the evidence of the effectiveness and quality of Internet interventions for the informal caregivers of patients with dementia; (2) to assess which types of interventions are most effective (i.e., provide the best outcome for the participants); and (3) to indicate the feasibility of such interventions.	Inclusion criteria: · studies that reported the effects (quantitative and qualitative) of an internet-based intervention · informal (nonprofessional) caregivers of patients with mild cognitive impairment/dementia Exclusion criteria: · interventions solely aimed at the patient instead of the caregiver	PubMed, PsycINFO, CINAHL, Web of Science, and the Cochrane Library Additional searches: searches of references listed in the reviewed papers and meta-analyses Search period: 1988-2013	5	12 studies Design: (pretest/posttest) RCT, mixed method, formative evaluation, quasi-experimental Control conditions: · usual care, waitlist controls · a limited version of the intervention	Informal caregivers of persons with dementia. Setting was not further specified	Number of intervention sessions/modules ranged from 3 to 7 Intervention duration ranged from 4 weeks to 12 months Professionals · caregiver-therapist · technical experts in caregiving
Chien et al. (2011) Taiwan	Meta-analysis	To provide an integrated analysis of the effectiveness of support group intervention for caregivers of patients with dementia and to identify the significant predictors variables of outcomes	Inclusion criteria: · nonprofessional caregivers of patients with dementia · articles using quantitative methods and excluding qualitative studies · support groups led by professionals · support group types including mutual support groups, educational psychology groups, and educational training groups · studies of quasi- or true experimental designs · control groups were general care, waiting list, or minimal support, including caregiving manuals and videos, information guides, personal consultation, traditional support groups, and short-break services · journal articles on caregivers' psychological well-being on burden and social consequence Exclusion criteria: · groups organized on the internet, by telephone, or in the community · single-subject or single-group design	Cochrane, Medline, PubMed, PsycARTICLES, PsycINFO, ERIC, Ageline, CINAHL, Psychology and Behavioral Sciences Collection Additional searches: Google search and reference lists of retrieved articles Search period: 1998-2009	7	30 studies Design of underlying studies is not reported (reported in inclusion criteria) Control conditions: · general care, waiting list · minimal support	Spouse (27-100%) of persons with dementia. Setting was not further specified	Number of intervention sessions is not specified Intervention duration (follow up after session) is not provided Professionals · single professional background · interdisciplinary

General and methodological characteristics of reviews included						Underlying studies in the reviews		
Reference, first author's country of origin	Review design	Review objective	Review's eligibility criteria	Information sources and search periods	Score methodological assessment:	Number, design and control conditions	Participants in underlying studies included in reviews	Number of sessions, intervention period and professional who delivered the intervention
Mantovan et al. (2010) Italy (correspond ence address)	Systematic review	To collect the current state of knowledge regarding relief or promoting interventions for family caregivers of people with dementia from international studies	Inclusion criteria: · caregiver and people with dementia (dyads) (> 18 years) · the care takes place at home (home care) by caregiver · relief and promotional offers through health and social service providers · Outcomes: stress, depression, wellbeing / quality of life, coping skills / management, institutionalization · quantitative studies of evidence Class 1-11 (Antes et al, 2003.) · publications from 2004-2009 · English, German, and Italian language studies (English abstracts in foreign languages) Exclusion criteria: · frail children (<18 years) · oncological care needed (terminal stage) · nursing care with congenital disabilities · care by professional nurses in social institutions · pharmacological interventions · studies of evidence Class 111-1V (Antes et al, 2003.) · gray literature · publications for 2004 · foreign language studies without English abstract	Cochrane Library, Medline (PubMed), Embase, Cinahl (Ebsco) und PsycINFO (Ebsco) Additional searches: journals were searched for relevant studies and their references in English and German Search period: 2004-2009	5	9 studies were reviewed Design: RCT, CT, secondary data analyses. In addition, 3 systematic reviews and 2 systematic reviews with meta-analysis were included Control conditions: · a limited version of the intervention	Family caregivers (not further specified) of person with dementia living at home	Number of intervention sessions ranged from 5 to 6 Intervention duration ranged from 3 to 18 months Professionals: · case manager, volunteer

General and methodological characteristics of reviews included						Underlying studies in the reviews		
Reference, first author's country of origin	Review design	Review objective	Review's eligibility criteria	Information sources and search periods	Score methodological assessment:	Number, design and control conditions	Participants in underlying studies included in reviews	Number of sessions, intervention period and professional who delivered the intervention
Marim et al. (2013) Brazil	Systematic review and meta-analysis	To examine the evidence available in the literature on how effective education and support programs are in reducing the burden of caregivers of patients with dementia	Inclusion criteria: · RCTs with blinded assessments · interventions which provided interdisciplinary education and support for caregivers of patients with dementia · outcomes: the scale of caregiver burden using the Zarit Burden Interview Exclusion criteria: · not provided	PubMed, LILACS, EMBASE, SciELO, The Cochrane Library, Web of Science, CINAHL Additional searches: www.controledtrials.com database and abstracts of conference papers, references to review articles, published systematic reviews and references to randomized clinical trials Search period: inception-2011	7	7 studies All studies were RCTs Control conditions: · usual care	Caregivers (not further specified) of person with dementia. Setting was not further specified	Number of intervention sessions is not provided Intervention duration ranged from 4 to 12 months Professionals: · not reported
Parker et al. (2008) Australia	Systematic review and meta-analysis	To assess the effectiveness of interventions that assist caregivers to provide support for people living with dementia in the community	Inclusion criteria: · caregivers who provide support for people with dementia living in the community · three categories of intervention types: (1)Interventions designed to support caregivers in their role (Skills training, Education to assist, Support groups/programs). (2)Interventions of formal approaches to care designed to support caregivers in their role (Care planning, Case management, Specially designated members of the healthcare team (dementia nurse specialist or volunteers trained in caring for someone with dementia). (3)Multi-component interventions that involve any of the above · systematic reviews, meta-analyses, randomized control trials, quasi-experimental studies, cohort studies, case control studies and observational studies without control groups. · studies from 2000 to 2005 · outcomes: Health service utilization, caregiver satisfaction with health service utilization, psychological morbidity of caregivers, caregiver quality of life, caregiver self-reported perception of knowledge or competence in caring for someone with dementia in the community Exclusion criteria: · outcomes concerning respite care	CINAHL, MEDLINE, PsycINFO, Cochrane (CDSR, DARE, CCTR, CENTRAAL), APAIS health, Current Contents, ERIC, Professional Development Collection, Psycarticles, Dissertation and Thesis Abstracts, NHMRC guidelines, Social Science Citation, Ageline, Econlit, Sociological Abstracts Additional searches: hand searching reference lists of articles retrieved, foundation works older than five years referred to in the literature were also included in the review Search period: 2000-2005	5.5	34 studies All studies were RCTs. In addition 3 meta-analyses and 3 systematic reviews were included Control conditions: · usual care, waiting list · a limited version of the intervention	Spouse (52%) Caregivers taking responsibility for the care of a person with dementia living in the community	Number of intervention sessions ranged from 1 to 38 Intervention period: post test ranged from 1 to 24 months 2nd post test ranged from 3 to 24 months 3rd post test ranged from 6 to 36 months Professionals: · project staff member, occupational therapist, psychologist, nurse(s), volunteers who had been caregivers

General and methodological characteristics of reviews included						Underlying studies in the reviews		
Reference, first author's country of origin	Review design	Review objective	Review's eligibility criteria	Information sources and search periods	Score methodological assessment:	Number, design and control conditions	Participants in underlying studies included in reviews	Number of sessions, intervention period and professional who delivered the intervention
Peacock & Forbes (2003) Canada	Systematic review	To determine the effectiveness of a range of interventions to enhance the well-being of caregivers of elderly persons with dementia living in the community	Inclusion criteria: · studies published in 1992 or later · interventions directed at caregivers of an elderly individual with dementia living in the community · caregiver outcomes: well-being (physical, mental, social, or financial), depression, strain, and/or other (e.g., institutionalization, health-care expenditure) · incorporated a control group or a pre-test-posttest design with a sample size greater than one Exclusion criteria: · not provided	CINAHL, PubMed, PsycINFO Additional searches: hand searching the table of contents of The Gerontologist, Journal of Gerontological Nursing, and Journal of the American Geriatrics Society as well as searches in the reference lists of retrieved studies Search period: 1992-2002	5.5	11 studies All studies were RCTs Control conditions: · usual care · Interventions: respite care, a limited version of the intervention	Caregivers (not further specified) of persons with dementia living in the community	Number of interventions sessions ranged from 14 to 72 Intervention period ranged from 12 weeks to 8 years Professionals: · family coordinator, case manager, clinical psychologist, clinical nurse specialist, family counselors, nurse
Pinquart & Sörensen (2006) Germany	Meta-analysis	To investigate effects of interventions on caregiver burden, depression, indicators of positive subjective well-being, ability/knowledge of caregivers, symptoms of care receivers and the risk of institutionalization. To compare effects of different forms of interventions (such as caregiver education, general support, and respite) To analyze the impact of study characteristics on intervention effects, such as group-based versus individualized interventions	Inclusion criteria: · care receiver has dementia · an intervention condition was compared to a control condition that did not receive the treatment · outcomes: caregiver burden, depression, subjective wellbeing (e.g. life-satisfaction, happiness), knowledge and/or coping abilities of the caregiver, CR symptoms and institutionalization · statistics could be converted into effect sizes · studies written in English or German, or in a language for which we could get translation Exclusion criteria: · not provided	PsycINFO, MEDLINE, Ageline, Psyndex Additional searches: cross-referencing Search period: 1982-2005	6	127 studies were reviewed of which 111 consist SMS interventions (16 studies are respite interventions) Design of underlying studies are not reported Control conditions were not reported	Spouse (60%), adults child (39%) of people with dementia living at home (two exceptions)	Overall: Number of intervention sessions ranged from 1 to 180 (median = 9). Intervention period: range of intervention period is not provided. Follow up (in n=32) was on average after 11 months (SD=11.1) Professionals: · not reported

General and methodological characteristics of reviews included						Underlying studies in the reviews		
Reference, first author's country of origin	Review design	Review objective	Review's eligibility criteria	Information sources and search periods	Score methodological assessment:	Number, design and control conditions	Participants in underlying studies included in reviews	Number of sessions, intervention period and professional who delivered the intervention
Thompson et al. (2007) United Kingdom	Systematic review and meta-analysis	To assess the effectiveness of interventions based around information and support provision for informal caregivers of people with dementia in community settings	Inclusion criteria: · RCTs · principal informal caregiver (not a paid professional) and care recipient (diagnosed with dementia) dyad living in the community · information and/or support interventions · outcomes: caregiver outcomes (quality of life, physical and mental health, burden or satisfaction); and patient outcomes (activities of daily living or behaviours); health service utilization (numbers of in-patient, outpatient or primary health care contacts); economic outcomes (time spent on caring activities) Exclusion criteria: · not provided	Search of the Specialized Register of the Cochrane Dementia and Cognitive Improvement Group Additional searches: citation searches for key papers, reference checking and contact with authors Search period: inception - 2005	5	44 studies All studies are RCTs Control conditions: · wait list, usual care · interventions: a limited version of the intervention	Informal caregivers (individuals who provide extraordinary, uncompensated care, predominantly in the home, carried out primarily by family members) of persons with dementia living in the community	Number of sessions ranged from 2 to 72 Intervention period ranged from 1 month to 24 months Professionals: · nurse moderator, case manager, counselor, psychologist, volunteers
Van 't Leven et al. (2013) Netherlands	Systematic review	To update Smits et al.'s (2007) systematic review, and to provide the current best evidence about psychosocial programs for the dyads that involve face-to-face contact between professional caregivers and both the patient and the caregiver	Inclusion criteria: · effect studies evaluating dyadic psychosocial interventions for both older people with dementia living in the community and their caregivers. · interventions had to involve face-to-face contact between care professional and the person with dementia as well as the informal caregiver and the same care professional · interventions had to target psychosocial outcomes, improving mental health or well-being · RCTs Exclusion criteria: · RCTs involving respite interventions, and technological devices, as well as cost-effectiveness studies, studies among nursing home residents, and integrated studies where results could not be related to a specific intervention or program	PsycINFO, EMBASE, MEDLINE, and CINAHL for single studies and reviews, and the Cochrane Library for systematic reviews Search period: 2005-2012 (also update of review of Smits et al.)	5.5	23 studies All studies were RCTs Control conditions: · usual care, waiting list · interventions: educational materials/visits, medication · not reported	Informal caregivers (not further specified) of person with dementia living in the community	Number of sessions ranged from 2 to 15 Intervention period ranged from 5 weeks to 3 years Professionals: · professional with master's degree, occupational therapist, multidisciplinary team, home health prof, nurse/case manager/coordinator, home care advisor psychiatrist, primary care physician/nurse practitioner/psychologists

General and methodological characteristics of reviews included						Underlying studies in the reviews		
Reference, first author's country of origin	Review design	Review objective	Review's eligibility criteria	Information sources and search periods	Score methodological assessment:	Number, design and control conditions	Participants in underlying studies included in reviews	Number of sessions, intervention period and professional who delivered the intervention
Vernooij-Dassen et al. (2011) Netherlands	Systematic review	To evaluate the effectiveness of cognitive reframing interventions for carers of people with dementia To indicate the nature and quality of the evidence available To contribute to providing an evidence base for clinical practice	Inclusion criteria: · RCTs · family carers taking care of a person with any type of dementia; spouse, child, other family member or friend · interventions aimed at reduction of caregiver problems; family carers' beliefs about their responsibilities, about own need for support and assistance and their interpretations of behaviors of people with dementia. No restrictions regarding control interventions · outcomes: psychological morbidity and distress of family carers (including depression and anxiety), QoL of family carers, family carers' appraisal of their role performance (burden, coping, self-efficacy and problem behaviors), healthcare utilization outcomes (admission to residential care or number of general practice visits) Exclusion criteria: · not provided	Cochrane Dementia and Cognitive Improvement Group (CDCIG) Specialized Register including The Cochrane Library, MEDLINE, EMBASE, PsycINFO, CINAHL and LILACS Additional searches: ongoing trial databases and other gray literature sources Search period: inception-2009	7	11 studies All studies were RCTs Control conditions: · usual care, wait list · interventions: telephone calls, multiple different control groups · not reported	Spouse (40.2%) Adult child (28.1%) and other (6.7%) of community-dwelling people with dementia (25% of carers no relationship to person with dementia was specified)	Number of sessions ranged from 8 to 14 Intervention period ranged from 9 weeks to 4 months Professionals: · not reported

Additional file 4. Outcome and effects of reviews included

	Outcome and effects of reviews included				
Reference	Type of self-management support interventions	Outcome variables of reviews included	Results of intervention as reported in review	Participant and intervention characteristics	Conclusion of the authors of included reviews
Boots et al. (2013)	Internet-based interventions including: · website with information and support · website with additional caregiving strategies · website combined with telephone support website with additional e-mail support · website with a combination of individual work and exchange with other caregivers online	Various e.g.: · self-efficacy · stress/burden · depressive symptoms · coping · social contact/ support · knowledge · (utilization of) health services	· (small) significant improvement of caregivers' well-being in measurement of depression, sense of competence, decision-making confidence, self-efficacy, and burden. However caregiver burden did not decrease significantly in all studies. Significant differences were found in caregiver burden between non-users and frequent users of the program. Increased intention to seek support was reported, as well as caregiver gain and self-control whereas caregiver stress and strain decreased · no significant effects between groups or within the treatment group on quality of life or coping skills · stress management techniques among caregivers and social isolation and health status did not improve. One study reported improvements in the control group: anxiety and depression decreased significantly, and well-being and quality of life increased.	No effects for participant and intervention characteristics were reported based on an analysis	Internet interventions for informal dementia caregivers may improve caregiver well-being
Chien et al. (2011)	Caregiver support group interventions including: · mutual support group · psychoeducational group · educational group	· mental health · depression · burden · social outcome	· caregivers' mental health significantly improved (g= -0.44[95% CI= -0.73, -0.15] p= <0.001) · depression was significantly reduced in caregivers (g= -0.40[95%CI=-0.72,-0.08] p=<0.001) · support group interventions effectively relieved burden for caregivers (g= -0.23 [95% CI= -0.33, -0.13] p=0.286) · social outcomes significantly improved (g= 0.40 [95% CI=0.09, 0.71] p=<0.001)	· Intervention characteristics: use of theoretical models, length of group sessions and total hours impacted significantly on psychological wellbeing and depression. The following factors were associated with a more prominent and larger effect size: psycho educational groups, use of theoretical models, group size of 6-10 people, length of group sessions ≥ 8 weeks and total hours ≥16 and follow up. For burden: educational and training group, use of theoretical models, group size of 6-10 people, length of group sessions ≥ 8 weeks and total hours ≥16 and follow up. · Participant characteristics (female participants, younger age, severity of dementia) in between-groups comparison on the effect sizes of psychological well-being, depression and in some cases burden	Support groups are significantly effective for caregivers of patients with dementia, while the effect size varies with different outcome variables, including psychological well-being, depression, burden, and social outcomes

Outcome and effects of reviews included					
Reference	Type of self-management support interventions	Outcome variables of reviews included	Results of intervention as reported in review	Participant and intervention characteristics	Conclusion of the authors of included reviews
Mantovan et al. (2010)	· psycho-educational interventions · psychotherapeutic interventions · support interventions (individually or in groups) · case and care management · multicomponent interventions · training programs	Various	· psycho-educational intervention: 1 study reported improvements in competence, coping and total burden. 1 underlying review (Thompson) reported that technology-based psycho educational interventions have no effect on depression. Group based interventions were found to have a positive effect on depression. 1 underlying study (Pinquart) found effects for burden, depression, wellbeing and ability and knowledge · psychotherapeutic interventions (cognitive-behavioral) lead to a clear improvement of depression, while this showed inconsistent results for other interventions. · support interventions: 1 underlying review reported that none of their included studies showed effect on anxiety. 1 underlying study reported a reduction in depression. Another underlying study found no effects on burden and depression. · counseling / case management: 1 underlying review (Pinquart) reported a reduction of burden. 1 underlying study reported increased coping and a determination of coping. · multi-component: effects of underlying studies report significant effects in depression, burden and psychological health. In one underlying review (Pinquart) no effect was found for burden, depression, subjective wellbeing and ability/knowledge. · training program: effects of underlying studies reported mixed results on effects on the caregiver. 1 underlying study reported a reduction in burden. 1 underlying study (Pinquart) reported no effects on the caregiver. Coping, mood and competence were also reported to be improved. A significant improvement of competence was only found after 6 months.	No effects for participant and intervention characteristics were reported based on an analysis	The presentation of the results shows that psycho-educational, relieving, supportive, psychotherapeutic and multi-component interventions offered as well as counseling and case/care management among caring family members have significant effects on parameters such as burdens, level of depression, subjective well-being, skills/knowledge.
Marim et al. (2013)	· (psycho) educational programs	· caregiver burden	· decreased caregiver burden (Articles that used intention to treat (MD -1.10 [95%CI-2.25, 0.05] p=0.06). Articles without intention to treat (MD:-4.46 [95%CI-15.54, 6.62] p=0.43). After excluding 3 studies (to reduce heterogeneity): MD -1.62 [95%CI -2.16, -1.08])	No effects for participant and intervention characteristics were reported based on an analysis	The evidence obtained in this study suggests that educational and support programs have a positive impact on the reduction of caregiver burden when compared to standard care

Outcome and effects of reviews included					
Reference	Type of self-management support interventions	Outcome variables of reviews included	Results of intervention as reported in review	Participant and intervention characteristics	Conclusion of the authors of included reviews
Parker et al. (2008)	· psychoeducational interventions · support interventions · multi-component interventions · other	Various including: · depression · health · subjective well-being · self-efficacy · burden	· psycho-educational interventions: statistically significant results for depression (WMD -1.93[95%CI -3,79, -0.07] p=0.04) and subjective well-being (SMD -0.16 [95%CI -0.32, 0.00] p=0.04) but not for health (SMD 0.05 [95%CI -0.38, 0.48]), self-efficacy (SMD 0.30 [95%CI -0.04, 0.65]) and burden (SMD 0.02 [95%CI -0.37, 0.42]) · support interventions (2 studies out of 7) report significant effects on caregiver burden (SMD -0.41, [95% CI -0.80, -0.02], p=0.04). 5 studies did not report significant findings in their interventions · multi-component: Mixed results were found in the underlying studies and reviews across a variety of outcome measures.	No effects for participant and intervention characteristics were reported based on an analysis	From this review there is evidence to suggest that well designed psycho-educational or multi-component interventions may assist caregivers of people with dementia who live in the community. More studies are needed to provide evidence of the effect of support interventions
Peacock & Forbes (2003)	· case-management interventions · education interventions · psychotherapy interventions · computer-networking interventions	· caregiver depression · caregiver strain · caregiver stress · use of formal services	· case management interventions did not impact on levels of strain or depression for caregivers. · education interventions are insufficient to improve overall caregiver psychological well-being, such as decreasing strain and depression. · psychotherapy: only outcomes on the person with dementia were given · computer networking intervention: a significant increase in decision-making confidence; no significant differences between the groups were found in relation to decision-making skills, social isolation, or use of health services	No effects for participant and intervention characteristics were reported based on an analysis	This systematic review reveals few significant effects for caregiver interventions, although non-significant findings were more common.

	Outcome and effects of reviews included				
Reference	Type of self-management support interventions	Outcome variables of reviews included	Results of intervention as reported in review	Participant and intervention characteristics	Conclusion of the authors of included reviews
Pinquart & Sörensen (2006)	Various interventions included namely: · psycho-educational interventions · cognitive behavioral therapy (CBT) · counseling/case management · general support · training of the care receiver · multi-component interventions · miscellaneous interventions	· burden · depression · subjective wellbeing · ability/knowledge	· psycho-educational interventions had significant effects on burden (-0.15 [95% CI -0,25,-0.04] t-2.76), depression (-0.27, [95% CI -0.41, -0.13], t-3,88), subjective wellbeing (0.24 [95% CI 0.04, 0.44] t2,35), and ability/knowledge (0.46, 95%CI 0.28, 0.64, t4,90) · cognitive-behavioral therapy had significant effects on burden (-0.36 [95% CI -0,73,-0.01] t-1,89), depression (-0.70 [95% CI -1.10, -0.30] t-3,45), No significant effects were found on subjective wellbeing (0.37 [95% CI -0.27, 1.01] t1,13) and ability/knowledge (1.12 [95%CI -0.23, 1.62] t1.62) · counseling/ case management had significant and moderately sized effects on burden (-0.50 [95% CI -0.86,-0.14], t-2.73). No significant effects were found on depression (-0.20 [95% CI -0.63, 0.23] t-0.92), subjective wellbeing (0.42 [95% CI -0.01, 0.85] t1.93) and ability/knowledge (0.43 [95%CI -0.01, 0.86] t1.94) · supportive interventions had significant effects on subjective wellbeing (based on 1 study, 2.03 [95% CI 1.36, 2.70] t5.95). No significant effects were found for effects on burden (0.01 [95% CI -0.33, 0.35] t0.07), depression (0.05 [95% CI -0.68, 0.78] t0.13) and ability/knowledge (0.29 [95%CI -0.03, 0.61] t1.77) · training of the care recipient had no significant effects on burden (-0.17 [95% CI -0.60, 0.27] t-0.76), depression (0.01 [95% CI -0.56, 0.58] t0.03), subjective wellbeing (0.42 [95% CI -0.18, 1.01] t1.36) and ability/knowledge (-0.12 [95%CI -0.78, 0.49] t-0.37) · multi-component interventions had no significant effects on burden (-0.03 [95% CI -0.11, 0.05] t-0.74), depression (-0.10 [95% CI -0.26, 0.06] t-1.19), subjective wellbeing (-0.13 [95% CI -0.68, 0.41] t-0.48,) and ability/knowledge (0.55 [95%CI -0.55, 1.55] t0.93,) · miscellaneous interventions: no significant effects on burden (-0.20 [95% CI -0.42, 0.02] t-1.76), depression (0.12 [95% CI -0.15, 0.38] t0.86), subjective wellbeing (0.37 [95% CI -0.09, 0.83] t1.58), ability/knowledge (0.35 [95%CI -0.13, 0.82] t0.82)	· longer interventions were more likely to improve depression · a higher percentage of women showed more improvements in depression and knowledge/abilities, less improvement in subjective wellbeing	Caregiver interventions have significant but small effects on reducing burden, depression, subjective wellbeing, ability/knowledge and care recipient symptoms. Psycho-educational interventions have the broadest effects, but only if they call for active participation

Outcome and effects of reviews included					
Reference	Type of self-management support interventions	Outcome variables of reviews included	Results of intervention as reported in review	Participant and intervention characteristics	Conclusion of the authors of included reviews
Thompson et al. (2007)	Information and support interventions including: · technology-based interventions · group-based interventions · individual-based interventions	Various including e.g.: · information · perceived social support · support satisfaction · depression · burden · self-efficacy	· technology-based interventions: no significant effects found on depression (WMD 0.62 [95%CI -1.98, 3.22] p=0.64) · group-based interventions: psychoeducational interventions had significant effects on caregiver depression: (-0.71 [95% CI -0.95,-0.46] p<0.00001). No significant effects were found on burden (-2.15 [95% CI -5.97,1.66] p=0.27). Support intervention (group-based): no significant effects found on burden (-0.40 [95% CI -5.69, 4.90] p=0.88) · individual (psycho-educational) interventions: no significant effects were found on depression (-0.21 [95% CI -0.61, 0.20] p=0.32) and on self-efficacy (0.37 [95% CI -0.28, 1.02] p=0.26)	No effects for participant and intervention characteristics were reported based on an analysis	There is little evidence that interventions aimed at supporting and/or providing information to caregivers of people with dementia are uniformly effective
Van 't Leven et al. (2013)	Most programs consist of multiple treatment components including: · information · psycho-education · skills training · coping strategies for the caregiver Also self-management support interventions for persons with dementia were included viz: · information, training for activities of daily life, walking or exercise, and environmental adaptation	· mood · burden · competence · quality of life (Also outcomes of persons with dementia were studied but not included in our meta-review)	· mood; 2 studies found significant positive effects, 1 study found a positive effect only on 18 months; 1 study a positive trend; 5 studies did not show statistically significant effects · perceived burden and competence; 13 studies showed significant positive effects (not at all follow up points), 4 studies did not show statistically significant effects · quality of life (n=10); 7 studies found significant positive effects, 3 studies did not show statistically significant effects	No effects for participant and intervention characteristics were reported based on an analysis	Dyadic psychosocial programs are effective, but the outcomes for the person with dementia and caregiver vary
Vernooij-Dassen et al. (2011)	Cognitive reframing interventions including e.g.: · cognitive behavioral therapy · skills building/training – coping/behavior management	· anxiety · depression · stress · carer burden · coping or self-efficacy · quality of life	· change in anxiety (SMD-0.21 [95%CI -0.39, -0.04] p= 0.02), depression (SMD -0.66 [95%CI -1.27, -0.05] p= 0.03) depression (subgroup analysis)SMD -0.24 [95% CI 0.42, -0.07]) and stress/ distress related to caregiving (SMD -0.24 [95% CI -0.40, -0.07] test overall effect p=0.006) indicated a significant benefit from treatment · no significant benefit from treatment was found on carer burden (SMD -0.14 [95%CI -0.32, 0.03], p=0.12), coping/ self-efficacy (SMD 0.64 [95% CI -0.17, 1,45] p=0.12) and RMBPC (SMD -0.21 [95%CI 0.45, 0.03] p=0.09)	No effects for participant and intervention characteristics were reported based on an analysis	Cognitive reframing for family carers of persons with dementia showed beneficial effects over usual care for psychological morbidity (anxiety, depression) and (dis)stress. No effects were found for coping or self-efficacy, carer burden and reaction to the relative's behavior.

Additional file 5. Evidence for self-management support interventions reported by the included reviews on outcome

			Outcomes														
	Review	Intervention as described by the authors	Burden	De-pression	Well-being	Ability/ knowledge	Coping skills	Self-efficacy	Decision Making confidence	Anxiety	Stress or distress	RMB-PC[1]	Quality of life	Social outcomes	Mood	Health	Sense of competence
Relationship with family	Mantovan et al. (2010)	· Case and care management	+ (1)				+ / - (1)										
	Parker et al. (2008)	· Support interventions	+ (2)*/ 0 (5)														
	Peacock & Forbes (2003)	· Case-management interventions		0 (1)													
		· Psychotherapy															
	Pinquart & Sorensen (2006)	· Counseling/case management*	+ (4)	0 (3)	0 (3)	0 (3)											
Psychological wellbeing	Chien et al. (2011)	· Caregiver support group interventions*	0 (24 ES)	+ (17 ES)	+ (19 ES)									+ (13)			
	Mantovan et al. (2010)	· Psychotherapeutic interventions	+ (2)/ 0 (1)	+ (3)						0 (2)							
		· Support interventions	0 (1)	+ (1)/ 0 (1)						0 (1)							
	Pinquart & Sorensen (2006)	· Cognitive behavioral therapy*	+ (9)	+ (11)	0 (1)	0 (3)											
		· Support*	0 (4)	0 (2)	+ (1)	0 (3)											
	Vernooij-Dassen et al. (2011)	· Cognitive reframing interventions*	0 (4)	+ (6)			0 (4)	0 (4)		+ (4)	+ (4)	0 (3)					

			Outcomes														
	Review	Intervention as described by the authors	Burden	Depression	Well-being	Ability/ knowledge	Coping skills	Self-efficacy	Decision Making confidence	Anxiety	Stress or distress	RMB-PC¹	Quality of life	Social outcomes	Mood	Health	Sense of competence
Techniques to cope with memory change	Mantovan et al. (2010)	· Trainingsprogram	+ (1)/ 0 (1)	0 (1)	0 (1)	0 (1)	+ (1)								+ (1)		+ (1)
	Pinquart & Sorensen (2006)	· Training of care recipient*	0 (6)	0 (4)	0 (3)	0 (2)											
Information	Boots et al. (2013)	· Internet-based supportive interventions	+ (2)/ 0 (2)	+ (2)/ — (1)	— (1)		0 (1)	+ (4)	+ (1)	— (1)	+ (1)		0 (1)/ — (1)			0 (1)	+ (1)
	Mantovan et al. (2010)	· Psychoeducation interventions	+ (3)	+ (1)/ 0 (1)	+ (1)	+ (1)	+ (1)	0 (1)									+ (1)
	Marim et al. (2013)	· Educational programs (analysis of sensitivity)*	+ (4)														
	Parker et al. (2008)	· Psycho-educational interventions*	0 (7)	+ (4)	+ (5)			0 (4)								0 (3)	
	Peacock & Forbes (2003)	· Education interventions		0 (2)													
		· Computer-networking intervention							+ (1)								
	Pinquart & Sorensen (2006)	· Psychoeducation*	+ (42)	+ (32)	+ (13)	+ (34)											
	Thompson et al. (2007)	· Information and support interventions (technology-based interventions)*		0 (3)													
		· Information and support interventions (group-based interventions)*	0 (3)	+ (5)													
		· Information and support interventions (individual-based interventions)*		0 (7)				0 (2)									

			Outcomes															
	Review	Intervention as described by the authors	Burden	Depression	Well-being	Ability/ knowledge	Coping skills	Self-efficacy	Decision Making confidence	Anxiety	Stress or distress	RMB-PC¹	Quality of life	Social outcomes	Mood	Health	Sense of competence
Multi-component	Mantovan et al. (2010)	· Multimodale interventions	**+** (1)/ **0** (1)	**+** (2)/ **0** (1)	**0** (1)	**0** (1)											
	Parker et al. (2008)	· Multi-component interventions	**+/0** (14)	**+/0** (14)	**0** (1)	**0** (1)							**+** (1)				
	Pinquart & Sorensen (2006)	· Multi-component interventions*	**0** (10)	**0** (8)	**0** (2)	**0** (2)											
		· Miscellaneous interventions*	**0** (11)	**0** (6)	**0** (1)	**0** (1)											
	Van 't Leven et al. (2013)	· Dyadic interventions with multiple treatment component	**+**(13)/ **0**(4)										**+** (7)/ **0** (3)		**+** (3)/ **0** (6)		**+** (13)/ **0**(4)

+ significant effect for the intervention on the outcome reported by the included review
– significant reversed effect for the intervention on the outcome reported by the included review
0 no (significant) effect for the intervention on the outcome reported by the included review
( ) number of underlying studies

*combined effect of the intervention on the outcome reported by the included review
¹Revised Memory and Behavior Problem Checklist

CHAPTER 4

Self-management-support in dementia care: A mixed methods study among nursing staff

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ABSTRACT

Background

Self-management in patients and family caregivers confronted with dementia is not self-evident. Self-management skills may be limited because of the progressive cognitive decline of the patient and because family caregivers are often also very aged. Self-management support by nursing staff is therefore of paramount importance.

Objectives

To gain insight into how nursing staff perceive their self-management support tasks, and how they put them into practice. Research questions are: 'What are the opinions and experiences of Dutch nursing staff working in home care or residential elderly care regarding self-management support for people with dementia and their family caregivers?' and 'Do nursing staff feel sufficiently trained and skilled for self-management support?'.

Methods

A mixed methods approach was used, combining cross-sectional quantitative survey data from 206 Dutch nursing professionals with qualitative interviews among 12 nursing staff working in home care or residential elderly care in The Netherlands.

Results

Nursing staff working in home care experienced self-management support of people with dementia as a part of their job and as an attractive task. They consider 'helping people with dementia to maintain control over their lives by involving them in decisions in daily care' the essence of self-management support. Nursing staff saw family caregivers as their main partners in providing self-management support to the patient. They were less aware that family caregivers themselves might also need self-management support. Nursing staff often felt insufficiently trained to give adequate self-management support. RN's and CNA's did not differ in their opinions, experiences and training needs.

Conclusions

Nursing staff in home care do consider self-management support an important and attractive task in dementia care. Their skills for providing self-management support to patients with dementia and family caregivers need improvement.

Recommendations

Nursing staff need sufficient training to enable the proper provision of self-management support for people with dementia. More attention should also be given to the support of self-management for family caregivers.

INTRODUCTION

Most people with progressive diseases like dementia prefer to have control over their own lives and health care for as long as possible. Keeping in control means, among other things, that patients perform self-management activities. In line with the well-known definition of Barlow *et al.* [1], we define self-management as *"the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition"*. Supporting people in decisions and actions that promote self-management is called self-management support, requiring a 'cooperative relationship' between the patient, the family and the professionals. A review by the Health Foundation shows that supporting self-management can have benefits for people's attitudes and behaviors, quality of life, clinical symptoms and use of healthcare resources [2]. By giving self-management support, nurses and other healthcare professionals can help patients and their families to manage their condition and develop the confidence to make choices about the care they need.

Although there is a growing awareness in health care that self-management and self-management support are important [3], the actual practice of self-management activities is not self-evident in all patient groups. For instance, self-management in people with dementia is hampered by their progressive cognitive decline. Nonetheless, people with dementia have to manage many problems related to their dementia every day: not just the 'forgetting', but often also behavioral and psychological problems like depression, apathy and agitation [4, 5]. Dementia often leads to much reliance by the patient on family care, which may cause stress, anxiety and depressed moods in family caregivers [6]. Therefore, it is important that family caregivers also have support from professionals, both in managing the patient's challenges and their own. Hence self-management support in people with dementia is about supporting the person with dementia and their family caregivers individually and together, in fulfilling their individual and shared needs. Self-management refers to how the systems of people with dementia and their family caregivers manage the symptoms, problems, treatment and other challenges related to the dementia in their daily life.

Nursing staff are particularly appropriate professionals for providing self-management support because a core competency of nursing staff is to empower patients and to enable people to understand and cope with their disease, its treatment and its consequences [7]. However, little research has been done on how nursing staff perceive their self-management support tasks, and how they perform these tasks in daily dementia care [8]. This paper aims to provide insight into how nursing staff working in those settings where dementia care is mostly delivered – home care and residential elderly care – perceive their self-management support tasks. Therefore, we address the following research questions:

- What are the opinions and experiences of nursing staff working in home care or residential elderly care regarding self-management support for people with dementia and their family caregivers?
- Do nursing staff feel sufficiently trained and skilled for self-management support?

METHODS

Study design

We used a mixed methods design, combining secondary analyses of cross-sectional quantitative survey data with qualitative semi-structured interviews.

Participants

Survey participants.

The study started with the secondary analysis of an existing quantitative dataset. This dataset came from a cross-sectional survey among a national representative sample of nursing staff known as the Nursing Staff Panel [9]. The data were collected in 2012. The data that were analyzed came from 206 nursing staff members, namely 46 Registered Nurses (RNs) and 160 Certified Nurse Assistants (CNAs). Only those data were eligible for analysis that were provided by nursing staff meeting the following criteria: (a) being an RN or CNA, (b) working in residential elderly care

Table 1 *Characteristics of the respondents in the secondary analyses of survey data (n= 206).*

Characteristics	%
Gender: Female	96.1
Age:	
•<35	10.7
•36–45	21.8
•46–55	37.4
•56–65	30.1
Healthcare sector:	
•Residential elderly care: nursing home	26.7
•Residential elderly care: home for the elderly	35.0
•Home care	38.3
Educational level	
•RN, bachelor level	8.3
•RN, associate level	14.1
•CNA, associate level	77.7

or home care, (c) caring for people with dementia (people with dementia were one of client groups that they worked with most). The characteristics of the 206 nursing staff whose data were used are presented in Table 1. As this table shows, nursing staff working in home care, staff working in assisted living facilities and staff working in nursing homes were all included. Assisted living facilities and nursing homes both fall in the category of 'residential elderly care'. The difference is that, in the Netherlands, more complex nursing and medical care is delivered in nursing homes than in assisted living facilities [10].

Semi-structured interview participants.

We then performed qualitative interviews in order to deepen, refine and illustrate the insights gained from the quantitative analysis. The interviews were held with 12 nursing staff working in home care or in residential elderly care. Regarding residen-

Table 2 *Demographic characteristics of the interviewees (N= 12).*

Participant	Gender	Age	Professional level	Healthcare sector	Area
1	Female	<30	RN with a bachelor degree	Residential elderly care	City, western part of the Netherlands
2	Female	40–50	CNA	Residential elderly care	City, southern part of the Netherlands
3	Female	30–40	CNA	Home care	Rural area, central part of the Netherlands
4	Male	<30	CNA	Home care	City, western part of the Netherlands
5	Female	40–50	RN with associate level degree	Home care	Rural area, western part of the Netherlands
6	Female	<30	RN with bachelor degree	Residential elderly care	City, southern part of the Netherlands
7	Female	50–60	CNA	Residential elderly care	City, central part of the Netherlands
8	Female	<30	RN with associate level degree	Residential elderly care	City, northern part of the Netherlands
9	Female	<30	RN with bachelor degree	Home care	City, southern part of the Netherlands
10	Female	<30	RN with associate level degree	Home care	Rural area, eastern part of the Netherlands
11	Female	30–40	RN with associate level degree	Residential elderly care	Rural area, western part of the Netherlands
12	Female	<30	RN with bachelor degree	Home care	Rural area, eastern part of the Netherlands

CNA: Certified Nursing Assistant, RN: Registered Nurse.

tial elderly care, we only recruited participants working in nursing homes. The decision not to recruit professionals from assisted living facilities was made because at the time of the interviews (January–February 2014) Dutch residential elderly care underwent a major transition. One of the consequences was that many assisted living facilities had to close or convert to a nursing-home function.

Participants for the interviews were recruited from within the research team's professional networks. Purposive sampling was conducted, aimed at having a range of different educational levels, ages, settings and geographical areas. Twelve participants were recruited and interviewed in total. Twelve interviews appeared to be sufficient to reach data saturation, which is consistent with a review by Guest *et al.* [11] indicating that 12 interviews are often sufficient to reach saturation in a relatively homogenous group. The characteristics of the 12 nursing staff who were interviewed are presented in Table 2.

Data collection

Survey data collection.

Secondary analyses were performed on an existent dataset from the Nursing Staff Panel. The survey questionnaire data were all collected in January–February 2012. The survey questionnaire had been tested for comprehensibility, clarity and content validity. It included items on nursing staff's experiences, opinions and perceived expertise regarding self-management support. Questions about self-management support were based on a large survey about the self-management support needs of chronically ill patients, described in van van Houtum *et al.* [12]).

Data collection for the semi-structured interviews.

The 12 interviews were conducted from March to May 2014 by the second author (PH), in all cases with a co-reviewer (a nursing science student or a PhD researcher). All interviews took place at the respondent's home or work address and lasted between half an hour and an hour. A semi-structured topic guide was used to ensure that all relevant topics came up for discussion. The content of the topic guide was based on insights from the analyses in the quantitative part of the study. The topics were: (1) what participants found essential in self-management support in dementia care; (2) whether they found self-management support an attractive task; (3) their actual practice and experiences with self-management support for dementia patients; (4) self-management support in relation to the family caregivers of people with dementia; (5) the skills and knowledge needed for self-management support in dementia care.

Data analysis

Survey data analysis.

Descriptive statistics (frequencies and percentages) and chi-squared tests were used to analyze the existent set of survey data. Analyses were performed using SPSS 19.

Data analysis for the semi-structured interviews.

The audio recordings of the interviews were transcribed verbatim and anonymized. Three authors (PJH, RV and JHV) were involved in the entire process of data analysis. They read the transcripts individually, and after every third interview they discussed the interim analyses together. The principles of the Qualitative Analysis Guide of Leuven, which are largely based on grounded theory methodology, were used as a guide for the steps in the qualitative data analysis [13]. The coding process started with open and axial coding to identify, code and categorize the main themes in the transcripts. Theme's mainly followed the topics of the interview guide. Next selective coding was done to find connections between the categories [14]. The software program MAXQDA, version 11.0.8, was used as an aid in the coding and analysis process. The use of this program, the adherence to the principles of constant comparison [15], and the discussions of the interim and final analyses within the research team all helped enhance the quality of the analysis.

Ethical considerations

As this was a questionnaire and interview based study of nursing staff with no patient involvement, approval from an ethics committee is not required under Dutch law. Study participation was voluntary. Participants to the interviews were informed about the study with an information letter and signed an informed consent form before the interview took place. Data were anonymized before analyses and storage.

RESULTS

Opinions about and experiences with self-management support

The survey data showed that a large majority (83.2%) of the responding nursing staff considered self-management support a part of their job. Those who worked in home care were more likely to think this (93.2%) than those working in assisted living facilities (81.1%) or in nursing homes (62%). No differences between RN's and CNA's were found. Self-management support activities that were frequently mentioned were self-management support in personal care and in dealing with an uncertain

Table 3 *Percentage of nursing staff who perform the following self-management support activities.*

I support self-management of my clients in the following activities:	Yes	No, because it is not my professional task	No, because it has never occurred to me, although it is one of my professional tasks	No, because clients do not need these tasks to be done for them
Deploying activities in personal care	87.9	0.5	0.0	4.4
Using tools for self-management support	85.0	1.0	0.5	6.3
Calling for help if needed (1)	83.0	1.9	0.5	7.8
Dealing with limited energy levels (1)	79.6	1.5	2.4	9.7
Learning to deal with emotions and stress (1)	79.1	2.4	2.4	8.7
Understanding the information from physicians or other healthcare professionals (1)	78.2	3.4	1.5	9.7
Encouraging medication adherence (1)	78.2	1.5	0.5	13.1
Learning to deal with pain or limitations (1)	77.7	2.9	1.0	11.2
Monitoring the clients’ symptoms (1)	74.8	1.5	2.9	12.6
Encouraging the clients’ autonomy (1)	74.8	1.9	1.9	13.6
Consulting healthcare professionals when needed (1)	71.8	6.3	2.4	11.2
Letting clients maintain control of their lives (1)	70.9	5.8	2.4	12.6
Using family caregivers and volunteers when needed (1)	67.5	8.3	3.9	12.6
Visiting physicians or other healthcare professionals (1)	60.2	12.6	1.5	18.0
Learning to deal with an uncertain future (1)	60.2	6.8	5.3	19.4
Letting clients monitor their own health (1)	56.8	7.3	4.9	23.8
Encouraging clients to use the (limited) possibilities to undertake activities outside the home (1)	50.5	12.1	4.9	24.3
Encouraging exercise in the home (1)	49.5	11.7	5.3	25.7
Making decisions about treatment (1)	48.1	18.4	4.9	18.9
Strengthening the client’s social network (1)	46.6	18.0	7.3	20.4
Making contacts with care and welfare services (1)	44.2	14.6	8.7	25.7
Using new technology (for example: internet or e-health programmes) to promote self-management	19.4	17.0	12.1	43.2

(1) a statistically significant difference among healthcare settings (chi^2 $p< 0.01$).

future. Activities that were mentioned less often were, e.g. supporting the patient in using new technologies (e.g. e-health programs) that promote self-management (see Table 3).

In addition, the majority (61.6%) thought that it would be appealing to spend more time on self-management support in the future (not in table). However, there were significant differences between healthcare settings in this regard (p= 0.001). Those who worked in home care were more likely to hold this opinion (75.7%) than nursing staff working in residential elderly care: only 38.8% in nursing homes and 62.7% in assisted living facilities found it an attractive idea to spend more time on self-management support in the future. RN's and CNA's did not differ in their opinions.

The qualitative interviews also show that nursing staff see self-management support as part of their work. In the interviews, participants were asked what they saw as the essence of self-management support in dementia care. Although some said that self-management support was not a word they often used, most said that they associated it with helping a person with dementia to maintain control over his/her life.

> *"That the client feels that he is still in control of his life and that he can make his own decisions [..]. That they still have the feeling that they can make their own choices in their lives. I think that is very important" (Participant no. 10, who works in a nursing home).*

In addition, participants mentioned that self-management support will become more important in the future because more patients will remain at home as long as possible and future patients will probably be even more willing to have control over their own lives.

> *"The generation of people aged around 70 are getting more emancipated and are willing to look things up by themselves, for example by attending a discussion group or searching on the Internet for information about the development of a disease in an early stage. I think that our current clients don't do that because they haven't grown up with it" (Participant no. 5, who works in home care).*

Most examples concerned self-management support in personal care (e.g. bathing, eating and getting dressed). The participants promoted self-management by encouraging the person with dementia to perform these activities themselves. They described their position as a 'guide' in this process.

Participants also said that they tried to involve family caregivers in the process of self-management support.

> *“It is good to have conversations with the family caregivers and to explain and check if they know what the process of dementia means. It is also important to explain the goals of your nursing interventions”. (Participant no. 6, who works in home care).*

Some participants said that they enhanced family involvement in the self-management support of the patient through planned and spontaneous conversations with the family. Some also said that they supported the family caregivers in dealing with the disease and its consequences by giving them information and by referring them to other facilities, such as Alzheimer Cafe´ s (meeting points for clients and family caregivers confronted with dementia) or a dementia case manager. However, some other participants mentioned that family caregivers were not yet getting sufficient support in the self-management of their own problems. They suggested that nursing staff are not always aware that family caregivers need support in managing their own problems as well (e.g. caregiver stress).

The interviews also show that, in general, participants experienced self-management support as an attractive part of their job, and they sometimes saw positive effects in their clients.

> *“If you allow clients to be in control of their own lives and [..] if you respect them, there will be less reason for aggression” (Participant no. 8, who works in a nursing home).*

Most participants described continuity in care (few changes in personnel), good contact with the family caregivers and the client’s cooperation as facilitators of self-management support. Some participants also said that it helps if self-management support is defined in the policy of their care organization.

Perceived barriers preventing the provision of self-management support were lack of time, and particularly in nursing homes, staff shortages and an advanced stage of dementia. Some participants also said that it is difficult to give a person with dementia an active role, particularly those in the advanced stages of dementia in nursing homes, because the staff are used to taking over care tasks rather than supporting patients in self-management. In addition, participants stated that not all persons with dementia want to participate in self-management activities because some believe it is the professionals’ task to care for them rather than have them doing things themselves.

Table 4 *Percentage of nursing staff for statements on having sufficient self-management knowledge and skills.*

Do you think you have enough knowledge and skills to perform SELF-MANAGEMENT SUPPORT activities for people who are already (chronically) ill?				
	Nursing home	Assisted living facility	Home care	Total
Yes	61.2	71.2	65.8	66.5
Enough knowledge, but not enough skills yet	16.3	7.6	5.5	9.0
Not enough knowledge, but sufficient skills	12.2	6.1	12.3	10.1
No, both my knowledge and skills should be further trained	10.2	15.2	16.4	14.4

Knowledge, skills and training needs regarding self-management support.

The secondary analysis of the survey data showed that 66.5% of the participants thought they had sufficient knowledge and skills to deliver self-management support (see Table 4). The other participants however thought that their knowledge and/or skills were inadequate for providing self-management support for chronically ill clients. Again, no differences between RN's and CNA's were found.

In the interviews, almost all participants pointed to training needs, especially in supporting self-management in people with advanced dementia in nursing homes.

> *"I am really curious about what you can do (concerning self-management) in people with advanced dementia. Because that seems difficult. ...in my opinion they do not have a good overview of (situations)... helping themselves in small tasks does seem possible however". (Participant no. 1, who works in a nursing home)*

Nursing staff preferred to have training in the form of case discussions in team meetings where they can learn from one another and talk about 'real-life' cases.

> *"I would like to have training. In my own team... So that you have statements or case descriptions, and discuss these... So that you could learn from one another. (Participant no. 3, who works in home care)*

Some participants also stated that they did not need additional training because they could consult professionals in other disciplines, such as a dementia case manager working in home care, whenever they had difficulties providing self-management support.

DISCUSSION

Main findings

Dutch nursing staff saw self-management support as part of their job. They defined self-management support as helping clients to maintain control over their lives by involving them in decisions in daily care.

Both in home care and in nursing homes, nursing staff saw family caregivers as partners in providing self-management support to the patient. This is an important result since involving both family caregivers and the person with dementia in self-management interventions contributes to its effectiveness [16]. Nursing staff were however less often aware that family caregivers themselves may also have a need for support in self-managing their own problems (e.g. caregiver stress).

The majority of staff working in home care thought that spending more time on self-management support in the future was an appealing idea, but fewer participants working in residential elderly care found this an attractive task. These results may be explained by the fact that clients in residential care, particularly those in a nursing home, are more likely to have advanced dementia than clients who live at home, and nursing staff see fewer opportunities for self-management support in advanced dementia.

Despite the importance they attached to self-management support as part of their work, nursing staff often said that they had limited skills and knowledge about self-management support for dementia patients and family caregivers. According to nursing staff, facilitators of self-management support for people with dementia and family caregivers are continuity in care personnel, good contacts with the family caregivers, cooperation from the client and attention to the issue of self-management support in the policy of the care organization involved. In contrast, limited time, staff shortages and an advanced stage of dementia in the client were mentioned as barriers impeding self-management support. These barriers particularly play a role in nursing homes.

Interestingly, no differences were found between RN’s and CNA’s regarding their opinions and experiences with self-management in dementia and their perceived skills and training needs. This might be related to the fact that for both professions self-management support in dementia is a relatively new task.

This is one of the few studies on self-management or self-management support in dementia and, to our knowledge, the first study specifically focusing on the opinions and experiences of nursing staff. Insight into the opinions and experiences of nursing staff is important because nursing staff are the key professionals in the provision of self-management support. Studies by Martin *et al.* [17] and Toms *et al.* [18] confirm the importance of a whole systems approach to self-management support for people with dementia, systems in which nursing staff are important players.

Results of the current study show that a whole-systems approach to self-management support in dementia is only partly recognized by nursing staff. Nursing staff see family caregivers as their main partners in providing self-management support to people with dementia. They are however less aware that family caregivers themselves might also need self-management support.

Another question is what type of self-management support interventions nursing staff should apply to support self-management in people with dementia and their family caregivers. In a recently published meta-review we show that evidence exists for the effectiveness of self-management support interventions targeting the *psychological wellbeing* of family caregivers and for support interventions targeting *the provision of information* to family caregivers [19]. For people with early dementia, a recent review by Quinn *et al.* [20] shows that self-management components have already been incorporated into group-based interventions. Further studies are needed to determine the effectiveness of self-management (support) interventions with this population.

Strengths and limitations

The validity of the results was enhanced by combining survey data and semi-structured interviews (method triangulation) [21]. Consequently we were able to present a realistic picture of how nursing staff perceive self-management support.

A limitation is that the dataset with survey data that we used for secondary analyses did not explicitly focus on self-management support in dementia care. Although we only analysed data from participants who had indicated that people with dementia constituted one of their main patient groups, they may have considered other chronically ill patients as well when answering the survey questions. This limitation was however compensated by the fact that in the qualitative interviews we focused very specifically on self-management support for people with dementia and their families. The data from the interviews confirmed and deepened the results from the survey data.

CONCLUSIONS

The opinions and experiences of nursing staff regarding self-management support in dementia care are generally positive. Nursing staff in home care see more possibilities for self-management support in dementia care than nursing staff in residential elderly care. RN’s and CNA’s do not differ in their opinions and experiences. Sufficient time and training are needed to enable staff to deliver self-management support properly to patients with dementia and their family caregivers. More attention should also be given to self-management support by nursing staff for family caregivers.

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CHAPTER 5

Self-management by family caregivers to manage changes in the behavior and mood of their relative with dementia: an online focus group study

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ABSTRACT

Background

Self-management is important for family caregivers of people with dementia, especially when they face changes in their relative's behavior and mood, such as depression, apathy, anxiety, agitation and aggression. The aim of this study is to give insight into why these changes in behavior and mood are stressful for family caregivers, what self-management strategies family caregivers use when managing these changes and the stress they experience.

Methods

A qualitative study was conducted using four online focus groups with 32 family caregivers of people with dementia living in the Netherlands. Transcripts of the focus group discussions were analyzed using principles of thematic analysis.

Results

Managing changes in the behavior and mood of their relative with dementia is stressful for family caregivers because of constantly having to switch, continuously having to keep the person with dementia occupied and distracted, the fact that others see a different side to the relative, and the fact that caregivers know what to do, but are often not able to put this into practice. Caregivers use calming down and stimulation as self-management strategies for influencing the changes in the behavior and mood of their relative. Furthermore, caregivers describe three self-management strategies that let them manage their own stress and keep up the care for their loved ones: looking for distractions, getting rest, and discussing their feelings and experiences.

Conclusions

Behavior and mood changes of a person with dementia are stressful for family caregivers. They use several self-management strategies to positively affect the mood and behavior changes, and also to manage their own stress.

BACKGROUND

Changes in behavior and mood are common in people with dementia. Approximately 90 % of people with dementia experience behavioral and mood changes in the course of their disease [1]. These changes concern symptoms (or clusters of symptoms), such as depression, apathy, agitation and aggression [2, 3]. Changes in behavior and mood are prompted in part by the interaction between the person with dementia and their family caregivers [4, 5]. This makes managing changes in behavior and mood a challenge for family caregivers, in all phases of the dementia of their relative [6] .

The term ‘self-management’ is widely used these days by experts and professionals when talking about managing the impact of a disease in daily life. Following the definition of the national Dutch care standard self-management [7], which is largely based on the well-known definition of Barlow *et al.* [8], we define self-management as managing the chronic condition (symptoms, treatment, physical and psychological and social consequences, and related changes in lifestyle) so that the condition is optimally incorporated into daily life. Self-management is important not only for the patient but also for family caregivers [9]. Because dementia is a progressive condition, the patient becomes increasingly dependent on the family caregiver. This is partly why family caregivers have to make a significant contribution to the self-management of mood and behavioral changes of their relative with dementia. Furthermore, caregivers also have self-management tasks in managing their own stress resulting from, for example, managing the depressed mood or aggressive behavior of their relative with dementia [10].

A limited number of previous studies also described ways in which family caregivers manage with changes in the behavior and mood of their relative with dementia in their daily life [11-13]. These studies use the terms “management strategies”, “strategies” or “types of approach”. In a previous study from The Netherlands, de Vugt *et al.* [11] found that nurturing and supporting were the most frequent strategies used, when family caregivers were faced with behavior or mood changes of their relative with dementia. In Australian research, Moore *et al.* [12] described various strategies that family caregivers use in response to behavioral and psychological symptoms of dementia: encouraging activities, utilizing psychotropic medications, identifying triggers, restraining or treating in a paternalistic manner, and meeting physiological needs, were the most commonly used strategies [12]. Furthermore, Turner *et al.* [13] described strategies as well, namely in a study among family caregivers with a Latino background living in the USA. These caregivers tried to manage challenging behaviors of their relative with dementia, by acceptance, love, patience, adaptability, and establishing routines of care [13]. The afore mentioned studies are scarce examples of research on family carers’ strategies to deal with behavioral and mood changes in a relative with dementia [11-13].

Even less research has been done on the self-management strategies family caregivers use for managing the stress they themselves experience when faced with behavioral and mood changes in a relative with dementia. One of the rare studies in this field is done by Grigorovich *et al.* [14] among adult sons caring for a parent with dementia in Canada. Strategies used to manage their stress included boundary setting and practicing self-care [14]. In addition, an integrated literature review of Caceres *et al.* [15] described that the most frequently used strategies to manage caregiver stress in dementia, concerned adaptation and reframing. Caceres *et al.* [15] also concluded that strategies to reduce family caregiver stress are poorly understood.

The aim of this paper is to give more insight into the stress that family caregivers experience when there are changes in behavior and mood of their relative with dementia, and into the self-management strategies of family caregivers for managing those changes and for managing their own stress. Such insights will be helpful for nurses, casemanagers and other health care professionals in supporting family caregivers' self-management.
The specific research questions are:

1. Which aspects do family caregivers experience as stressful when they are faced with changes in behavior or mood (such as agitation, restlessness, apathy, and aggression, depression and anxiety) in their relative with dementia?
2. What self-management strategies do family caregivers use to manage these changes in the behavior and mood of their relative?
3. What self-management strategies do family caregivers use to manage their own stress when faced with behavioral and mood changes of their relative?

METHODS

Design

We ran online qualitative focus group discussions with family caregivers of people with dementia. An online focus group involves using a secure website on the Internet to conduct group discussions [16, 17]. The online variant of the focus group was chosen as this made it possible to reach family caregivers who would not easily be able to travel because of the commitment of caring for their relative with dementia.

Sample and recruitment

We recruited participants from an existing nationwide panel of family caregivers that is regularly used by the Dutch Alzheimer's society (http://www.alzheimerpanel.nl/). A total of 240 family caregivers were selected at random from the panel (n = 1200).

These caregivers were sent an e-mail from the Dutch Alzheimer's society, inviting them to take part in an online focus group if they met the specified criteria for inclusion. The following inclusion criteria applied:

- The caregiver had to be a relative of a person diagnosed with dementia.
- The caregiver had to have contact with the person with dementia at least once a week.
- The person with dementia had to live at home (not in a care institution).
- The family caregiver had to have access to the Internet on a daily basis during the online focus group period.
- The family caregiver had to be aged at least 18.

In total, 37 family caregivers sent an e-mail expressing that they met the specified criteria for inclusion and that they were willing to participate. These family caregivers were sent an information letter by post with a form for giving consent. A total of 36 family caregivers returned the consent form saying that they wanted to take part. Of this group, 32 family caregivers actually participated in an online focus group by posting comments on the website. These 32 individuals are therefore considered to be the study participants.

Online focus groups

There were four online focus groups in total between October 2014 and March 2015. Each focus group had seven to ten participants. Prior studies showed that this is a good number of participants to have for online discussions [18]. Only people who received a personal login code from the lead researcher (JH) could access this secure website. Participation was anonymous.

Over a period of two weeks, participants could log in to the secure website 24 h a day. Every second day, with the exception of weekends, one of the researchers (JH) added a new question (see below). Two of the authors (JH and RV) led the discussion by posing questions and summarizing reactions. They also send e-mail messages to participants who had not yet responded, if needed.

The following topics and questions were – amongst others - addressed in the online focus groups and form the basis of this article:

- Dementia often goes hand in hand with changes in the behavior or mood, such as irritability, restlessness, lack of initiative, aggressive behavior, depression, and anxiety. Do you recognize these changes in behavior and mood?
- How do you respond to changes in the behavior and mood of your relative with dementia?
- What effect does your way of responding to changes in the behavior and mood of your relative with dementia have?
- As a family caregiver, what is important in enabling you to manage these changes in your daily life?

Data analysis

The data collection and analysis was an iterative process, following thematic analysis principles [19], and ultimately leading to data saturation.

The analysis started with familiarization with data, through reading and rereading the transcripts of the online focus groups. Following that, relevant excerpts within the transcripts were marked and tagged with keywords (codes). Initially, keywords were chosen that were close to the wording used by the participants. Then related codes were grouped as a way of identifying themes. After that, themes were named, and relationships between themes were studied and analyzed [19]. Main related themes are displayed in Additional file 1.

- To improve the quality of the analyses and the trustworthiness, we used several strategies:
- The coding and ordering process of excerpts in the transcripts was supported by the MAXQDA11 software package.
- Triangulation of researchers was performed: all transcripts were first analyzed by two researchers independently: one trained as a nurse and health scientist (JH) and one trained as psychologist (RV). The coding and the interpretation of the codes were then discussed by these two researchers to deepen their analyses and to reach consensus about what were main themes. In addition, the other authors (BM, PJV, WW, CH & AF) each read and analyzed at least one transcript.
- All authors commented on interim and final analyses of the online focus group discussions. The authors have various educational backgrounds (nursing, health sciences, medicine, ethics, psychology, sociology) and various professions (researcher, professor, casemanager dementia, staff member of Alzheimer association). Furthermore, some authors have personal experiences as family caregiver of a person with dementia, which was also important for the quality of the analyses and for the trustworthiness of the results.

The qualitative methods and reporting of results adhere to the COREQ (Consolidated Criteria for Reporting Qualitative Studies) guidelines [20].

RESULTS

Background characteristics

A total of 36 family caregivers signed up for an online focus group. Of these, 32 actually participated in the discussions in the online focus group. The group consisted of partners as well as children and children-in-law. The majority said that the first symptoms of dementia (usually Alzheimer’s disease) appeared two to five years ago (see Table 1).

Table 1 *Background characteristics (n=36)*

Background characteristic	Number
Age family caregiver	
Average age (years): 61	
Range: 42 - 80	
Sex family caregiver	
Men	4
Women	32
Relationship of family caregiver with person with dementia	
Partner	17
Child or child-in-law	19
Highest educational attainment	
Primary school	3
High school (preparatory to vocational education) and vocational training	7
High school (preparatory to university education)	6
Professional or academic university	16
Missing	4
Type of dementia of the relative with dementia	
Alzheimer's disease	14
Alzheimer's disease with vascular components	3
Vascular dementia	1
Lewy body dementia	1
Frontotemporal dementia	1
Dementia (no further description)	16
First symptoms of dementia (according to the family caregiver)	
2-5 years ago	10
6-10 years ago	8
11-15 years ago	4
Not reported	14

All the family caregivers recognized changes in the behavior and mood of their relative with dementia, such as depression, anxiety, agitation, restlessness, or aggression. Managing these changes was stressful for them. Family caregivers mentioned several themes related to self-management. These are shown schematically in Additional file 1, and are elaborated below.

Stressful aspects for the family caregiver

Changes in behavior and mood of the relative with dementia are stressful for family caregivers. Four stressful aspects are mentioned: (1) the continual switching; (2) continually keeping the relative with dementia occupied and diverted; (3) the fact that others see a different side to their relative; and (4) knowing what to do in theory, but often being unable to put it into practice.

Continual switching

Family caregivers indicate that the behavior of their relative can change during the day, for example from apathy to restlessness. This means that the family caregiver needs to keep switching between different self-management strategies, for example from a diversion strategy to a strategy involving acknowledgement. Continually switching is also needed to make the relative with dementia feel at ease.

> *"I vary my responses. Sometimes I'm distracting her, sometimes acknowledging her feelings, sometimes choosing a different perspective, sometimes humbling myself and taking the blame. In other words: varied responses, depending on her needs." (Respondent 28)*

Continually keeping the relative occupied and diverted

Family caregivers also indicate that it is hard to keep their relative occupied and diverted. The relative can be restless, for example if something is not in the usual place, if the family caregiver is doing something else, or if there are visitors. Keeping the person with dementia occupied and diverted is a real challenge. As a result, family caregivers may not have time for their own pursuits and hobbies. To cope with this, family caregivers "try to get over it" and look for the next source of distraction. However, they do not always manage this:

> *"I can't do my hobby at home any longer. Our mentor told me to spend an hour in my hobby room whenever our household help is here, but unfortunately he keeps coming to ask questions. I miss my hobby an awful lot." (Respondent 10)*

Others see a different side to the relative

It is also stressful to family caregivers that their relative can sometimes "put on a good show" in front of others. The people around them – not only friends and family but also healthcare professionals - do not see their relative like the family caregiver does. As a result, family caregivers can feel as if they have to defend themselves, because the real situation is different to how it appears to others. A partner said:

> *"The biggest trap when dealing with people with dementia is that they can temporarily put on a good show. The relative is then told: "it's not that bad" and "I didn't notice anything," etc.(...). It makes you feel like you constantly have to defend yourself and say they are not doing well at all." (Respondent 1)*

Partners in particular indicate that others see a different side to their loved one. Partners have to manage with changes in behavior and mood on a daily basis.

Knowing how to respond in theory, but being unable to put in practice

Family caregivers often know what to do in theory, but in practice things can be quite different. This can happen because the situation always develops in a different way to what was expected, or because it is difficult to accept the situation. Being able to accept a situation or not influences how you respond to your relative with dementia. A daughter said:

> *"It is very hard for me to handle her behavior. (...) I know that you shouldn't mention it and/or joke about it. But I've noticed that I still do it. I'm still having a hard time accepting how much my mother has changed (...)." (Respondent 24).*

Partners, children, and children-in-law all indicate that they learn every day how to respond better to changes in the behavior and mood of their relative with dementia. Family caregivers often read up about dementia, and they learn from their daily interactions with their relative. Sometimes family caregivers have experience themselves working in professional healthcare. However, theory is different from practice.

Self-management strategies of family caregiver to manage the changes in behavior and mood

Family caregivers use various self-management strategies to cope adequately with changes in the behavior and mood of their relative with dementia in their daily lives. In the analyses, these strategies were grouped into two themes: calming down and stimulation.

Calming down

Calming down involves for example remaining tranquil, being patient, and adapting to the mood state of the relative with dementia. Family caregivers say that they remain calm and keep their patience on those occasions when the relative with dementia is anxious or aggressive. These are self-management strategies intended to prevent the situation from getting out of hand, for example aimed at avoiding their relative becoming aggressive by exercising caution in their contact with their relative. Family caregivers also try to adapt to their relative's mood state in order to reduce tension or restlessness in their relative.

Stimulation

Family caregivers also mention stimulation as a self-management strategy. This includes telling stories, for example, humor, being positive, and encouraging activities and distractions. Family caregivers tell positive stories and try to be upbeat in an effort to haul their relative out of a negative spiral, for example in the case of depression or apathy, or help improve their mood. Family caregivers also mention encouraging activities and distractions such as getting out of the house for a bit or a trip to the shops. In distracting their relative, family caregivers are trying to make sure that the person with dementia does not become more restless or suspicious. A daughter-in-law explained:

> *"I try to change something in the situation, so that a new door opens in his head or an old one closes. For example by getting out of the house with him. Even if we just walk up and down a couple of streets on the sidewalk, or go into the garden and back. To see if we can find a different subject while we're out to keep his mind occupied. (…) But it's more likely that I end up looking for the next distraction. Off to the shops. Etc." (Respondent 35)*

Self-management strategies to manage the own stress

Self-management also means that the family caregiver needs to find a satisfactory way of managing the stress they experience in their daily lives from managing their relative's changes in behavior and mood. The self-management strategies adopted by family caregivers are: looking for distractions, getting rest, and discussing their feelings and experiences.

Looking for distractions

Looking for distractions is a strategy for managing changes in behavior and mood on a daily basis. Family caregivers deliberately plan activities for themselves, such as pursuing hobbies, meeting up with family and friends, or going on holiday.

> *"I definitely find caring for a mother with dementia who lives on her own hard and very stressful for everyone in my own family and my sister's family. It takes up a lot of time and energy that would otherwise be spent on my family and my social life. (…) We arrange to do (…) fun things with friends so that I can relax at least 1 day/evening and we plan short breaks a bit more often. I do explicitly make plans for relaxation." (Respondent 9).*

Getting rest

In addition to looking for distractions, getting rest is another strategy for managing the stress and being able to keep up the care. Family caregivers need to recharge their batteries in order to be able to carry on helping their relative during changes in behavior and mood.

> *“I make sure I get enough rest, so I don’t keep rushing around if it’s getting too much for me, in order to be able to cope properly with these changes. My husband can’t walk anymore so he often sleeps in his wheelchair. Then I have a lie-down too and relax with some music.” (Respondent 4).*

Discussing feelings and experiences

Talking to friends and family about the changes in the relative’s behavior and moods is another strategy that family caregivers use in order to be able to keep up the care. Discussing it with care professionals such as a case manager can also be a strategy:

> *“I often find my partner behaving irritably, which he never did before (…). He is more friendly to the home care people than he is to me, which is why I also find it difficult to be nice to him. Am I jealous? This is something I find I can discuss with my case manager.” (Respondent 4)*

DISCUSSION

Family caregivers experience stress from the changes in the behavior and mood of their relative with dementia, such as agitation, restlessness, apathy, aggression, depression, and anxiety. They find it stressful because they are continually switching, because they are continually having to keep the relative with dementia occupied and diverted, because others see a different side to their relative, and because family caregivers know what to do in theory, but are often unable to put this into practice. From previous research we do know that caregiver stress resulting from changes in the behavior or mood of the person with dementia is a very frequent problem, and exists in the initial stages as well as in subsequent stages of dementia [6] . This underlines the necessity to support family caregivers in their self-management of the changes in behavior and mood, and also in managing their own stress.

Keeping calm and stimulation are self-management strategies that family caregivers apply to influence changes in the behavior and mood of their relative. Calming down involves for example remaining tranquil, being reassuring, and adapting to the mood state. Stimulation can involve telling stories, encouraging activities, and providing distraction.

Self-management strategies that family caregivers use to manage their own stress in their daily lives and to keep up their care for their relative when there are behavioral and mood changes are looking for distractions, getting rest, and discussing feelings and experiences.

Calming down and stimulation by family caregivers in managing changes in the behavior of people with dementia have been mentioned in previous studies [11-13].

What our study adds is that family caregivers often know which strategies would be worthwhile but they are not always able to put this into practice. For example because the situation does not develop as they expected or because it is difficult to accept the situation. They can also experience stress from always having the person with dementia near them and from the fact that other people see a different side to the relative. As a result, they do not always manage to deal appropriately with the changes in behavior and mood. Quinn *et al.* [21] point out that family caregivers need to find a balance between giving the person with dementia the best care they can and caring for themselves [21]. Our study shows that looking for distractions, getting rest, and discussing feelings and experiences are important self-management strategies for family caregivers that enable them to manage the stress.

Practical recommendations

An understanding of what family caregivers find stressful and what self-management strategies family caregivers adopt can be used when giving shape to self-management support interventions. Self-management support can for example be provided by nursing staff and dementia case managers. This study showed that family caregivers experience a great deal of stress from the changes in the behavior and mood of their relative with dementia. Family caregivers find it stressful that other people do not believe them. Nursing staff can take note of this by listening to the family caregiver and asking them about the situations in which they see behavioral or mood changes.

Family caregivers also experience stress because, even when they do know how they should act, they are not always able to put this into practice. Despite the information they obtain from books, their day-to-day experiences and in some cases their professional knowledge, knowledge alone often turns out not to be enough. In addition to providing information, nursing staff can also support family caregivers in developing the skills that let them respond to changes in behavior and mood.

Professionals, such as nursing staff and dementia case managers need to be aware of the supportive needs of family caregivers. Talking about feelings and experiences is an important self-management strategy for managing the stress and being able to keep up the family care. Nursing staff and case managers can take this into account by explicitly inquiring into the feelings and experiences of family caregivers when faced with changes in the behavior and mood of their relative with dementia. In addition, giving information about how to manage with behavioral and mood changes is important, as well as informing family caregivers about the opportunities of support groups of family caregivers appears to be important: a recent systematic meta-review showed that evidence exists for support groups, which were shown to relieve stress of family caregivers [9]. Evidence was also found for self-management support interventions that increased family caregivers' knowledge about how to deal with problems, such as behavioral and mood changes [9].

Limitations and strengths of the study

A strength of this study is that we used several strategies to improve the quality of analysis and trustworthiness of results: coding and ordering through support of software package for qualitative analysis, triangulation of researchers, and discussions of interim and final analyses with authors with different backgrounds, among which also authors who have personal experiences with family care for a person with dementia. However, a limitation of this study is that most of the family caregivers had a high level of education. This will have consequences for the transferability of the results [22]. The study by de Vugt *et al.* [11] showed that highly educated family caregivers adopt more often supportive care strategies and are better able to adjust to the functioning of the person with dementia than other family caregivers. A second limitation that could affect the transferability is that the participating family caregivers were all members of an existent family caregiver panel, run by the Dutch Alzheimer's society. This group may be more aware of developments and knowledge about dementia and possible self-management strategies for managing changes in behavior and mood than the average family caregiver.

Finally, a limitation is that we did not look at all the factors that cause stress. It is known that family caregivers can also find it difficult to manage other aspects of dementia, such as changes in the relationship or no longer being able to undertake shared activities [23]. While this article focuses on self-management by family caregivers in response to changes in behavior and mood, the daily stress that family caregivers have to manage with, is broader than just managing with these changes.

CONCLUSIONS

For family caregivers changes in behavior and mood of their relative with dementia, such as agitation, restlessness, apathy, aggression, depression, and anxiety, are stressful. The continual switching, keeping the relative with dementia occupied and distracted, the fact that others see a different side to their relative, and knowing what to do, but being unable to do so in practice, are particularly stressful.

The family caregivers of people with dementia use both calming down and stimulation as self-management strategies for managing changes in the behavior and mood of their relative. They also describe self-management strategies (looking for distractions, getting rest, and discussing their feelings) for keeping up the day-to-day care in the face of these changes.

An understanding of self-management by family caregivers when managing changes in the behavior and mood of their relative can help professionals to provide suitable support to family caregivers.

Ethics approval and consent to participate

The study protocol was approved by the Medical Ethics Committee of the VU University Medical Center (reference 2014.323). This committee had no objections to the study. All participants received written information about the purpose and method of the online focus groups and signed an informed consent form prior to participation in the online focus groups.

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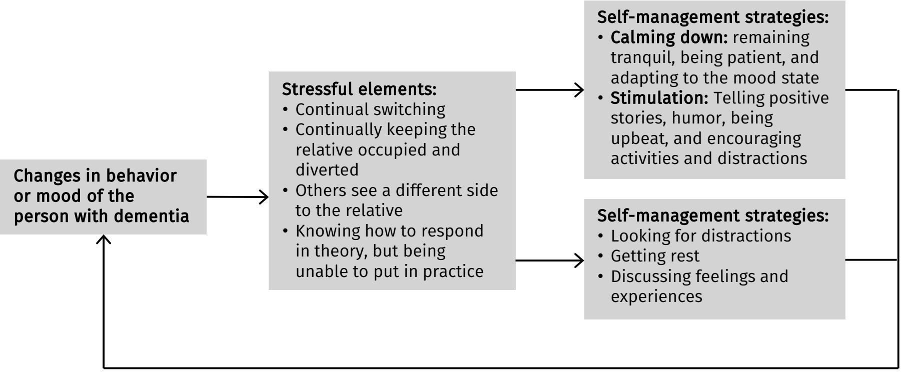
Additional file 1. Stressful elements and self-management by family caregivers when there are changes in their relative's behavior and mood



CHAPTER 6

Self-management support and eHealth when managing changes in behavior and mood of a relative with dementia. An asynchronous online focus group study of family caregivers' needs

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ABSTRACT

The current article discusses how and by whom family caregivers want to be supported in their self-management when managing changes in behavior and mood of relatives with dementia and whether family caregivers consider eHealth a useful tool for self-management support. Four asynchronous online focus groups were held with 32 family caregivers of individuals with dementia. Transcripts of the online focus groups were analyzed using qualitative thematic analysis. Family caregivers need support from professionals or peers in the form of (a) information about dementia and its symptoms, (b) tips and advice on managing changes in behavior and mood, (c) opportunities to discuss experiences and feelings, and (d) appreciation and acknowledgement of caregiving. The opinions of family caregivers about self-management support through eHealth were also reported. Findings suggest a personal approach is essential to self-management support for family caregivers managing changes behavior and mood of relatives with dementia. In addition, self-management support can be provided to some extent through eHealth, but this medium cannot replace personal contacts entirely.

BACKGROUND

Self-management is a topical theme within health care. Health policies encourage individuals to manage their health themselves, and most individuals prefer to maintain control of their life and health care for as long as possible. A commonly used definition of *self-management* is *"the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition"* [1]. Self-management includes the ability to choose the extent to which individuals and their families wish to stay in control of their lives and how available care is used [2, 3].

The term "self-management" is often associated exclusively with activities performed by individuals themselves. However, particularly in individuals with dementia, family caregivers also have self-management tasks, as dementia is a progressive disorder accompanied by increasing dependence of the individual on the family caregiver. Corbin and Strauss [4] distinguish three categories of self-management tasks: "illness work," in the sense of managing medical aspects; "everyday life work," which concerns behavior management, and "biographical work," which concerns managing the emotions that emerge from coping with a chronic disease. As the ability of the ill individual to self-manage decreases, the responsibility for the "work" shifts towards family members [4]. In dementia, the everyday life work and biographical work tend to be more important than the illness work [5, 6].

Everyday life work requires that certain tasks be performed in a complex context [4]. One of the biggest daily challenges for family caregivers constitutes managing changes in behavior and mood of their relative with dementia [7] . Common changes in behavior and mood include agitation, aggression, apathy and depression [8]. Changes in behavior and mood are often prompted by interactions between the individual with dementia and his/her family caregivers [9, 10], which makes managing these changes even more difficult. Family caregivers can use multiple strategies for managing changes in behavior and mood [11-14], such as calming and/or providing encouragement for their relative with dementia [14]. Calming the relative involves remaining tranquil, being patient, and adapting to the mood state of the relative with dementia. Providing encouragement encompasses telling positive stories, using humor, and encouraging activities and distractions [14].

In addition to managing changes in behavior of their relative, family caregivers also have to self-manage their own stress or other emotions if they are to care for their relatives. Managing behavioral changes and their own stress may cause serious disruption to an individual's biography [4]. Self-management strategies used by family caregivers for this purpose include looking for distractions, getting rest, and discussing their feelings and experiences with professionals or other family caregivers [14].

Faced with these self-management tasks, family caregivers may need support. Previous studies have investigated the overall support needs of informal caregivers of individuals with dementia [7, 15-17]. The current article provides insight into the specific support needs of family caregivers regarding the management of changes in behavior and mood of their relative with dementia as well as regarding the self-management of their own caregiver stress and other emotions. This insight is needed to provide customized self-management support, especially by nursing staff, who are often unaware of the support needs of family caregivers in this regard [18].

The current study also considers whether eHealth might be a useful tool for self-management support. eHealth is on the rise and offers new opportunities for dementia care [19, 20]. Inspired by Eysenbach's well-known definition [21], the current article defines eHealth as dementia-related information and/or support delivered or enhanced through the Internet or related technologies. Several systematic reviews suggest that eHealth in the form of online information and support might be effective (e.g., in managing caregiver stress or other psychological problems) [19, 20, 22-24]. On the other hand, family caregivers might prefer face-to-face support rather than support through eHealth when managing relatives' behavioral or mood changes.

The following research questions will be addressed:

- How and by whom do family caregivers want to be supported when managing changes in behavior and mood of their relative with dementia?
- What do family caregivers think of the application of eHealth as a tool for self-management support for managing behavior changes in their relative with dementia?

METHOD

The methods described herein have been also reported in a companion study that used the same methodology [14].

Design

Online discussions were organized for asynchronous focus groups comprising family caregivers of individuals with dementia. Online focus group discussions involve a secure website where group discussions can take place [25]. The decision to organize the discussions online was motivated by the fact that this would enable contact with family caregivers who could not easily travel because of the commitment of caring for their relatives with dementia.

Sample and recruitment

Participants were recruited from an existing nationwide panel of family caregivers (access http://www.alzheimerpanel.nl/). A random selection was made of 240 family caregivers from the 1200 panel members. Selected family caregivers were sent an e-mail by the Alzheimer's Society, inviting them to take part in the online focus group if they met the specified criteria for inclusion. Inclusion criteria were: the family caregiver: (a) is a relative of an individual with dementia who lives at home (not in an institution), (b) has contact (by phone or face-to-face) with the individual with dementia at least once a week, (c) has daily access to the internet during the online focus group period and (d) is 18 or older.

A total of 37 family caregivers sent an e-mail stating that they met the criteria for inclusion and would like to take part in the focus group discussions. These family caregivers were sent an information letter by post with an informed consent form. In total, 36 family caregivers completed and returned the consent form. Of these individuals, 32 family caregivers participated in the discussions by posting comments on the website. These 32 individuals therefore constitute the study participants.

Asynchronous online focus groups

The main themes addressed in the current article are:

- whether caregivers received information or support when managing changes in behavior and mood of the relative with dementia;
- the support needs of caregivers when managing changes in behavior and mood of the relative with dementia; and
- eHealth as a tool for self-management support.

Table 1 provides examples of questions that were addressed in the online focus groups and form the basis of this article.

Table 1 *Questions Addressed in Online Focus Groups*

Have you received information or support, now or in the past, from health care professionals when coping with changes in the behavior and mood of your relative with dementia? What information or support helped you the most?
Do you feel a need for information or support from health care professionals when dealing with possible changes in the behavior and mood of the individual with dementia?
In addition to face-to-face contact, information and support are increasingly being provided via the internet, e-mail, or cell phone applications (apps). An example is e-mail contact with a case manager, nurse, or other health care professional. How can information and guidance via the internet or e-mail help you and your relative with dementia cope with possible changes in the behavior and mood of your relative with dementia?

A total of four online focus groups were organized between October 2014 and March 2015. Each focus group had seven to 10 participants. Earlier studies have shown this to be an appropriate number of participants for online discussions [26]. Participation was anonymous. The only individuals able to access the private website were those who had received a personal login code from the lead researcher (JH). Participants could log in 24 hours per day during a 2-week period. One researcher (JH) added a new question every second day, excluding weekends. Participants posted their reactions at times that were convenient for them and they could read contributions of others. Two authors (JH, RV) moderated the discussion by adding questions and sending e-mail messages to participants who had not yet responded.

Data analysis

An iterative process was used for data collection and analysis, which was based on thematic analysis principles [27]. The analysis started with researchers reading and rereading the transcripts. Relevant excerpts in the transcripts were marked and coded with keywords. Initially, codes were chosen that were close to the participants' wording. Related codes were then grouped as a means of identifying themes. In the next step, the relationships between themes were analyzed [27]. The MAXQDA-11 software package was used as an aid in the coding process. Analyses were independently performed by two researchers independently (JH, RV) as a way of improving the quality. These two researchers then discussed the coding and the interpretation of the codes until a consensus was reached. Each of the other authors (BM, PJV, WW, CH, AF) also read and analyzed one transcript. In addition, they commented on the interim analyses of the online focus group discussions.

Ethical procedures

The study protocol was approved by the Medical Ethics Committee of the VU University Medical Center. This committee had no objections to the study. All participants received written information about the purpose and method of the online focus groups and signed an informed consent form prior to participation.

RESULTS

Participants background characteristics

A total of 36 family caregivers signed up for an online focus group. Of these, 32 family caregivers participated in an online focus group. Participants were partners, children, or children-in-law of a individual with dementia. When asked their relatives' form of dementia, more participants mentioned Alzheimer's disease than any other form. Of the family caregivers who commented on when they saw the first symptoms, the majority reported 2 to 5 years ago (see Table 2).

Table 2 *Caregivers' Characteristics (N = 36)*

Characteristic	Mean (SD)
Age (years)	61 (42 to 81)
	n (%)
Sex	
•Female	32 (89)
•Male	4 (11)
Relationship with individual with dementia	
•Child or child-in-law	19 (53)
•Partner	17 (47)
First symptoms of dementia[a]	
•2 to 5 years ago	10 (28)
•6 to 10 years ago	8 (22)
•11 to 15 years ago	4 (11)
•Not reported	14 (39)
Type of dementia	
•Dementia (no further description)	16 (44)
•Alzheimer's disease	14 (39)
•Alzheimer's disease with vascular components	3 (8)
•Vascular dementia	1 (3)
•Lewy body dementia	1 (3)
•Frontotemporal dementia	1 (3)
Highest educational attainment	
•Primary school	3 (8)
•High school (preparatory to vocational education) and/or vocational training	7 (19)
•High school (preparatory to university education)	6 (17)
•Applied university or academic university	16 (44)
•Missing	4 (11)

[a] According to the family caregiver.

Support needs

Participants were asked what type of support had helped them now or in the past, and what needs they would have in the future when managing changes in behavior and mood of their relatives with dementia. The elements of self-management support were categorized into (a) information about dementia and its symptoms, (b) tips and advice on managing changes in behavior and mood, (c) discussing experiences and feelings, and (d) appreciation and acknowledgement of caregiving.

Information about dementia and its symptoms

Information about changes in behavior and mood is important for family caregivers. Knowledge about how the body and mind start to “lose function” as a result of dementia offers an explanation for the occurrence of changes in behavior and mood. This background information helps prevent family caregivers from being taken by surprise by behavioral changes. As one participant commented,

> *“I noticed that after reading about the behavior, I am less surprised whenever my mother reacts ‘strangely’ from my point of view (...)”.*

Many family caregivers have read about changes in behavior and/or mood that can occur. Participants reported they attend meetings, such as those held in the Alzheimer Cafe. Case managers were also mentioned as a source of information.

However, information about changes in behavior and mood is not necessarily pleasant and useful for all family caregivers. Some family caregivers, in particular partners, indicated there can somethings be too much information. This is overload, because not all information about changes in behavior and mood apply to the relative in question with dementia. This overload of information sometimes causes family caregivers to worry unnecessarily about things that end up not being relevant to their situation.

Tips and advice

Participants reported that they have benefited, now and in the past, from tips and advice from other family caregivers or professionals about how to respond to changes in the behavior and mood of their relative with dementia, but they continue to determine what works in each individual situation. Participants considered themselves experts by virtue of their experience. Tips given to family caregivers by professionals, for example, are often tips they had already figured out for themselves, such as avoiding getting into a discussion and staying calm. Despite this, tips from other family caregivers or professionals also serve as support because they provide confirmation of the family caregiver’s own approach, successes and failures. One participant noted:

> *“Most tips are recommendations that my mother and I had actually already discovered ourselves. (...) But there are also things that don’t work at all.(...) Tips from other caregivers help, too, sometimes. At any rate, they’re a kind of confirmation of your own approach and successes/failures”.*

Family caregivers receive the most tips from other family caregivers, friends who also have (or have had) a parent with dementia, and professionals (e.g., case managers). Aside from tips and advice from fellow family caregivers, some participants reported that they would also like to attend a course to learn skills that would help them manage their relatives' changes in behavior and mood.

Discussing experiences and feelings

Contact with fellow family caregivers is an important form of self-management support. Most participants reported that they like swapping experiences about changes in behavior and mood and how to manage them. Aside from tips and advice, this exchange allows them to let off steam and provides a sounding board. Family caregivers feel supported because they recognize the experiences of other family caregivers, which confirm that they are not alone in their situation. As one participant stated:

> *"I get a great deal of support from a very good friend, who I can always talk to. The contact with a fellow caregiver is also nice; we can swap experiences and give each other suggestions".*

Sons and daughters reported that they share experiences with friends whose parents also have a form of dementia. Sons, daughters, and partners swap experiences with other family caregivers in the Alzheimer Cafe. Partners emphasize that managing changes in behavior and mood is different for them than for the children of an individual with dementia. Children return to their own home at the end of the day, escaping from the situation for a while. Partners, on the other hand, live permanently with the individual with dementia in their home. However, one partner reported that it is difficult for children because, aside from caring for their parents, they have to take care of their own family.

Appreciation and acknowledgment

Changes in relatives' behavior and mood form a daily challenge for family caregivers. Participants reported that receiving appreciation and acknowledgment for the everyday care they provide is essential in enabling them to cope with this daily challenge. Changes in behavior and mood are difficult, complex, and different for individuals. Receiving appreciation and acknowledgement from family, friends, and professionals makes family caregivers feel as though they are sharing the care so they do not have to do everything by themselves. Family caregivers who do not receive this appreciation and acknowledgement reported that they miss it. A number of participants reported that the circle of individuals who understand their situation keeps getting smaller. They perceived that others believe dementia is annoying. A number of family caregivers feel misunderstood or disbelieved. Family caregivers also feel misunderstood by professionals. An example of this misunderstanding is when a relative with dementia acts differently when others are around, as reported by a daughter in regard to her mother with dementia:

> *"Because my mother puts on a good show when others are around, (...) they will never know what she is really like. Only the family doctor experienced this, one time. The others don't really believe us, which is what frustrates me the most. Feeling like people don't believe you. . . So perhaps that's a job they [the professionals] could do: listening to family caregivers!".*

Opinions about eHealth

The online focus groups discussed whether eHealth has a place in support for managing changes in relative's behavior and mood. Participants were asked if they would like to receive information and/or support via the internet, e-mail or smartphone applications (apps). Opinions of family caregivers were categorized into four themes: (a) eHealth via the internet is a good medium for finding information, (b) contact with other family caregivers through eHealth is valuable, (c) a personal approach is essential, and (d) eHealth support is not possible for the relative with dementia.

eHealth via the internet is a good medium for finding information

Participants viewed the internet as a good medium for searching and requesting general information about changes in behavior and mood. Family caregivers like accessing information on the internet, because it is always available at any time of the day. Participants mainly visit the Dutch Alzheimer's Society website if they want information about changes in behavior and mood. Although a large amount of information is available, a number of participants reported that much of the information is only about Alzheimer's disease and not other forms of dementia. Some participants also reported they would like a website page with frequently asked questions where they could enter symptoms and search for relevant information, or obtain advice about what to do in a certain situation.

Contact with other family caregivers through eHealth is valuable

A number of participants reported that they use the internet, e-mail or smartphone to share their experiences and ask for support and help with changes in their relatives' behavior and mood. Participants who mentioned that they have contact with other family caregivers via the internet reported that this is valuable to them. Others who do not yet have contact with other family caregivers reported that sharing experiences and getting good tips could be valuable to them. This contact could be possible through a forum or with an app where family caregivers and professionals can talk to one another. Some participants reported that they use a website for sharing experiences with other family caregivers within their own circle, such as family or friends. A number of family caregivers also reported that they use the smartphone app Alzheimer's Assistant:

> *"I use the Alzheimer's Assistant almost every day, mostly to write my report of the day and share it with family who live further away and my three children. This way, they are aware of the day-to-day life of their father and brother-in-law.(...) I also write about my own emotions so that there will be no 'surprises' if there are big changes. They all enjoy it very much, and I feel like I'm not alone".*

A personal approach is essential

As mentioned above, participants reported that information via the internet, e-mail or smartphone can be useful. They mention general information about changes in behavior that is applicable to different phases of dementia. Participants reported that finding or getting information, advice, and tips about their personal situation is more difficult via eHealth. Support through eHealth is often seen as impersonal and distant. Family caregivers are afraid that they will miss the nuances and misinterpret things when communicating through eHealth. Not only are changes in behavior and mood different for every individual with dementia, family caregivers also handle them differently. Consequently, advice and tips aimed at a specific situation need a personal approach. Face-to-face contact with friends, family, or professionals is important, according to participants. Participants also emphasized that support through eHealth cannot replace face-to-face contact. Information and support through eHealth can be seen as an additional service but should not replace direct contact, as one participant stated:

> *"For me the advantage of support via the internet, e-mail or apps is that I can take the time for it when it's convenient for me. I see this support as support and not as a substitute. It is a supplement to my need for information and communication about this subject. It would be a drawback if this were to replace direct contact or conversations."*

eHealth is not possible for the relative with dementia

Most participants reported that information and/or support through eHealth is not possible for individuals with dementia, as learning new things is difficult for these individuals. Using a cell phone or computer makes their relative with dementia nervous. Digital support is a step too far for individuals with dementia and is therefore not (or no longer) an option.

DISCUSSION AND IMPLICATIONS

Family caregivers perceived information about the dementia, tips and advice, talking about experiences, and appreciation and acknowledgement of caregiving as important elements of self-management support when managing changes in behavior and mood of their relatives with dementia. Family caregivers reported that information about dementia and the illness course was vital in understanding the changes in their relatives' behavior and mood. Different types of information sources were mentioned, such as peers, nurses, and case managers. However, some family caregivers indicated that sometimes they were overloaded with information. Therefore, they had to select information that was relevant to their specific context. In addition, the information, tips, and advice that family caregivers received often simply confirmed what they already knew. Even so, they found support for their successes and failures in managing the changes in behavior and mood.

Participating family caregivers often searched for information on the internet, and some used online forums to meet peers. They found eHealth via the internet to be a good medium for looking for information, sharing experiences, and asking for help. Family caregivers mentioned the ability to look up information at any time as one advantage of the internet.

Furthermore, family caregivers needed to talk about experiences. They mentioned the difficulty of accepting that their loved one was changed. Learning to managing emotional impacts and changing circumstances is part of the biographical work required to manage the illness [28]. Sharing experiences and letting off steam with other family caregivers or professionals gives family caregivers a feeling that they are not alone. Individuals who do not have this kind of support revealed that this is a great lack in their lives. Some family caregivers reported that they lost contact with friends and family due to misunderstandings.

Acknowledgement by peers and health care professionals is also an important aspect of self-management support. Being acknowledged as a caring family member and an expert in the care of his/her loved one is often of great importance to the family caregiver. eHealth might be helpful in proving this kind of support. However, participants in the current study indicated that in many cases eHealth is not geared to their personal situation. Family caregivers note that changes in mood and behavior are different for each individual with dementia and family caregivers also differ in their approach.

Practical Recommendations

The current study suggests that eHealth can be a valuable addition to but it cannot entirely replace personal contacts with professionals. Moreover, participating family caregivers considered eHealth inappropriate for use by their relatives with dementia. Nevertheless, a recent systematic review [29] established that in the early stages of dementia, technologies could support persons with dementia.

In addition, the current study shows that it is crucial that family caregivers receive appreciation and acknowledgement for what they do, and that they can swap experiences, for instance with nurses or other professionals. In another study, it was found that nurses are not always aware that family caregivers need support [18]. Because even subtle behavioral changes can lead to distress, anxiety, and loneliness [30], it is essential that family caregivers be acknowledged and supported by health care professionals. Therefore, an awareness that support and acknowledgment of family caregivers is important should be promoted (e.g. in training programs and campaigns).

It is also important that nurses, case managers and other professionals tailor their support to the needs of individual family caregivers. Professionals can take these needs into account by explicitly inquiring about them. In doing so, it is essential that they acknowledge family caregiver and show appreciation of their work in the tough task of providing care.

In the further development of self-management support, how to customize support in a way that will empower family caregivers in managing mood and behavioral changes must be considered. An example of such support could be online information and tips combined with online personalized support from a health care professional. However, support via eHealth will not be able to replace face-to-face contacts with professionals (e.g., case managers, nurses, or family physician).

Strengths and limitations

Online focus groups seemed to be a good way of discussing issues with often busy and burdened family caregivers, as there was no travel time involved in participating in the study. Another advantage of this method was that family caregivers did not have to arrange for someone to take over the care tasks, as they were able to take part in the online focus group in their own home at a time that was convenient for them [26].

In some previous online focus group studies, it appeared to be difficult to stimulate a lively discussion [25, 26, 31]; however, this was not the case in the current study. Family caregivers reacted to the questions of the moderators but also commented on the posts of other participants. This interaction could be related with the perceived relevance of the topics addressed: changes in behavior and mood in individuals with dementia are common and these changes have often impact the daily life of caregivers [7] .

The online focus group study had a number of limitations. First, family caregivers with a high level of education were overrepresented, and self-management support needs might be different for people with less education [32]. A second limitation is that the participating family caregivers were all members of a family caregiver panel run by the Dutch Alzheimer's Society. This group may be more informed on developments in self-management support interventions and eHealth and have more computer skills than the average family caregiver. Therefore, the current study results cannot be assumed to apply to the entire population of family caregivers of individuals with dementia. However, future generations of family caregivers can be expected to have better internet access (and skills) and will therefore be able to make more use of the possibilities that eHealth offers.

CONCLUSION

Support for family caregivers in their self-management of changes in behavior and mood of their relatives with dementia can take different forms: information, tips and advice, opportunities for discussing experiences and feelings, and appreciation and acknowledgement. Self-management support for family caregivers can be provided to some extent through eHealth, but this cannot replace personal contacts entirely. Support must always be geared to the personal situation.

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CHAPTER 7

Online self-management support for family caregivers to help them manage behavior changes in their relative with dementia: study protocol for a randomized controlled trial and a process evaluation

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ABSTRACT

Background

Online interventions are potentially effective ways to support family caregivers in the management of behavior changes in their relative with dementia.

Objective

The objective of this paper is to present the design of a study evaluating and comparing 3 intervention arms for online self-management support.

Methods

A randomized controlled trial (RCT) will be conducted with a total of 81 family caregivers of community-dwelling people with dementia in the Netherlands. Family caregivers will be randomly allocated to one of the following intervention arms: (1) a major self-management support intervention consisting of personal email contacts with a nurse specialized in dementia care, online videos, and electronic bulletins (e-bulletins); (2) a medium self-management support intervention consisting of only online videos and e-bulletins; and (3) a minor self-management support intervention with only e-bulletins. The primary outcome is the self-efficacy of the family caregiver. The secondary outcomes are the behavior problems of the person with dementia as reported by the family caregiver, and positive and negative aspects of the relationship. Background characteristics (eg, type of family relationship) will also be assessed. All data for the RCT will be collected via online questionnaires, administered before the intervention (T0), after 6 weeks (T1), and after 12 weeks (T2). Alongside the RCT, a process evaluation will be conducted, based on a number of evaluation questions and semi-open interviews with family caregivers.

Results

Data collection will be completed in August 2017. Study results will be reported in early 2018.

Conclusions

The study will shed more light on the effect of online self-management support interventions and insights will be gained into whether a major intervention, consisting of personal email contacts with specialized nurses, videos, and e-bulletins, has more effect than smaller online interventions. This is relevant in an age with increasing numbers of people with dementia, growing pressure on family caregivers, more and more people using the Internet, and increasing healthcare costs.

Trial Registration

Nederlands Trial Registry (NTR): NTR6237; http://www.trialregister.nl/trialreg/admin/rctview.asp?TC=6237 (Archived by WebCite at http://www.webcitation.org/6v0S4fxTC)

INTRODUCTION

Background

Dementia is a progressive disorder characterized by cognitive and physical decline and behavior and mood changes. The most common forms of dementia are Alzheimer's disease and vascular dementia, followed by Lewy body dementia and frontotemporal dementia [1]. There is still no effective treatment that can influence the progression of Alzheimer's disease and other dementia subtypes. Eventually, someone will die with or from dementia [2].

Most people with dementia live at home, often supported by spouses, adult children, or other family members [3]. Although the family often cares for them with love and dedication, family care can be a big burden [4, 5]. For family caregivers it can, for instance, be stressful to deal with their relative's behavior changes, such as dependent behavior, aggressive behavior, suspicious behavior, apathy or indifference, night-time restlessness, and masking behavior. These are often symptoms of the disease and are found in up to 90% of people with dementia [6, 7]. Changes in behavior are "challenging" when this causes distress to the person with dementia and/or family caregivers and negatively affects the quality of life of at least one of these parties [8]. A Dutch study [9] found that about three quarters of the family caregivers of persons with dementia experienced problems in dealing with changes in the behavior or mood of their relative, in both the initial and later stages of the disease. In a recent focus group study, family caregivers reported that what they found most difficult was constantly having to switch between different strategies and that they had to keep their relative constantly occupied and distracted [10]. Furthermore, they found it stressful that other people often had a different view of the behavior and mood of the relative with dementia. Lastly, they also found it difficult that in theory they knew what to do in caring for their relative, but were often not able to put it into practice [10].

To support family caregivers (e.g., in dealing with the relative's behavior changes), an increasing number of self-management support interventions are being developed, some of which are Internet-based [11]. From the perspective of family caregivers, Internet support might be attractive, since they can use it at a time that is suitable for them, without travelling [12]. Boots *et al.* [13] performed a systematic literature study of Internet-based support, such as a website with information and support on various aspects of care giving. The review by Boots *et al.* [13] suggested that Internet-based support had positive effects (eg, regarding self-efficacy or other psychological and psychosocial outcomes for family caregivers). However, the review authors also concluded that the evidence was still scarce because of the low quality of the studies they had identified [13].

Previous research also did not provide a definitive answer about the effectiveness of incorporating personal contacts with a healthcare professional in online interventions, although some relevant studies have been conducted in this area [12, 14-16]. For instance, in a study by Boots [14], face-to-face sessions with an experienced professional (psychologist or psychiatric nurse) and family caregivers were added to an online support intervention. The face-to-face sessions were seen as a valuable addition, as they provided an opportunity to tailor the support to the needs of the family caregivers and deepened the relationship [14]. In addition, Schaller *et al.* [15] evaluated an interactive Web portal providing individualized information and support by dementia experts to family caregivers via a messaging function [17]. The interaction between family caregivers and experts was found to be useful, particularly because of the timely reaction to symptoms and because of the opportunity to reach immobile caregivers [15]. Comparable results were found in the study by Torkamani *et al.* [16], which evaluated a computerized platform for contacts between the caregivers and health professionals aimed at reducing the burden on the caregiver, improving quality of life, and delaying institutionalization of the person with dementia. Furthermore, Blom *et al.* [12] evaluated Internet-based information combined with online personal support. In this study, a psychologist provided online feedback on assignments about dealing with depression or other psychological problems in relatives of persons with dementia. The study by Blom *et al.* [12] recommended further research to clarify the necessity of personal contacts with a professional; a completely self-help Internet program would be less expensive, which is an advantage in the current era with increasing numbers of persons with dementia and limited healthcare budgets. However, personal contacts with a healthcare professional might help people translate generic information to their own situation [12].

Objectives

The aim of this study is to investigate whether a major intervention, consisting of personal email contacts with a specialized nurse in combination with videos and electronic bulletins (e-bulletins), is more effective than more minor interventions. Based on the results of this study we will be able to inform about which elements of online self-management support are effective (on their own or in combination) for family caregivers when managing changes in the behavior of their relative with dementia.

The research questions are (1) Is a major online self-management support intervention consisting of personal email contacts with a specialized dementia care nurse, videos, and e-bulletins more effective than smaller online interventions without personal email contacts, with regard to self-efficacy of family caregivers in managing the behavior changes of their relative with dementia, behavior problems in the persons with dementia, as reported by family caregivers, and positive and negative aspects of the relationship between the family caregiver and the person with dementia? (2) What background and baseline characteristics of family caregivers or the persons with dementia (e.g., type of family relationship, baseline level of care pressure, and the specific behavior problems of the person with dementia) are associated with effects on the outcome variables mentioned in question 1? (3) How do the family caregivers evaluate the online self-management support intervention, with or without personal email contacts with a specialized nurse, regarding feasibility, usability, and satisfaction with the intervention?

METHODS

Design and Randomization

To answer research questions 1 and 2, a randomized controlled trial (RCT) with 3 repeated measurements will be performed, involving the following intervention arms: (1) a major-intervention arm, (2) a medium-intervention arm, and (3) a minor-intervention arm.

Family caregivers will be randomly allocated to 1 of the 3 self-management intervention arms. Block randomization will be used to achieve balance in the allocation of participants to intervention arms [18]. An independent epidemiologist (NJV) prepared a randomization schedule to assign participants to an intervention arm, using several block sizes of 6 and 9. Following this randomization schedule, the researcher (JGH) will allocate participants to an intervention arm. The participants will then receive an email from the researcher (JGH) containing elements of the intervention arm in question. Participant and researcher blinding is not possible due to the nature of the intervention arms and the organization of the study.

Alongside the RCT, a process evaluation will be conducted to answer research question 3. For the process evaluation, a mix of qualitative and quantitative methods will be used.

Power Calculation and Sample

We hypothesize that (1) both the major and medium intervention arms improve the self-efficacy as compared to the minor intervention arm; and (2) the major intervention arm gives better results for self-efficacy compared to the medium intervention arm. Considering a difference of 0.8 standard deviation units between the groups and assuming a significance level of .05, a power of 80%, and a correlation of .6 between the 2 repeated measures, 20 participants are needed per group. Taking into account a drop out percentage of 20%, we will include 24 participants per group.

In this study, providing self-management support through email is a relatively new task for the specialized nurses involved, with possible learning effects during the study. To take this into account, 1 extra block of 9 participants will be added to allow for a brief learning curve. Hence, in total 81 family caregivers of persons with dementia will be included.

The participants will be family caregivers of people with dementia who meet the following inclusion criteria: (1) the family caregiver is a relative of a person diagnosed with dementia (all types of dementia are eligible, with no restriction on the severity of the dementia); (2) the family caregiver must have contact with the person with dementia at least once a week; (3) the family caregiver's relative with dementia has to live at home (not in a care institution); (4) the family caregiver has access to the Internet and has basic skills in using the Internet and email; (5) the family caregiver has to be aged at least 18 years of age; and (6) the family caregiver is able to read and write Dutch.

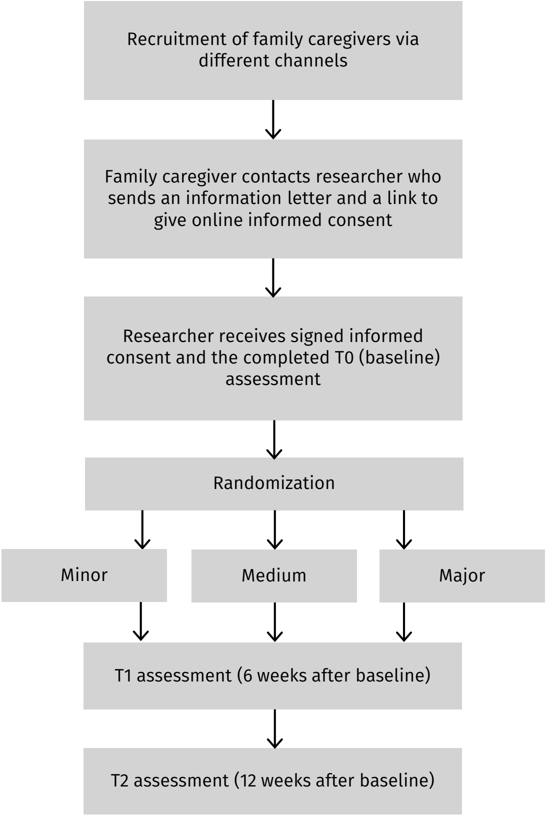

Figure 1 *Study Flow Chart*

To recruit family caregivers for our study, we will use several channels. The panel of the Dutch Alzheimer Society (in which more than 3000 informal caregivers participate) will be sent an email with an open call. Open calls will also be posted on the online forum of the Dutch Alzheimer Society (with 7000 monthly visitors), on the Dementie Nederlands website, and on the social media accounts (Facebook/Twitter) of the Dutch Alzheimer Society.

Recruitment via the aforementioned channels of family caregivers will proceed with first, a very short study description in the open call. In this description, family caregivers will be asked if they are interested in participating in the study. If so, they can send their name and email address to the principal researcher (JGH). The principal researcher will then send an email containing an information letter about the aims and procedures of the study to the family caregiver. This email will have a link to an online informed consent form, which the family caregiver can use to give their consent for participation. The participation flow chart is shown in Figure 1.

Intervention Arms and Components

In the RCT, 3 intervention arms will be studied, all focusing on self-management support in dealing with behavior changes, but varying in the number of elements. The intervention arms are referred to as major, medium, and minor.

Major Self-Management Support Intervention

The major intervention arm consists of the following elements: (1) 3 personal email contacts with a nurse specialized in dementia care, (2) provision of online videos about how to manage behavior changes in a relative with dementia and to improve your self-efficacy in managing with this behavior, and (3) provision of e-bulletins with practical information about different types of behavior changes and how to manage them.

The personal email contacts will be handled by a nurse with a Bachelor's or Master's qualification in nursing and with follow-up training in dementia care. In the email contact, the nurse will support the family caregiver in managing behavior changes. The nurse will also give feedback on assignments and will give feedback on the plan that the family caregiver came up with in the assignments. The nurse will tailor their support to the personal needs and questions of the family caregiver, while guided by an intervention protocol developed by project group members (JGH, ALF, PJV, IvA), in consultation with the nurses who had to use the intervention protocol. The number of email contacts was discussed and agreed with experts in dementia care who have experience with online support. Three email contacts are thought to be sufficient and feasible.

The Dutch-language intervention protocol (available on request from the first author) is based on the 5 steps of the "5A model" of self-management support [19] and the person-centered care theory of Kitwood [20]. The "5A model" consists of the following steps: (1) assessing the state of behavior, beliefs, and motivation; (2) advising based upon personal health risks; (3) agreeing on a realistic set of goals; (4) assisting in anticipating barriers and developing a specific action plan; and (5) arranging follow-up [19, 21, 22].

There are 6 videos about different types of behavior changes that occur frequently (dependent behavior, aggressive behavior, suspicious behavior, apathy or indifference, nighttime restlessness, and masking behavior). Family caregivers can choose the number of videos they watch and the accompanying assignments that they do themselves, depending on their own needs and the behavior changes that occur in their relative with dementia. The videos (as well as the e-bulletins mentioned below) were developed by the Trimbos Institute, of which 2 of the developers are involved in the present study (BMW, IvA), in close cooperation with the Dutch Alzheimer's society, other dementia experts, and family caregivers of people with dementia. As a first step in the development trajectory, a desk search was performed to gain insight into what is known in the literature about how family caregivers perceive different types of behavior changes in their relative with dementia and the theory of person-centered care [20]. Experts also provided input for the components of the videos (eg, principles of cognitive behavioral therapy [CBT], modeling, persuasive communication, and active learning). At several stages in the development trajectory, video scripts and pilot videos were tested by family caregivers.

The behavior changes covered in the bulletins are the same as in the videos. The e-bulletins involve assignments to help caregivers translate the generic information to their own situation and to reflect on possible causes of the behavior changes, how they want to influence the behavior, and how they want to cope with it. The e-bulletins were tested in conjunction with the testing of the videos and they also have the same theoretical base as the videos.

Medium Self-Management Support Intervention

The medium self-management support intervention consists only of the online videos and e-bulletins as described above.

Minor Self-Management Support Intervention

The minor self-management support intervention consists only of the e-bulletins, the same as those in the major and medium support interventions.

Measurement Procedures

Measurements will be performed in the RCT at 3 time points: baseline assessment (T0), which is just before the family care intervention arms start; the assessment 6 weeks after the baseline (T1); and the assessment 12 weeks after the baseline (T2).

Measurements will be based on self-reporting by the family caregiver and will be administered through the Internet. Up to 2 email reminders will be sent (if necessary) 1 and 2 weeks after the measurement time point to remind participants to complete the questionnaires.

Primary Outcome

The primary outcome in the RCT is self-efficacy, measured by the Trust in Own Abilities (TRUST) instrument, a Dutch language questionnaire to be completed by family caregivers of the person with dementia [23]. The questionnaire has been used before to measure self-efficacy in caregivers of people with dementia living at home [24]. The TRUST contains 32 items (alpha .97) divided into 3 subscales: resilience (15 items, alpha .94), solution orientation (8 items, alpha .90), and proactive competence (9 items, alpha .81). Items are measured on a 5-point Likert scale, ranging from 0 (not at all) to 4 (very good). A higher score is associated with higher perceived competence in taking care of the person with dementia [24].

Secondary Outcomes

The secondary outcome will be the presence and number of behavior and mood problems, assessed with the Dutch version of the Revised Memory and Behavioral Problem Checklist (RMBPC) [25, 26]. Family caregivers have to rate the frequency of the occurrence of a specific behavior or mood problem on a scale from 0 (never) to 4 (always) where 1 is seldom, 2 regularly, and 3 is often. The total number of behavior and mood problems (0 to 24) will be calculated as well as the mean overall score. The RMBPC can be divided into scales for depression (9 items), disruptive behavior (8 items), and memory-related problems (7 items).

Another secondary outcome is the positive and negative aspects of the family relationship between the family caregiver and the person with dementia and they will be measured by the Dyadic Relationship Scale (DRS). The family caregiver version includes 11 items in 2 subscales: dyadic strain and positive dyadic interaction. Family caregivers have to rate the quality of the relationship using 4 answer categories: 1 (strongly disagree), 2 (disagree), 3 (agree), and 4 (strongly agree) [27].

Analyses of Effects

The quantitative data from the RCT will be analyzed using SPSS software (Statistics 22). Baseline characteristics will be described for each arm using proportions for dichotomous variables and means (SD) or medians (IQR) for continuous variables. In the primary analysis, primary and secondary outcomes will be compared between the 3 different groups using mixed-models analysis. All mixed model analysis will be adjusted for baseline differences between the groups.

All randomized caregivers who completed the follow-up will be included in this analysis (modified intention-to-treat). The first 9 caregivers, who are in the learning-curve block, will not be included in the primary analysis. We will use sensitivity analyses to evaluate the effect of missing data and of the prior inclusion of key baseline variables.

Process Evaluation

Alongside the RCT, a process evaluation will be conducted. Mixed-methods and sources will be used for this.

Firstly, evaluation questions will be included in the T2 survey questionnaire (12 weeks after the baseline). The number of evaluation questions varies between 5 and 11 depending on which of the 3 intervention arms the family caregiver is in. The evaluation questions are based on earlier research about the perceived feasibility and usability of interventions and satisfaction with the interventions [28, 29].

Secondly, semi-structured interviews will be conducted with a purposive sample of about 15 participant family caregivers (5 participants in each intervention arm). The participants will be purposively recruited to achieve a spread in the intervention arms and background characteristics (eg, sex, age, and living with or separately from the relative with dementia). Topics will include family caregivers' satisfaction with and the perceived feasibility and usability of the self-management support interventions. The interviews will be conducted by telephone by 1 of the members of the research team (IvA) and will be audio-recorded.

Thirdly, usability in the sense of actual usage of the different elements of the online self-management support intervention will be measured by analyzing the clicks on links and how long the family caregivers spent watching the videos, divided into the following categories: (1) started video, (2) played video (25%), (3) played video (50%), (4) played video (75%), and (5) completed video. These data will be collected with Google Analytics. All participating family caregivers will be given a unique code that is known only by the research team.

To collect data on actual use of the personal email contacts, nurses will be asked to complete a registration form on the number of personal email contacts per family caregiver and time spent on giving feedback to the family caregiver.

Fourthly, the content of the email contacts between the family caregivers and the nurses will be analyzed qualitatively. The email contacts will be analyzed from 3 angles: with a focus on nurses’ questions and responses, with a focus on family caregivers’ questions and responses, and with a focus on the interactions between the two. The focus on the nurses will be on how they delivered the self-management support as defined by the intervention protocol based on the "5A model" (assess, advise, agree, assist, and arrange). The responses by the family caregivers in the email contacts will be analyzed to get information on the uptake of the intervention and how they integrated the personalized advice from the nurse in their daily lives.

The data from the structured evaluation questions in the T2 survey questionnaire, data on actual usage from Google Analytics, and registration data on the number of personal email contacts will be analyzed descriptively using SPSS software. The semi-open interviews and the content of the email contacts will be analyzed qualitatively using the principles of thematic analyses [30]. This qualitative method was chosen because it is a useful and flexible method for identifying relevant themes within qualitative data. It consists of the following steps: (1) familiarizing yourself with the data, (2) generating initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes, and (6) reporting [30]. The interview transcripts will be analyzed by 2 researchers (JGH and IvA) independently. Coding and interpretation of the codes will be discussed by the researchers until consensus is reached. In addition, other authors will comment on the interim analyses of the interviews.

Ethical Procedures

The study protocol was approved by the Medical Ethics Committee of the VU University Medical Center (reference 2016.559).

Informed consent will be asked from all participants via an online informed consent form, which the family caregiver can use to give consent for participation. Consent from the family caregivers and the nurses will be explicitly requested in the informed consent for the analysis of the content of the email contact between the family caregivers and the nurses.

Only members of the research team (the co-authors) will have access to the data. Agreements on how to share, archive, and store data will be signed by the organizations that will be collecting the data.

RESULTS

Enrollment of participants began in March 2017. Data collection was complete in August 2017. The study results will be reported in early 2018.

DISCUSSION

This study will contribute to the growing body of knowledge about online support in dementia care. This is important since future generations will increasingly use the Internet, which will also affect the extent in which family caregivers will be open to receiving online self-management support. However, we also expect that if online support is tailored and involves personal email contacts with a specialized nurse, this will be more effective and more satisfying for the family caregiver than if only online videos or e-bulletins are provided. The study results will be used to inform care professionals and family caregivers about which forms of online support intervention are most effective and best match family caregivers' needs.

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CHAPTER 8

Process evaluation of online self-management support for family caregivers to deal with behavior changes of a relative with dementia

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ABSTRACT

Background

Coping with behavioral changes is a daily challenge for family caregivers in all phases of dementia and assistance is needed for it. An online self-management support intervention was therefore developed and conducted involving various elements: a) e-mail contacts with a specialized dementia nurse, b) online videos, and c) e-bulletins containing information about behavior changes and how to manage them.

Objective

The objective of this process evaluation was to gain an understanding of a) family caregivers' actual use of various elements of the online self-management support, b) family caregivers' evaluation and satisfaction with the various elements, and c) nurses' evaluations of the online support through the tailored e-mail contacts.

Methods

A mixed-method design was used in this process evaluation, combining quantitative and qualitative methods including analyses of dementia nurses' registration forms, the numbers of clicks on online videos and e-bulletins, evaluation questions filled out by family caregivers in a survey questionnaire, semi-structured interviews with family caregivers and nurses, and analysis of the content of the e-mail contacts.

Results

The actual use of the various elements of the online self-management support by family caregivers varied: 78% of family caregivers had e-mail contact with the specialist nurse, 80% of family caregivers clicked on an online video and 37% clicked on an e-bulletin. Family caregivers showed positive evaluations and satisfaction. The tailor-made approach in the personal e-mail contacts in particular was valued by the family caregivers. Nurses' evaluations about providing self-management support online were mixed as it is a relatively new task for them.

Conclusions

An important insight is that not all participants made optimum use of the various elements of the intervention. Nurses also said that the e-mail contacts were more often used to express feelings about coping with behavioral changes. More research is needed to investigate the reasons why people accept, adopt and adhere to online interventions in order to reduce cases where they are not used and to back them up appropriately with tailored (online) information and advice for their personal situations.

INTRODUCTION

Family caregivers of people with dementia often face many challenges in everyday life while caring for their relative [1], most prominently regarding changes in behavior of the person with dementia [2, 3]. People with dementia may exhibit behavior that is dependent, aggressive, suspicious, apathetic or indifferent, or night-time restlessness and masking behavior. Approximately 80% to 90% of people with dementia show behavior disturbances during the disease process [4], often distressing both the person with dementia and their family caregivers [3, 5].

Coping with behavioral changes is a daily challenge for family caregivers in all phases of dementia [6]. These days, the term 'self-management' is widely used when referring to managing consequences of a disease in daily life. Following the well-known definition of Barlow *et al.* [7], we define self-management as *"the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition"*. Self-management applies not only to the patient but also to family caregivers. Especially in dementia care, the person often becomes increasingly dependent on support from family caregivers. This is stressfull for family caregivers, especially when coping with behavioral changes [5, 6]. They use strategies to respond to behavioral changes by remaining calm or encouraging activities and distractions. Moreover, family caregivers have self-management strategies to manage their own caregiver stress and problems related to their relative's dementia [5, 8].

However, family caregivers might need assistance coping with this daily challenge. In particular nurses are in the best position to help them because they develop an close partnership with individuals and their families throughout their lives [9]. This nurse–patient contact can also occur online [10] and might be especially useful for reaching family caregivers who are short of time due to providing care, have transportation difficulties or don't want to leave the person with dementia alone at home [11, 12]. In addition to professional support online, family caregivers may also benefit from multicomponent online interventions that combine e.g. information and tailored caregiving strategies [13].

In this paper we present a process evaluation of an online self-management support intervention addressing behavioral changes in dementia. The intervention consists of various online elements. The process evaluation was performed alongside a Randomized Controlled Trial (RCT) [14]. The aim of the RCT was to explore 1) whether a major online self-management support intervention involving e-mail contacts with a specialist dementia nurse in combination with online videos and e-bulletins, is more effective than minor interventions not involving the e-mail contacts with the nurse, and 2) if a medium intervention including videos and e-bulletins is more effective than a minor intervention including e-bulletins only. The results showed no statistically significant effects on family caregivers' self-efficacy for the major and medium online self-management support interventions compared to the minor intervention [15].

It is important to carry out a process evaluation alongside RCTs to allow effects (or the lack thereof) to be interpreted. It enables researchers to understand whether and how interventions are used, and how interventions are being evaluated by the people involved. Process evaluations alongside RCTs are even more important when evaluating online interventions because these studies are complicated, given the high numbers of non-adherent participants compared to face-to-face interventions [16, 17].

The overall objective of the process evaluation was to get a picture of the actual usage and evaluations of the interventions components. Related sub-objectives were to understand:

a. actual usage by family caregivers of the various elements of the online support,
b. family caregivers' evaluation of and satisfaction with the various elements,
c. nurses' evaluations of the online support through the tailored e-mail contacts.

METHODS

Design

The process evaluation had a mixed-method design in which quantitative and qualitative methods were combined and various sources were used (see the 'Data collection' section). The process evaluation was performed alongside the RCT involving three intervention arms (see the section on 'Interventions: content and development trajectory'). The design of the RCT is described elsewhere [14].

Participants

Family caregivers as well as specialized dementia nurses participated in the process evaluation.

Inclusion criteria for family caregivers were the same as the criteria used in the RCT: family caregivers aged at least 18 who were a partner or relative of a person diagnosed with dementia who is living at home, having contact at least weekly with the person with dementia, with Internet access and who provided online consent [14]. In total 81 family caregivers participated in the RCT (major (27), medium (27) or minor (27) intervention arms).

Inclusion criteria for the specialized dementia nurses were having e-mail contacts with family caregivers in the major intervention arm (see below), having a

Bachelor's or Master's degree in nursing and having received advanced training in dementia care. In total four nurses participated.

Interventions: content and development

Family caregivers were randomly allocated to the I (major), II (medium) or III (minor) intervention arms.

I. The major intervention arm was the most comprehensive and consisted of the following three elements (a, b, and c):
    a. three e-mail contacts with a specialized dementia nurse. In the e-mail contacts, the nurse helped family caregivers online to manage behavioral changes, guided by an intervention protocol developed by project team members (JGH, ALF, PJV, IvA), in consultation with the nurses themselves. The Dutch protocol (available on request from the first author) was structured using the steps of the 5A model of self-management support [18, 19] and Kitwood's person-centered care theory [20]. The 5A model comprises the following five steps: Assessing; Advising; Agreeing on goals; Assisting in anticipating barriers and developing a specific action plan; and Arranging follow-up [18, 19, 21, 22].
    b. providing online videos on how to manage the relative's behavior changes and how to improve self-efficacy in managing this behavior. There were six videos dealing with different common types of behavior changes: dependent behavior, suspicious behavior, aggressive behavior, apathy or indifference, restlessness at night, and masking behavior. Each video had the same structure, starting with possible causes and related solutions for responding or coping with the specific behavior, and ending by emphasizing that it is important that family caregivers take good care for themselves. Family caregivers could choose how many videos they watched depending on their personal needs and the behavioral changes encountered in their relative with dementia. The videos (along with the e-bulletins mentioned below – see element c) were developed by the co-authors BMW, IvA and AMP, in close collaboration with colleagues from the Trimbos Institute and the Dutch Alzheimer's Society, family caregivers of people with dementia and other experts. In the first step of the development process, a desk search was performed to obtain an impression of what is known in the literature about methods of influencing behavior approached from a person-centered perspective [20] and how family caregivers experience different kinds of behavioral changes in their relative with dementia. Experts also provided input for various aspects of the videos (e.g. Cognitive Behavioral Therapy principles, persuasive communication, modeling, and active learning). Video scripts and pilot videos were tested by family caregivers at several points during development. The videos are available on https://dementie.nl/online-training.

c. providing e-bulletins containing practical information about various types of behavioral changes and how to manage them. The same behavior changes were covered in the e-bulletins as in the videos. The e-bulletins included assignments that were designed to help caregivers interpret the generic information in the context of their own situation, to reflect on what might be causing the behavior changes, how they would like to cope with the behavior, and how they would like to respond. During the development process, the e-bulletins were tested together with the online videos. They have the same theoretical basis as the videos, and the people involved in the development of the videos were also involved in developing the e-bulletins.

II. The medium intervention, consisting only of the online videos and e-bulletins (elements b and c above);

III. The minor intervention, consisting only of the e-bulletins (element c).

Data collection

A schematic overview of the data collection methods used is given in Table 1. In some parts of the process evaluation, the sample concerned all family caregivers participating in the RCT (n=81), whereas in other parts of the process evaluation only sub samples participated.

As can be seen in the second column of Table 1, quantitative data involved nurses' records of the number of personal e-mail contacts per family member, clicks on links to the online videos and e-bulletins and evaluation questions filled out by family caregivers in a questionnaire. The evaluation questions were part of the questionnaire used at the end of the RCT [15].

As shown in the third column of Table 1, qualitative data concerned semi-structured interviews with family caregivers. In the last questionnaire used at the end of the RCT, family caregivers were asked if they would like to take part in such an interview. In total, 41 family caregivers were willing to participate. Of these, 12 were purposively recruited with a spread of intervention arms and background characteristics (e.g. gender, age, and living with or separately from the relative with dementia). They were sent an information letter by e-mail and were asked to give their consent by e-mail if they were willing to be interviewed. All interviews were conducted by telephone by one of the co-authors.

Semi-structured interviews were also conducted with the four specialized dementia nurses who provided the personalized e-mail contacts with de family caregivers. The topic list addressed how the nurses evaluated their support in the personal tailored e-mail contacts. All interviews with the nurses were carried out by one

Table 1 *Data collection methods (quantitative and qualitative) used for each research question.*

Research aims	Quantitative data	Qualitative data	Data collection period
To gain understanding of the actual use of family caregivers of the elements of the self-management support	Recording the actual use of personal e-mail contact with nurse by 27 family caregivers		March to August 2017
	Clicks on the video links by 54 family caregivers		March to August 2017
	Clicks on the e-bulletin links by 81 family caregivers		March to August 2017
To gain understanding of family caregivers' evaluation and satisfaction with the various elements of the online self-management support interventions.	Evaluation questions in a survey with Likert scale, send to 81 family caregivers		March to August 2017
		Semi-structured interviews with 12 family caregivers	Between July and August 2017
To gain understanding of nurses' evaluations of the online support through tailored e-mail contacts		Semi-structured interviews with 4 nurses	September 2017
		Analysis of the content of e-mail contacts of 27 family caregivers between family caregiver and nurse	March to August 2017

researcher (IvA). Three interviews were conducted by telephone; one interview took place at the Trimbos Institute.

Lastly, the content of e-mail contacts was analyzed regarding family caregivers' request for help, referral to the online videos and nurses' use of the intervention protocol based on the 5A model.

Data analysis

Quantitative data

Records and clicks on links were descriptively analyzed using Microsoft Excel (version 2010). The evaluation questions in the questionnaire were analyzed descriptively (frequencies and percentages) using SPSS software.

Qualitative data

The literally transcribed audio-recorded interviews were analyzed independently by two researchers (JGH and IvA) using the principles of Thematic Analysis [23]. Firstly, the researchers repeatedly read the data and looked for meanings and patterns in the data. Secondly, an initial list of codes was generated about what was in the data and what was interesting for the research questions. Thirdly, the various codes were sorted into potential themes and then fourthly refined so that data within the themes fitted together meaningfully. Fifthly, the themes were further refined by analyzing the data within the themes. Sixthly, once there was a set of fully detailed themes, the final analyses were written down [23]. Coding and interpretation of the codes were discussed at several moments in the analysis process by the researchers to reach consensus and to refine the analyses. In addition, interim and final analyses were also discussed with other co-authors. Furthermore, member checking was performed by discussing interim and final analyses with one of the nurses who was involved in the e-mail contacts (PJV).

The content of e-mail contacts for 27 family caregivers between them and the nurses was analyzed by one researcher (JGH) looking at their request for help, referral to the online videos and the use of the 5A model. A second reviewer (ALF) screened a random selection (e-mail contacts of 3 family caregivers).

Ethical procedures

The Medical Ethics Committee of the VU University Medical Center approved this study (reference 2016.559). All participating family caregivers and dementia nurses gave informed consent. All data were stored according to the rules of the Dutch Data Protection Act.

RESULTS

Family caregivers’ usage of e-mail contacts with nurses

Twenty-seven family caregivers were assigned to the major intervention arm, meaning that they had the opportunity to have personal e-mail contact with a dementia nurse in addition to the videos and e-bulletins. Twenty-one of the 27 family caregivers (78%) actually made use of the opportunity. Almost half the family caregivers (n=13; 48%) had three e-mail contacts, four had two e-mail contacts (15%) and another four (15%) had one e-mail contact (see Table 2).

Table 2 *Data from the recording form for personal e-mail contacts kept by the nurses*

Personal e-mail contacts	N
Family caregivers in the major intervention arm	27
Three e-mail contacts	13
Two e-mail contacts	4
One e-mail contact	4
None	6
Total amount of e-mail contacts	51
	Range (mean)
Time spent per e-mail contact (nurses)	20-55 minutes (35 minutes)

Family caregivers’ evaluation and satisfaction with e-mail contacts with nurses

Twenty-seven family caregivers assigned to the major intervention arm were asked to complete evaluation questions about the e-mail contacts (Table 2, second column). Sixteen completed the evaluation questions and had e-mail contact with a nurse. The majority (n=12; 75%) valued the personal e-mail contacts with the nurses in addition to the videos and e-bulletins. The nurses’ explanation and advice given in the e-mail contacts was clear for most family caregivers (n=12; 75%) and more than half of them (n=9; 56%) said they could immediately use the nurses’ advice in managing the behavior of their relative with dementia (see Table 3).

Four family caregivers in the major intervention arm were interviewed about how they evaluated the personal e-mail contacts with the nurse. They stated that they got the most out of these contacts, compared to leave videos and e-bulletins, because of the personal aspect. They liked the fact that the mirror was held up in front of them making you aware that you had to take a step back in some situations. They also liked the tips and ideas that the nurses gave them about how to act in their situation. In addition, they said that it was good to get confirmation that you were doing it correctly.

> *“Now like I said: you talk. At least you are then communicating with somebody [the nurse] who understands what it's about. You don't have to keep on reinventing the wheel then, in fact. You can just say, well, I'm coming up against this and that. Oh – watch out for this, watch out for that. That's simply very pleasant, I reckon.”*

One family caregiver said that she did not use the e-mail contacts. The reasons were not only the lack of time but also that the counselling by e-mail was not attractive

Table 3 Evaluation questions on Likert scales

Survey questions	Major	Medium	Minor
Family caregivers who completed the evaluation questions	16	21	15
	N (%)		
The personal e-mail contacts with the nurse added value to the video and e-bulletins			
completely agree / agree	12 (75)		
neutral	2 (12)		
disagree / completely disagree	2 (12)		
The nurse's explanation and advice were clear			
completely agree/ agree	12 (75)		
neutral	3 (19)		
disagree/ completely disagree	1 (6)		
I was able to use the advice of the nurses immediately in managing the behavior of my relative with dementia			
completely agree/ agree	9 (56)		
neutral	6 (37)		
disagree/ completely disagree	1 (6)		
The videos and e-bulletins fitted my situation			
completely agree/ agree	10 (62)	9 (43)	
neutral	6 (37)	11 (52)	
disagree/ completely disagree	0 (0)	1 (5)	
The videos and e-bulletins helped me to manage the behavior of my relative with dementia			
completely agree/ agree	11 (69)	10 (48)	
neutral	5 (31)	10 (48)	
disagree/ completely disagree	0 (0)	1 (5)	
In addition to videos and e-bulletins, I would have liked to receive extra support from a nurse by e-mail			
completely agree/ agree		6 (29)	
neutral		13 (62)	
disagree/ completely disagree		2 (10)	
The e-bulletins fitted my situation			
completely agree/ agree			7 (47)
neutral			6 (40)
disagree/ completely disagree			2 (13)
The e-bulletins helped me to manage the behavior of my relative with dementia			
completely agree/ agree			8 (53)
neutral			5 (33)
disagree/ completely disagree			2 (13)
In addition to the e-bulletins, I would have liked to receive extra support from a nurse by e-mail			
completely agree/ agree			6 (40)
neutral			6 (40)
disagree/ completely disagree			3 (20)

because you then have to put your emotions and questions on paper. That was a barrier for this family caregiver, who also said that the barrier would have been much lower if the counselling had been by phone.

Family caregivers' usage of online videos

In total, 54 family caregivers (27 in the major intervention arm and 27 in the medium intervention arm) had access to six videos about how to manage behavioral changes in their relative with dementia. Of them, 43 (80%) clicked at least one video. Clicks on the videos are listed in Table 4.

Table 4 *Clicks on the links to the videos and e-bulletins*

Clicks on videos and e-bulletins	N (%)
Total family caregivers who clicked on videos (n= 54)	43 (80)
Family caregivers in the major intervention arm who watched at least one video (n= 27)	22 (81)
Family caregivers in the medium intervention arm who watched at least one video (n= 27)	21 (78)
Total clicks on e-bulletins (n=81)	30 (37)
Family caregivers in the major intervention arm who watched at least one e-bulletin (n= 27)	5 (19)
Family caregivers in the medium intervention arm who watched at least one e-bulletin (n= 27)	7 (26)
Family caregivers in the minor intervention arm who watched at least one e-bulletin (n= 27)	18 (67)

Family caregivers' evaluation and satisfaction with the videos and e-bulletins

Fifty-four family caregivers were asked to complete evaluation questions about the videos (Table 3, second column). Thirty-seven watched at least one video (16 in the major intervention arm and 21 in the medium intervention arm). Half of them (both major and medium arms, total n=19; 51%) said that the videos and e-bulletins fitted their personal situation and more than half stated that they helped them to better manage with the behavior of the person with dementia (n=21; 57%).

In total, 9 family caregivers who had access to the videos (4 in the major intervention arm and 5 in the medium intervention arm) were interviewed about how they evaluated the videos. They said that they thought the videos were well-structured and pleasant to watch. They also found the content clear and useful. The tips given in them were reckoned to be useful; watching the videos gave them new ideas for coping with the behavioral changes in their relative.

> *"Well, because it's important for you to have a clear picture as well. It's useful to know what I ought to be doing. That really does help quite a bit. Otherwise there's a lot of conflict and so forth, instance defiance or whatever – quite a lot. It lets you know how to tackle the situation: let's put it like that."*

Some of the family caregivers found the content and the stories of other family caregivers recognizable and helpful. Others said they didn't relate to much that was in the videos because there was no change in behavior in their situation or the behavior was expressed differently. They said that this meant the videos were less useful to them.

> *"With my husband, it was mostly about the aggression and waking up at night and that wasn't something I really saw in the video or in the text. And that was what I find so typical. There were a few bits in that I recognized, but I didn't get the feeling that the situation really fitted in very well with ours."*

One family caregiver also remarked that the videos and the e-bulletins were suitable primarily in the early phases of dementia; another said that the information was too sketchy for family-based carers dealing with dementia in its later stages.

Family caregivers' usage of e-bulletins

All family caregivers (n=81) had access to the e-bulletins (through a link). The e-bulletins contained practical information about various types of behavioral changes and tasks to help reflect on their possible causes and how to influence and cope with them. In total, 30 family caregivers out of 81 (37%) clicked at least one e-bulletin. In the minor intervention arm, the percentage who clicked the e-bulletins was the highest (n=18; 67%) (see Table 3).

Family caregivers' evaluation and satisfaction with the e-bulletins

Fifteen of 27 family caregivers (56%) in the minor intervention arm filled in the evaluation questions (see Table 3, fourth column). Almost half (n=7; 46%) said that the e-bulletins fitted their situations and that the e-bulletins helped them to manage behavioral changes in the person with dementia (n=8; 53%).

In total, 12 family caregivers (4 in the major intervention arm, 5 in the medium intervention arm and 3 in the minor intervention arm) were interviewed on how they evaluated the e-bulletins. A number of family caregivers stated that the information in the e-bulletins was clear and recognizable as well as being helpful to read again. Some also said that one of the benefits was that there was one e-bulletin of each type of behavior. Conversely, others felt that the content of the e-bulletins was not always recognizable and that they were unable to translate it well to their own situations. One family caregiver said that the text sometimes circumvented the unpleasant core issue and they also felt some of the recommendations were patronizing. Some of the group who had also seen the video felt that the e-bulletin was a good addition to the videos, whereas others set more store by it because information from the videos was enough for them.

The family caregivers who only received the e-bulletins mostly thought they were informative, although one family caregiver said that information did not help in her situation. Others said that the information meant they were more aware of what they could come up against and that it put a different perspective on the behavior for them. Moreover, understanding the behavior better because of the information from the e-bulletins let them be more patient in dealing with the behavior.

> *“Explaining the behavior and how you have to respond to it, right? Most of the time you have to count to ten first or – as I always say – sometimes a hundred. Like that.”*

The family caregivers would recommend the e-bulletins to others. One of them advised distributing this information among professionals too, having noted that they do not always know enough about behavioral changes.

Nurses’ evaluation and satisfaction with providing tailored e-mail contacts

Four specialized dementia nurses provided online self-management support via e-mail. In total, the nurses had 51 e-mail contacts with family caregivers. The time spent by the nurses varied from 20 to 55 minutes (mean 35 minutes) per e-mail contact (see Table 1).

Semi-structured interviews were held with four nurses to get a picture of their evaluations of providing online self-management support. Categorization resulted in four themes: background characteristics and expectations of family caregivers, evaluation of the online assistance, evaluation of the intervention protocol with the 5A model, number of e-mail contacts, and the perceived effect.

Background characteristics and expectations of family caregivers

Two specialist nurses said that the family caregivers had partners in an advanced stage of dementia. One nurse said that she got the impression that the family caregivers were overloaded. Moreover, the nurses noted that some of the caregivers had one or more people helping them and were deliberately busy collecting information about the condition. In addition, one nurse said that the family caregivers were not aware that they were also tackling their situations too.

In terms of the expectations of the family caregivers, the majority of the nurses had the impression that family caregivers were looking for a release valve and a listening ear. A number of the caregivers needed concrete ideas about how to deal with behavioral changes in their relative. One nurse also said that she noticed that she was being asked questions about case management, for instance about coordinating care for the relative.

Evaluation of the online assistance

The nurses said that there were pros and cons to giving online assistance. One nurse said that putting the situation down on paper was one of the benefits of online counselling because the family caregivers then got a better picture of the severity and the situation would sink in more quickly:

> *"Yes [...] because the family caregivers are e-mailing and putting things into words, the seriousness of the problem is made a bit clearer, I reckon. I get that idea quite strongly. Putting it on paper can in fact point out the severity – almost as if they're saying they can't cope any more. Yes, that does help. It paints a picture of the changed behavior, and shows that action is needed as well."*

They also felt it was an advantage that you can ask encouraging questions, but the nurse wondered whether this matched the family caregivers' expectations of this online assistance.

Giving online counselling was also felt to be 'awkward' because you cannot look anyone in the eye and it is then more difficult to assess the situation. They found it tricky to get the right tone for approaching the family caregiver. Because the counselling was online, the nurse did not know if the advice had been understood by the family caregiver. If the caregiver no longer responded, the nurse did not know if they had said something wrong or if there was another, unrelated reason.

Another nurse said that online assistance is suitable for practical questions, but that you need more time and need to know more in the role of health care provider if it is about people being overburdened or about changed behavior. Another nurse believed that it became easier as you did it more often. A certain amount of practice is needed if this counselling is to be provided properly.

Evaluation of the intervention protocol with the 5A model

One nurse said that the 5A model could help a lot in the online counselling but that the nurses had difficulties with the application of the model. The link between the video content and the 5A model was also unclear. The reason was that they had a feeling that the family caregivers needed other assistance, e.g. providing a listening ear. The videos and e-mail counselling focused on coping with the changed behavior, but the nurses noticed that the family caregivers had more of a need to talk about things. Getting them to talk about the behavioral changes and think about them felt like the nurses were pushing.

Number of e-mail contacts

Opinions varied as to whether the number of e-mail contacts was sufficient. Two of the nurses said that it was enough. One nurse did state as a condition that the contacts should then only focus on the behavioral changes and not on other questions and advice. Another nurse doubted whether three contacts were enough to have an effect. The e-mails from the family caregivers contained a lot of information, not only about to change behavior but also about the other problems involved. Another nurse said she got the impression that family caregivers enjoyed watching the videos, but did not think that they actually wanted to do anything as result.

The perceived effect

Most of the nurses said that their assistance meant that family caregivers could get things off their chest or that the family caregivers felt they had been listened to. One nurse said that it was a help that the family caregivers had taken a moment to think about the behavioral changes in their relative with dementia. She also thought that the tips she had given about how to make thorny subjects open to discussion had helped. According to one nurse, effective elements were the attention paid to the personal situations of the family caregivers and being able to reflect on them together. This nurse was also able to give the family caregivers tips about other forms of assistance. Another nurse believed that the e-mail contacts had helped the family caregivers translate what was happening in the videos to their own situations. In the case of one family caregiver, a nurse had the impression that the counselling had no effect because the person in question was already so overburdened that e-mail contact was too much. Another nurse did not believe that it had given the family caregivers a better picture of behavioral changes because the nurses did not have the right skills for online counselling and because the need for assistance among family caregivers was so diverse.

Analysis of the content of e-mail contacts between family caregiver and nurse

Twenty-one of 27 family caregivers (78%) had e-mail contact with a nurse. As data was missing for two family caregivers, e-mail contacts from 19 family caregivers were analyzed. Eleven of them (58%) did not express an explicit goal in the e-mail contacts. In fifteen cases (79%), the content of the e-mails was about behavioral changes in their relative with dementia. Four family caregivers (21%) (also) discussed caregiving stress. Six (32%) discussed other caregiving issues not related to behavioral changes. In five cases (26%), the nurse referred in the e-mail contacts to the online videos (see Table 5).

The first step in the 5A model ('Assessing') was used by the nurses in all e-mail contacts. The second step ('Advising') was used in about half of the cases. The other steps of the 5A model ('Agreeing on goals', 'Assisting in anticipating barriers and developing a specific action plan', and 'Arranging follow-up') hardly occurred at all in the e-mail contacts.

Table 5 *Content of all e-mail contacts between family caregivers who had e-mail contact with a nurse (n=19)*

	N (%)
Explicitly formulated request for help	
Yes	8 (42)
No	11 (58)
Content discussed in one or more e-mails	
Behavioral changes	15 (79)
Managing caregiver stress	4 (21)
Other caregiving issues (other than behavioral changes of the relative with dementia)	6 (32)
A link to the online videos	
Yes	5 (26)
No	14 (74)

DISCUSSION

Through this process evaluation, we aimed to gain a picture of a) actual use by family caregivers of the various elements of online self-management support, b) family caregivers' evaluation and satisfaction with the various elements, and c) nurses' evaluations of the online support through the tailored e-mail contacts. This process evaluation was performed alongside an RCT [14] in which the effectiveness was studied of an online self-management support intervention involving tailored e-mail contacts with a specialized dementia nurse combined with online videos and e-bulletins. Contrary to our expectations, no statistical evidence was found for the major and medium online self-management interventions compared to minor intervention (involving e-bulletins only) on family caregivers' self-efficacy [15]. Although no effects were found, this evaluation noted that family caregivers valued the e-mail contacts with the specialist nurse. They mentioned that receiving confirmation from a professional that they were doing the right thing was really important to them. Previous studies also found that being acknowledged by professionals and peers for the everyday care they provided is extremely important for family caregivers in helping them cope with daily challenges [8, 24]. They also felt that the e-mail contacts offered added value above the videos and e-bulletins. Family caregivers who received the videos and e-bulletins mentioned difficulties in translating the information and advice to their own situations. It could therefore be suggested that an online personal approach is needed in order to acknowledge the highly complex situation of family caregivers and subsequently assist them by providing tailored online information and advice for their personal situations.

This process evaluation also suggests possible explanations for the unexpected results in the RCT by understanding how the intervention was used and was evaluated by the people involved. Firstly, this process evaluation showed variation in the extent that family caregivers made use of the various elements of the online self-management support. Seventy-eight percent of family caregivers had e-mail contact with a nurse (21 out of 27), 80% watched one or more online videos (43 out of 54) and 37% clicked an e-bulletin (30 out of 81). The distinction between the three intervention arms consequently becomes less, making it difficult to demonstrate effects [17]. Non-use of an intervention is a methodological known difficulty in web-based trials and may explain why interventions fail to show a measurable effect for the intervention [17, 25, 26]. For eHealth interventions to present an effect, they need to be accepted and used in the intended way to benefit the participants the most [27]. However, improving the use of eHealth interventions is complex and more insights are needed investigating the reasons why people accept, adopt and adhere to eHealth interventions so that their behavior can be influenced [27].

Secondly, according to the nurses, the participants involved in the e-mail contacts were mainly family caregivers who used one or more health professionals and were highly engaged in collecting information about dementia. This group would then already have information and advice on how to cope with behavioral changes, which might explain why family caregivers wanted to share their stories and express their feelings instead of finding other ways to self-manage the behavioral changes of their relative with dementia. For future research, it is important to determine which family caregivers will benefit most from what type of support. This would provide insight that can be used to provide the intervention in a more cost-effective way. This, for example, means that nurses' support can be provided to the people who are likely to benefit most.

Another possible explanation for finding no statistical evidence for the benefits of e-mail contact between family caregivers and nurses (combined with videos and e-bulletins) may be how the intervention was carried out. In many cases, only the first two As ('Assessing' and 'Advising') were completed. Using the 5A model turned out to be difficult as it was new to the nurses. Previous studies' results were comparable, as the last two A's ('Assist and 'Arrange') seem to be delivered least often by nurses [18, 28, 29]. However, those components are most important for producing meaningful and lasting behavioral changes [18]. Future research therefore needs to investigate how all steps of the 5A model could be performed online.

When providing online support, the dosage of online intervention should also be considered. It is for instance striking that only a few (37%) family caregivers clicked e-bulletins. This could be explained by the fact that not everything that is offered will also be used. This may be illustrated by the low usages rates of the e-bulletins by family caregivers who also had e-mail contact with a nurse and access to the online videos. This indicates that informal caregivers do not stick to the intervention, but decide for themselves what care is needed and fits their unique situation. Tailored information and advice should therefore be offered in a way that is geared to family caregivers' needs [30]. This could include a differentiated offer of support instead of offering multiple kinds of support. This enables family caregivers get help that is based on their needs, self-management abilities and home situations.

Strengths and limitations

The mixed-method design combining quantitative and qualitative data enabled better understanding of how online self-management support interventions were used and evaluated by both the family caregivers and dementia nurses involved. The information gathered can be used to develop online self-management support further for families facing dementia. Furthermore, the validity of the results was enhanced by combining quantitative and qualitative data [31]. However, findings of this study need to be considered within the context of a number of methodological limitations. Firstly, tracked usage data were measured in clicks that represent page views. People who click a link do not however necessarily watch the whole online video or read the e-bulletin. The numbers found could therefore overestimate family caregivers' utilization of an intervention component. Click data should therefore be seen in combination with other evaluation methods [32]. Secondly, no data was collected for the six family caregivers who did not use the e-mail contacts. Barriers preventing family caregivers from making e-mail contact with a nurse could therefore potentially have not been detected.

CONCLUSIONS

To conclude, there was variation in the extent to which family caregivers utilized the various elements of online self-management support. They valued the tailor-made approach in the e-mail contacts. According to the nurses involved, online personal e-mail contacts were mostly used to express feelings concerning coping with changing behavior. Nurses' evaluations of providing self-management support online were mixed, as it is a relatively new task for nurses. More research is needed to investigate the reasons why people accept, adopt and adhere to online interventions in order to reduce non-use and to support them appropriately by providing tailored (online) information and advice for their personal situations.

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CHAPTER 9

Effects of online self-management support of family caregivers to deal with behavior changes of the relative with dementia: a randomized controlled trial

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ABSTRACT

Background

Online contacts with a health professional have the potential to support family caregivers of people with dementia.

Objective

To study the effects of an online self-management support intervention in helping family caregivers to deal with behavior changes of the relative with dementia. The intervention - involving among others personal e-mail contacts with a dementia nurse - was compared to online interventions without these e-mail contacts.

Methods

A randomized controlled trial (RCT) was conducted with 81 family caregivers of people with dementia who live at home. Participants were randomly assigned to one of (1) a major self-management support intervention consisting of personal e-mail contacts with a specialist dementia nurse, online videos, and e-bulletins; or (2) a medium intervention consisting only of online videos and e-bulletins; or (3) a minor intervention consisting of only the e-bulletins. The primary outcome was family caregivers' self-efficacy in dealing with behavior changes of the relative with dementia. Secondary outcomes were family caregivers' reports of behavior problems in the people with dementia and the quality of the relationship between the family caregiver and the person with dementia. Measurements were performed at the baseline and at six (T1) and twelve weeks (T2) after the baseline. A mixed-model analysis was conducted to compare the outcomes of the three intervention arms.

Results

Family caregivers participating in the major intervention involving e-mail contacts showed no statistically significant differences in self-efficacy after the intervention compared to the minor intervention involving only e-bulletins (difference -0.02, p-value 0.99). In the adjusted analysis, the medium intervention (involving videos and e-bulletins) showed a negative trend over time (difference -4.21, p=0.09) and at T1 (difference -4.71, p=0.07) compared to the minor intervention involving only e-bulletins. Neither were any statistical differences found between the intervention arms in terms of the reported behavior problems and the quality of the relationship between the family caregiver and the person with dementia.

Conclusion

The expectation that an online self-management support intervention involving e-mail contacts would lead to positive effects and be more effective than online

interventions without personal e-mail contacts was not borne out. One explanation might be related to the fact that not all family caregivers who were assigned to that intervention actually made use of the opportunity for personal e-mail contact. The online videos were also not always viewed. To obtain more definite conclusions, future research involving extra efforts to reach higher usage rates is required.

Trial Registration

Netherlands Trial Registry (NTR): NTR6237; http://www.trialregister.nl/trialreg/admin/rctview.asp?TC=6237
(Archived by WebCite at http://www.webcitation.org/6v0S4fxTC)

INTRODUCTION

Most people with dementia live at home and are often supported by family members, who show great dedication in their care [1]. Even so, family care can be a large burden [2], for instance because dealing with their relative's behavior changes is stressful for family caregivers [3]. Changes in behavior include e.g. dependent behavior, aggressive behavior, suspicious behavior, apathy or indifference, restlessness at night, and masking behavior. These behavior changes are 'challenging', as they often cause distress to family caregivers and/or the person with dementia and adversely affect the quality of life of at least one of the parties [4]. A Dutch nationwide survey found that about three in four family caregivers of people with dementia experienced problems in dealing with changes in their relative's behavior or mood, in both the initial and the later stages of the disease [5].

In addition to caring for their relative, family caregivers also have to deal with their own health and the consequences of dementia in their lives [6]. An increasing number of self-management support interventions have been developed to help family caregivers [7], e.g. in dealing with their relative's behavior changes. Some of these are online-based [7]. Using online interventions for support has several opportunities such as offering the possibility of getting access to help at any time at any place, without leaving the person with dementia alone [8].

Available systematic reviews suggest that online support might have positive effects for family caregivers, e.g. on their self-efficacy and other psychological or psychosocial outcomes [8-11]. Family caregivers could benefit from multicomponent online interventions combining *inter alia* information and tailored caregiving strategies [9]. In particular, family caregivers might benefit from additional personal online contact with health professionals [9, 12] as health professionals can help them apply generic information to their specific situation [13] and give tailored advice based on their needs. Although studies including online professional support have been developed and evaluated, most of them are aimed at general caregiving issues [14-17] and their overall quality of evidence is low due to there being relatively few RCTs [12]. Further research is required to clarify the necessity of personal contacts with a professional [16] when coping with behavior changes in their relative with dementia.

The aim of this study is therefore to assess (1) if a major multicomponent intervention, consisting of e-mail contacts with a specialized dementia nurse, videos, and e-bulletins is more effective than interventions without personal contacts and (2) if a medium intervention including videos and e-bulletins is more effective than a minor intervention including e-bulletins only.

The effectiveness of the major and medium interventions was determined by measuring changes in (a) self-efficacy of family caregivers in managing behavior changes of their relative with dementia, (b) behavior problems in the people with dementia, as reported by family caregivers, and (c) the quality of the relationship between the family caregiver and the person with dementia.

METHODS

A three-arm randomized controlled trial (RCT) was carried out between March 2017 and August 2017 in the Netherlands. The study is registered in the Netherlands Trial Registry (NTR) (NTR6237). The study protocol has been published previously [18]. Alongside the RCT, a mixed-method process evaluation was performed to evaluate the online self-management support intervention in terms of usability and satisfaction [18].

Design, Intervention Arms, and Elements

To answer the research questions, a three-arm RCT was performed with repeated measurements at three time points. The three intervention arms all focused on helping family caregivers deal with behavior changes in their relative with dementia but varied in the number of elements involved. The intervention arms are referred to as the major, medium, and minor intervention arms. The intervention arms are described elsewhere in more detail [18]. In short, the major intervention arm consisted of **(a)** three personal e-mail contacts with a specialist dementia nurse (in a period of 12 weeks), **(b)** providing six online videos, and **(c)** providing six e-bulletins containing practical information about different types of changes in behavior and how to manage them. The medium intervention arm consisted only of the online videos and e-bulletins (see elements b and c above) and the minor intervention arm consisted only of the e-bulletins (see element c).

Inclusion and Randomization

Family caregivers were eligible to participate in the study if they were at least 18 years old, were a partner or relative of a person diagnosed with dementia who lives at home, had at least once-weekly contact with the person with dementia, had access to the Internet and gave online consent. Family caregivers were recruited via the Dutch Alzheimer Society's panel, the Dutch Alzheimer Society's online forum (with 7000 monthly visitors), the Dementie.nl website (https://dementie.nl), and the Dutch Alzheimer Society's social media accounts (Twitter and Facebook). Details of the recruitment procedure have been described elsewhere [18].

After online consent was given (see the study protocol for more detail [18]), family caregivers were randomly allocated by the researcher (JGH) to one of the three intervention arms using a randomization schedule. Block randomization was applied to achieve an equal likelihood of the participant being allocated to each of the three intervention arms [19]. An independent epidemiologist prepared a randomization schedule using several block sizes of 6 and 9.

Participants could not be blinded as it is impossible to blind participants to the sort of eHealth intervention they are receiving [20].

Sample Size

In this study, we expected that (1) both the major and medium intervention arms would lead to a greater improvement in self-efficacy than the minor intervention arm and that (2) the major intervention arm would show larger improvements in self-efficacy than the medium intervention arm. Based on a difference of 0.8 standard deviation units between the groups and assuming a significance level of 5%, a power of 80%, and correlation of 0.6 between the two repeated measures, the number of subjects needed per group was 20. Taking into account a drop-out rate of 20%, 24 participants per group were needed.

Another consideration was that the specialist dementia nurses had limited previous experience of providing self-management support through e-mail contacts. We therefore expected a learning curve for the dementia nurses during the study, which might also have had consequences for the measured effects on family caregivers. One additional block of 9 participants (3 in each group) was added to the sample so that we could take a brief learning curve into account. This brought the total number of participants that had to be recruited to 81.

Measurement Procedures

Measurements were performed at three points in time: (T0) baseline assessment, (T1) six weeks after the baseline assessment and (T2) twelve weeks after the baseline assessment.

Measurements were done by online questionnaires administered to the participating family caregivers through an e-mail link. After one and two weeks, participants were reminded (if needed) to complete the questionnaires.

Primary Outcome

The primary outcome variable (self-efficacy) was measured using the ‘Trust in Own Abilities’ (TRUST) instrument, a questionnaire in Dutch. The questionnaire had been used previously to measure self-efficacy in family caregivers of people with dementia living at home [21]. The TRUST questionnaire has 32 items divided into three subscales: solution orientation (8 items), resilience (15 items), and proactive competence (9 items). For this study, one item from the original 37-item TRUST questionnaire was added as this item reflected the main goal of this intervention. This item was queried as "*How well can you, in your own opinion, deal with changed behavior of your relative, such as aggression, apathy, and dependence?*" (translated from Dutch). Since the TRUST questionnaire is quite new and has only been validated and tested with pilot data, a principal component analysis was performed. A total of 33 items were tested in a principal component analysis. All 33 items were loading on the same factor. However, four of the 33 items were not loading strongly enough (cut-off point < 0.4) [22]. When these items were dropped, Cronbach's alpha for our sample was 0.925. Only the revised sum score (29 items) will therefore be studied.

Items ranged from 0 ('not at all') to 3 ('very good'). The higher the score, the greater the perceived competence in caring for someone with dementia [21].

Secondary Outcomes

The first secondary outcome variable was the presence and reaction scores for mood and behavior problems, measured using the Dutch version of the Revised Memory and Behavioral Problem Checklist (RMBPC) [23, 24]. The RMBPC is a self-assessment questionnaire which can be broken down into scales for disruptive behavior (8 items), depression (9 items), and memory-related problems (7 items).

For this study, only disruptive behavior will be studied as this was the outcome of interest. Family caregivers were asked to rate the occurrence of specific behavior on a scale from 0 to 4 (0 = never; 1 = rarely; 2 = regularly; 3 = often; 4 = always) and parallel their reaction scores for the degree of distress (0 = not upset; 1 = not very upset ; 2 = quite upset; 3 = extremely upset).

The mean scores of the occurrence of behavior and family caregivers' reaction to these problems were calculated. For behaviors that did not occur, a reaction score of 0 (not upset) was assigned [25].

A second secondary outcome variable concerned the positive and negative aspects of the relationship between the person with dementia and the family caregiver. This was measured by the Dyadic Relationship Scale (DRS). The family caregiver version has 11 items in two subscales: dyadic strain (5 items) and positive dyadic interaction (6 items). Family caregivers were asked to rate the separate items on a 4-point scale (1 = 'strongly disagree', 2 = 'disagree', 3 = 'agree', 4 = 'strongly agree') [26].

Analyses

All data were analyzed using SPSS Software (version 22.0). Mixed-model analyses were carried out to compare primary and secondary outcomes between the major and the minor intervention arm and between the medium and minor intervention arm over time and at T1 and T2. Mixed-model analyses were performed to take account of the correlation between the two repeated measurements within the subject (T1 and T2). To obtain the intervention effect at two different time points, time and interaction between intervention and time were added to the model. All mixed-model analyses were adjusted for the baseline value of the particular outcome. In addition to crude effects, effects adjusted for gender, type of relationship, appearance of first symptoms, education level and shared caregiving were also estimated.

Ethics Procedures

The study was approved by the VU University Medical Center's Medical Ethics Committee (reference 2016.559). It had no objections to the study. All participants were required to give their informed consent for participation via an online informed consent form. Only the research team members had access to the data. Agreements about how to archive, share, and store data were signed by the organizations responsible for collecting the data.

RESULTS

Participants' Characteristics

A total of 158 family caregivers expressed their interest in participating in the study. After sending an information letter, the first 81 caregivers who signed the online informed consent form and completed the baseline assessment were included.

After completing the baseline questionnaire, the participants were randomly allocated to the major (27), medium (27), or minor (27) intervention arms following the block randomization schedule. A total of 70 (86.4%) family caregivers completed the T1 assessment (6 weeks after baseline), and 66 (81.5%) family caregivers completed the T2 assessment (12 weeks after baseline).

Baseline data for the caregivers included are listed in Table 1. At baseline, family caregivers were on average 56.5 years old (range 23-80; SD 12.5), primarily female (87.7%) and half of them had completed a professional or academic degree (49.4%). The relatives with dementia they were caring for were mostly their mother or father (or a parent-in-law) (56.8%) or their partner (39.5%). The individuals with dementia were on average 75.1 years old (range 49-96; SD 9.9) and more often male (51.9%), with Alzheimer's disease

Table 1 *Baseline data for the caregivers included*

Group, N (%)	81 (100)
major	27 (33.3)
medium	27 (33.3)
minor	27 (33.3)
Gender of family caregiver; Female, N (%)	71 (87.7)
Age of family caregiver, mean (range; SD)	56.5 (23-80; 12.5)
Gender of person with dementia; Female N (%)	39 (48.1)
Age of person with dementia, mean (range; SD)	75.1 (49-96; 9.9)
Relationship of family caregiver to person with dementia, N (%)	
partner	32 (39.5)
mother or father (or in-laws)	46 (56.8)
other family member	3 (3.7)
Person with dementia has their own household, N (%)	25 (30.9)
Same household as person with dementia, N (%)	33 (40.7)
First symptoms of dementia (according to the family caregiver), N (%)	
<2 years	15 (18.5)
2 to 4 years	24 (29.6)
>4 years or more	42 (51.8)
Type of dementia of the relative with dementia, N (%)	
Alzheimer's disease	47 (57.0)
Vascular dementia	13 (16.0)
Frontotemporal dementia	3 (3.7)
Dementia with Lewy bodies (DLB)	2 (2.5)
Mixed dementia	9 (11.1)
Not known	7 (8.6)
Highest educational attainment, N (%)	
Primary school	8 (9.9)
High school (preparatory to vocational education) and vocational training	17 (21.0)
Professional or academic/university	40 (49.4)
Missing	16 (19.8)
Burden (at baseline), N (%)	
barely	6 (7.4)
somewhat	35 (43.2)
fairly	31 (38.3)
high burden	9 (11.1)
Behavior that family caregiver has the most difficulty dealing with, N (%)	
dependent behavior	22 (27.2)
aggressive behavior	9 (11.1)
suspicious behavior	12 (14.8)
apathy or indifference	9 (11.1)
night-time restlessness	10 (12.3)
masking behavior	19 (23.5)

Table 2 *Results for the major intervention arm compared to the minor intervention arm over time, at T1 and at T2 on the outcomes TRUST, RMBPC and DRS*

	MAJOR INTERVENTION ARM																							
	Analyses over Time								Analyses at T1								Analyses at T2							
	Crude analysis[a]				Adjusted analysis[b]				Crude analysis[a]				Adjusted analysis[b]				Crude analysis[a]				Adjusted analysis[b]			
	B	P value	95%CI		B	P value	95%CI		B	P value	95%CI		B	P value	95%CI		B	P value	95%CI		B	P value	95%CI	
TRUST	-0.02	.99	-4.16	4.12	-1.12	.65	-5.98	3.74	1.97	.40	-2.65	6.59	0.30	.91	-5.14	5.73	-2.16	.36	-6.86	2.53	-2.40	.38	-7.77	2.97
RMBPC Dis	0.35	.71	-1.56	2.27	0.60	.59	-1.62	2.83	0.58	.59	-1.55	2.70	1.06	.40	-1.42	3.54	0.12	.91	-2.04	2.27	0.13	.93	-2.33	2.59
RMBPC-R Dis	0.59	.42	-0.88	2.06	1.09	.21	-0.63	2.81	1.22	.16	-0.49	2.94	2.02	.05	0.04	4.00	-0.08	.93	-1.81	1.65	0.14	.89	-1.84	2.12
DRS-S	0.33	.55	-0.76	1.41	0.24	.70	-1.02	1.52	0.56	.37	-0.68	1.79	0.41	.57	-1.05	1.87	0.08	.90	-1.18	1.34	0.06	.93	-1.38	1.51
DRS-I	-0.46	.47	-1.72	0.80	-0.37	.62	-1.86	1.11	-0.39	.59	-1.84	1.06	-0.35	.69	-2.05	1.36	-0.53	.47	-2.00	0.93	-0.37	.66	-2.05	1.31

[a] Adjusted for the baseline value of the outcome variable.

[b] Adjusted for the baseline value of the outcome variable, gender, type of relationship, appearance of first symptoms, education level and shared caregiving

Abbreviations: TRUST, revised total score for Trust in Own Abilities (29 items); RMBPC, Revised Memory and Behavioral Problem Checklist; Dis, Disruptive behavior; RMBPC-r, RMBPC-R Dis, family caregivers' reaction scores for disruptive behavior of the relative with dementia; DRS-S, Dyadic Relationship Scale - Strain; DRS-I, Dyadic Relationship Scale - Interaction.

Table 3 *Results for the medium intervention arm compared to the minor intervention arm over time, at T1 and at T2 on the outcomes TRUST, RMBPC and DRS*

	MAJOR INTERVENTION ARM																							
	Analyses over Time								Analyses at T1								Analyses at T2							
	Crude analysis[a]				Adjusted analysis[b]				Crude analysis[a]				Adjusted analysis[b]				Crude analysis[a]				Adjusted analysis[b]			
	B	P value	95%CI		B	P value	95%CI		B	P value	95%CI		B	P value	95%CI		B	P value	95%CI		B	P value	95%CI	
TRUST	-3.03	.14	-7.06	1.00	-4.21	.09	-9.01	0.60	-3.04	.18	-7.49	1.41	-4.71	.07	-9.94	0.52	-2.95	.20	-7.52	1.63	-3.63	.18	-8.93	1.68
RMBPC Dis	0.32	.73	-1.54	2.18	0.96	.38	-1.23	3.15	0.29	.78	-1.78	2.35	1.13	.35	-1.25	3.52	0.37	.72	-1.72	2.47	0.89	.46	-1.52	3.31
RMBPC-R Dis	0.53	.46	-0.88	1.95	0.49	.56	-1.20	2.18	0.87	.29	-0.75	2.49	1.13	.23	-0.76	3.02	0.21	.81	-1.47	1.88	-0.09	.93	-2.01	1.84
DRS-S	0.03	.95	-1.02	1.09	0.52	.40	-0.70	1.75	0.54	.37	-0.65	1.74	1.05	.13	-0.32	2.42	-0.53	.39	-1.76	0.69	-0.53	.94	-1.45	1.34
DRS-I	-0.76	.22	-1.99	0.47	-0.81	.27	-2.28	0.66	-0.62	.38	-2.01	0.77	-0.84	.31	-2.47	0.79	-0.92	.21	-2.35	0.51	-0.85	.31	-2.51	0.81

[a] Adjusted for the baseline value of the outcome variable.

[b] Adjusted for the baseline value of the outcome variable, gender, type of relationship, appearance of first symptoms, education level and shared caregiving

Abbreviations: TRUST, revised total score for Trust in Own Abilities (29 items); RMBPC, Revised Memory and Behavioral Problem Checklist; Dis, Disruptive behavior; RMBPC-r, RMBPC-R Dis, family caregivers' reaction scores for disruptive behavior of the relative with dementia; DRS-S, Dyadic Relationship Scale - Strain; DRS-I, Dyadic Relationship Scale - Interaction.

being the most prevalent form of dementia (57.0%). In most cases, the first symptoms of dementia had appeared 4 years or more previously (51.8%). Behaviors that family caregivers had the most difficulty dealing with were dependent (27.2%) and masking behavior (23.5%). At baseline, most family caregivers stated that they were somewhat (43.2%) or significantly (38.3) burdened by the care for their relative with dementia.

Sensitivity Analyses

The initial analyses were performed without the first randomized nine caregivers (who were the 'learning-curve-block'). These initial analyses among 72 family caregivers revealed no differences with analyses of data for the overall group of 81 family caregivers. The final analyses were therefore conducted on all 81 randomized family caregivers. Tables 2 and 3 show the results of the mixed-model analyses.

Effects on Self-Efficacy

Figure 1 shows the observed mean scores for the sum score of the TRUST questionnaire. In the mixed-model analyses, the major intervention (involving personal e-mail contacts as well as videos and e-bulletins) did not show significant differences in self-efficacy in both the crude and adjusted analysis compared to the minor intervention arm. Also no statistical differences were found between the medium intervention (involving videos and e-bulletins) and minor intervention (only involving e-bulletins) in the crude analyses.

However, the medium intervention unexpectedly showed a negative trend over time in the adjusted analyses (difference -4.21, P =.09) and at T1 (difference -4.71, P =.07) compared to the minor intervention involving e-bulletins only.

Effects on Behavior Changes in the Relative with Dementia

Figure 2 shows the observed mean scores for behavior changes in the person with dementia as reported by the family caregivers. Figure 3 shows the observed mean scores for family caregivers' reaction scores for disruptive behavior (disruption subscale of the RMBPC questionnaire). No statistical differences were found in the crude and adjusted analyses between the major and minor intervention arms or between the medium and minor intervention arms regarding the occurrence of behavior changes.

However, statistical differences were found between the major and minor intervention arms in the adjusted analyses at T1 for the family caregivers' reaction scores for disruptive behavior (difference 2.02, P =.05).

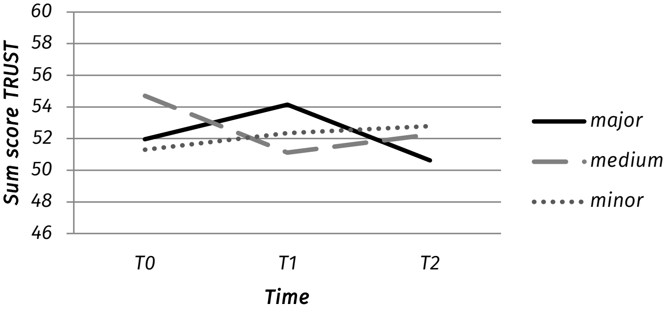

Figure 1 *Observed mean scores for the sum score of the TRUST questionnaire (possible range 29 items = 0-87).*

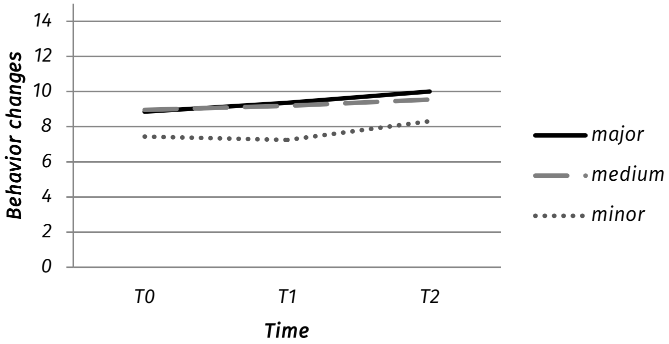

Figure 2 *Observed mean scores for behavior changes (disruption subscale of the RMBPC questionnaire, 8 items, possible range 0-32).*

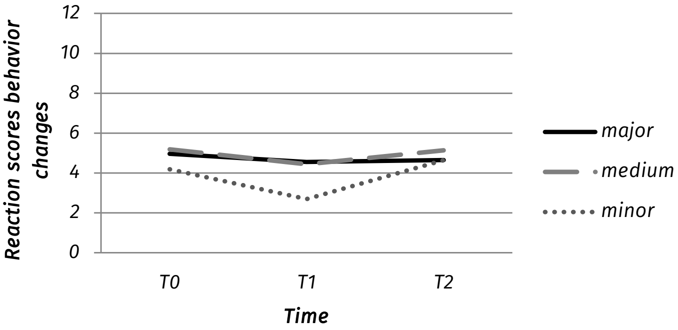

Figure 3 *Observed mean scores of family caregivers' reaction scores for disruptive behavior of their relatives with dementia (subscale disruption of RMBPC questionnaire, 8 items possible, range 0-24).*

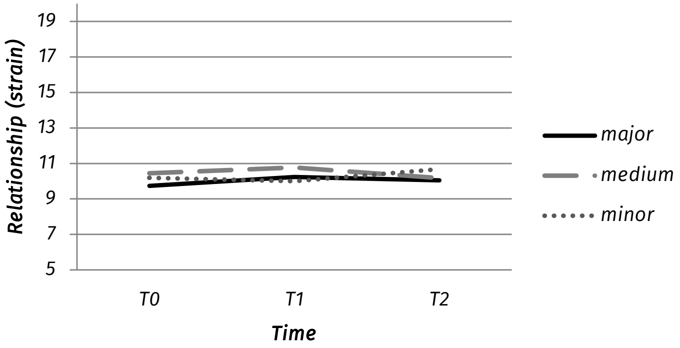

__Figure 4__ Observed mean scores for the strain in relationships (DRS questionnaire, 5 items, possible range 5-20).

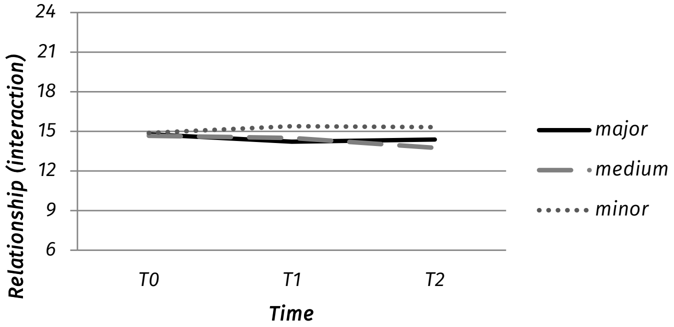

__Figure 5__ Observed mean scores for interaction in relationships (DRS questionnaire, 6 items possible, range 6-24).

Effects on the Quality of the Relationship

Figures 4 and 5 display the observed mean scores for the DRS questionnaire subscales ‘strain’ and ‘interaction.’ No statistical differences were found in the quality of the relationship in both the crude and adjusted analysis between the major and minor intervention arms and the medium and minor intervention arms at all measurements (over time, at T1 and T2).

DISCUSSION

Online self-management support involving e-mail contacts with a specialist dementia nurse, videos and e-bulletins showed no significant difference in family caregivers’ self-efficacy caregiver compared to online interventions not involving personal e-mail contacts. Furthermore, no measurable improvements could be found for the medium intervention involving online videos and e-bulletins compared to the minor intervention only involving e-bulletins.

In addition, no differences were found between the online intervention arms for the quality of the relationship between the person with dementia and the family caregiver and the occurrence of behavior changes. These results are contrary to our expectation that family caregivers who received e-mail support would be better assisted in dealing with and responding to changes in behavior and would therefore improve in terms of self-efficacy. We expected that increased self-efficacy and better response of the family caregiver would also have an effect on the person with dementia and would therefore result in less strain on the relationship, better interaction and an decrease in the occurrence of behavior changes. However, as no effect was found on self-efficacy, this could also explain why no effect on the quality of the relationship and the occurrence of behavior could be detected in this study.

Moreover, the medium arm (consisting of video and e-bulletins) showed a negative trend in family caregivers' self-efficacy over time, and shortly after the intervention (at T1). One possible explanation may be that the online videos made family caregivers more aware of how they were dealing with behavioral changes of their relative with dementia. This understanding - obtained from watching the online videos - may have influenced their confidence in the ability to successfully influence the behavioral changes. This only seems to affect family caregivers at the moment of watching the video (six weeks after baseline) and did not remain after a longer period of time (twelve weeks after baseline).

An explanation for the lack of improvement in self-efficacy could be that family caregivers had not been able to translate the information and advice into their personal situations [6], despite of the fact that in the major intervention arm the dementia nurses tried to tailor their mail contacts to the individual situation of the family caregiver.

Contrary to our expectations, it was found that family caregivers in the major intervention arm were significantly more distressed at T1 by the disruptive behavior of their relatives with dementia, than family caregivers who only received e-bulletins. An explanation for this can be that, initially, a more intensive and major intervention (involving personal e-mail contacts, videos and ebulletins) sharpened caregivers' focus on behavioral changes in their relative with dementia. This initially might have increased awareness, which may have led to an increased report of distress shortly after the intervention at T1. However, there was no statistical difference between these two groups longer after the intervention at T2.

Alongside the RCT presented in this paper, a process evaluation was carried out [27]. The process evaluation showed that the personal contacts with the nurse were highly valued and felt to add value to the online videos and the e-bulletins. Nonetheless, these qualitative results were not reflected in the quantitative results in this paper.

The process evaluation also gave some additional explanations for the unexpected results in de RCT. Firstly, the process evaluation showed variation in the extent to which family caregivers made use of the various elements. Seventy-eight percent of the family caregivers in question used the opportunity of having e-mail contacts, 80% of the family caregivers clicked the links of one or more videos, but just 37% of all family caregivers clicked the links of at least one e-bulletin. Also, the use of e-mail contacts, videos and/or e-bulletins varied considerably within in each group. Therefore, the distinction between the three intervention arms became less, which makes it less likely to find statistically significant differences between the intervention arms. Low usage rates and differences in the use of online interventions are known problems [28, 29] which could explain why no positive effects were found in this study.

Secondly, both family caregivers and nurses mentioned that the e-mail contacts helped family caregivers to share their stories about their experiences with the changing behavior of their relative with dementia. The e-mail contacts seemed therefore less focused on finding ways to deal with behavioral changes. Although receiving appreciation and acknowledgment is essential for family caregivers [30], this could explain why the present study found no effects on self-efficacy, measured behavior or quality of the relationship.

Lastly, positive effects can be left out because the participants already relatively knew a lot about dementia and how to deal with behavioral changes of their relative. According to the dementia nurses, the participants involved were mainly family caregivers who were already consciously engaged in collecting information about the dementia. These family caregivers all had Internet access, were often relatively young and well-educated. This group already had previously gained information and advice about coping with behavioral changes, which might explain the lack of positive effects on for instance self-efficacy.

Strengths and Limitations

Several strengths of this study can be noted. Firstly, the online component of this study helped provide accessible and tailored support for family caregivers. Caregivers could participate nationwide and use the online assistance at times that suited them. Secondly, selective drop-out was reduced by using a mixed-model analysis that also includes ‘incomplete’ cases (i.e. participants who did not fill out the online questionnaire either at 6 or 12 weeks follow-up). Finally, selection bias was reduced by using a prepared randomization schedule to randomly allocate family caregivers to one of the three intervention arms [19].

However, some limitations of this study are worth mentioning. Firstly, in the power calculation, we had estimated a difference of 0.8 between the intervention arms to detect a significant effect of the major self-management support intervention compared to the other intervention arms. The estimated difference proved to have been an overestimate. The small sample size might therefore have played a part in the null findings for our hypothesis that the major intervention arm would have a greater effect on self-efficacy than the other intervention arms. We acknowledge that our study may have been underpowered for detecting an effect of the online self-management support intervention. For future studies, larger studies are required to establish the effectiveness of online self-management support interventions [31].

Secondly, due to the small sample size, we were unable to determine the effects on participants who actually used the intervention components. Instead, data of all included participants were analyzed. Future research should focus on which intervention components best fit specific family caregivers. It is important to determine the family caregivers who will benefit the most from additional online assistance in order to provide tailored personalized support. This will be more cost-effective, allowing nurses’ support to be offered to the people who need it the most.

CONCLUSION

To conclude, the online self-management support intervention involving e-mail contacts did not lead to positive effects compared to online interventions without personal e-mail contacts. Furthermore, the medium intervention involving online videos and e-bulletins showed no statistical improvements compared to the minor intervention involving e-bulletins only. One explanation might be that not all family caregivers assigned to the intervention type in question actually made use of the opportunity for personal e-mail contacts. Moreover, the online videos were not always viewed. To come to more definitive conclusions, future research involving extra efforts to achieve high usage rates is required.

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CHAPTER 10

Summary and general discussion

The main aim of this PhD research was to investigate how nurses can make an effective contribution to self-management by people with dementia and their informal caregivers. The role of eHealth as part of self-management support by nurses was explored as well. In this final chapter, the main findings are summarized and a number of methodological issues are discussed. Furthermore, the implications for dementia care and future research are described.

SUMMARY OF THE MAIN FINDINGS OF THE THESIS

1. What scientific evidence is there for the effectiveness of various types of professional self-management support interventions for (a) people with dementia and (b) informal caregivers of people with dementia?

Self-management involves "*the individual's ability to manage symptoms, treatment, physical and psychological consequences and lifestyle changes inherent in living with a chronic condition*" [1]. For people with dementia, self-management is far from being a matter of course and support may be needed. As insight into the effects of self-management support interventions on people with dementia was required, a systematic meta-review was conducted (**Chapter 2**). Seven systematic reviews were found that met the inclusion criteria. It was not possible to draw clear conclusions about the effectiveness of self-management support interventions for people with dementia based on these systematic reviews. The main reason for this was that most of these self-management interventions were part of comprehensive intervention programs, which also included other interventions such as cognitive stimulation therapy. As a result, the separate effects of the self-management components could not be distinguished properly. Nevertheless, the systematic meta-review produced some interesting insights and led to relevant recommendations for future research. It revealed that existing self-management support interventions comprised a variety of elements and focused primarily on the psychological wellbeing of the person with dementia. The meta-review also showed that self-management support interventions were primarily performed by psychologists, occupational therapists and psychiatrists. Nursing staff – i.e. the professionals with the most intensive contact with patients with dementia – had a modest share in the implementation of these interventions.

As dementia progresses, self-management tasks increasingly become the responsibility of informal caregivers. This may impose a high burden on informal caregivers [2] and self-management support from peers or professionals may be needed. To study the effectiveness of self-management support interventions for informal caregivers, a second systematic meta-review was conducted (**Chapter 3**). Ten relevant systematic reviews were identified, all of high methodological quality. Results were categorized based on self-management targets distinguished by

Martin *et al.* [3], which include 1) maintaining the relationship with the family, 2) maintaining an active lifestyle, 3) pursuing and maintaining psychological wellbeing, 4) coping with memory changes, and 5) information about dementia [3]. The meta-review shows that there is scientific evidence for the effectiveness of professional self-management support interventions targeting the psychological wellbeing of informal caregivers of people with dementia. Effective interventions targeting psychological wellbeing consisted mainly of caregiver support group interventions and cognitive reframing interventions. Evidence was also found for the effectiveness of professional self-management support interventions aimed at providing information about dementia.

2. *What are the opinions and experiences of nursing staff working in home care or residential elderly care regarding self-management support for people with dementia and their informal caregivers?*

Nurses are in a favorable position for providing self-management support given their close contact with patients in daily care [4-7]. However, not much research has been done into nursing staff's perceptions of self-management support and how they integrate such support into daily dementia care. The perceptions of nursing staff of self-management support in dementia care and their skills in providing this support were therefore explored (**Chapter 4**). A mixed-methods approach was used combining cross-sectional quantitative survey data from 206 Dutch nursing professionals with additional qualitative interviews of twelve nursing staff. Results of the quantitative survey showed that a large majority of the nursing staff felt that self-management support of people with dementia was part of their job. In addition, the majority thought it would be attractive to spend more time on self-management support in the future. Nursing staff working in the home care sector were more likely to hold this opinion than nursing staff working in residential elderly care.

Some nurses said in the interviews that self-management support was not a commonly used term for them. They associated it with helping people to maintain control over their lives by involving them in decisions in daily care. In addition, nursing staff saw informal caregivers as the main partners in providing self-management support to the person with dementia, but they were not always aware that informal caregivers themselves might need support in managing their caregiver burden. Furthermore, the survey showed that only 66.5% of participants considered themselves sufficiently skilled in providing self-management support, with others saying that they had limited skills and knowledge about self-management support for people with dementia and their informal caregivers. Sufficient time and training are considered important for enabling nursing staff to provide adequate self-management support. Lastly, this sub-study showed that nursing staff in home care saw more possibilities for self-management support than nursing staff in residential elderly care.

3. *What are (a) the self-management strategies and (b) the self-management support needs of informal caregivers when managing behavioral and mood changes in their relative with dementia?*

Behavioral and mood changes in the person with dementia (such as agitation, restlessness, apathy, aggression, depression, or anxiety) are challenging for informal caregivers [8, 9]. In **Chapter 5,** we explored the stress factors and the self-management strategies applied when informal caregivers are challenged by behavioral and mood changes of their relative. Four online focus groups were held with 32 informal caregivers of people with dementia, including partners and children or children-in-law. The study revealed that informal caregivers experienced a great deal of stress when managing behavioral and mood changes in the person with dementia. In particular, the following stress factors were mentioned: 1) constantly having to switch in response to these challenging behaviors, 2) continually having to keep the relative with dementia busy and distracted, 3) the fact that others have a less problematic picture of their relative, and 4) knowing what to do in theory, but not being able to put it into practice.

Informal caregivers use several strategies to deal with behavioral and mood changes of the person with dementia, such as 1) remaining calm in order to prevent further escalation of the challenging behaviors and 2) stimulating and distracting the person with dementia. Remaining calm goes hand in hand with adapting to the mood state of their relative with dementia in order to reduce tension or restlessness. Stimulating and distracting the person with dementia included telling stories, humor, being positive and encouraging activities and distractions.

Self-management of informal caregivers also entails managing the stress they experience in daily life due to the behavioral and mood changes in their relative with dementia. Informal caregivers mentioned looking for distractions, such as pursuing hobbies or meeting up with family and friends. Another strategy for informal caregivers for managing stress and maintaining care tasks was getting rest on a regular basis to ‘recharge their batteries’. In addition, informal caregivers felt the need to share their personal feelings and burden with friends, family, or professionals so that they could manage their own daily stress.

In order to provide tailored professional support, a clear understanding of self-management support needs of informal caregivers is vital. In **Chapter 6**, we explored how and by whom informal caregivers want to be supported when dealing with behavioral and mood changes of their relative with dementia. In addition, we studied the perceptions of informal caregivers regarding using eHealth as a tool for self-management support. The same methodology was used as in **Chapter 5**. Results showed that informal caregivers need support from professionals or peers including 1) information about dementia and its consequences, 2) tips and advice on managing changes in behavior and mood, 3) opportunities to discuss experiences and feelings, and 4) appreciation and acknowledgement for their caregiving.

EHealth was considered to be useful for finding general information about dementia and related behavioral and mood changes and for sharing experiences or asking for help via the Internet or e-mail. But informal caregivers stressed that a personal approach is important. Accordingly, self-management support can be provided through eHealth to some extent, but cannot replace personal contacts entirely.

4. *Does an online self-management support intervention consisting of personal e-mail contacts with a specialized dementia nurse have an effect and does it get positive evaluations compared with online interventions without personal e-mail contacts?*

Chapter 7 presents the design of a randomized controlled trial (RCT) with three intervention arms for online self-management support:

1. a ‘major’ self-management support intervention, consisting of personalized e-mail contact with a nurse who is specialized in dementia care, online videos, and electronic bulletins (e-bulletins);
2. a ‘medium’ intervention consisting of only online videos and e-bulletins; and
3. a ‘minor’ intervention with e-bulletins only.

The personalized e-mail contact with a nurse in the major self-management support intervention were guided by an intervention protocol.

This protocol was based on the five steps of the 5A model of self-management support [10, 11]:

1. Assessing the state of behavior, beliefs and knowledge;
2. Advising by providing specific information about the disease;
3. Agreeing on realistic goals;
4. Assisting by identifying, anticipating and resolving barriers that are an obstacle to achieving the set goals;
5. Arranging follow-up.

These five steps assist the nurses in structuring the online self-management support within a dynamic and tailored process.

The online self-management support (personalized e-mail contact, videos and e-bulletins) was developed to provide support for informal caregivers at home, thus indirectly also helping the person with dementia they are caring for. Outcome measures were self-efficacy of the informal caregiver, occurrence of perceived behavioral changes in the person with dementia, and positive and negative aspects of the relationship between informal caregivers and people with dementia. It was hypothesized that increased informal caregivers’ self-efficacy in managing behavioral changes would positively affect the relationship between the informal caregiver and the person with dementia, and also would reduce the occurrence of behavioral changes in the person with dementia.

Measurements were performed at baseline (T0), six weeks after baseline (T1) and twelve weeks after baseline (T2). Outcome measures between the three intervention arms were compared using a mixed-model analysis.

From March 2017 to August 2017, the three-arm RCT with 81 informal caregivers was carried out (**Chapter 9**). Alongside the RCT, a process evaluation was conducted to evaluate the online self-management support intervention. A mixed-method design was used combining quantitative and qualitative methods. The process evaluation showed that informal caregivers put a high value on the e-mail contacts with the specialized nurse (**Chapter 8**). For them, the confirmation they received from a professional that they were doing the right thing was very important. The informal caregivers valued the e-mail contacts in addition to the videos and e-bulletins. Informal caregivers also valued the fact that information and advice was tailored to their specific situation. As a result of the self-management support, informal caregivers felt acknowledged by the nurses.

The positive findings of the process evaluation were not reflected in the RCT. The RCT study demonstrated no statistically significant difference in self-efficacy, behavioral changes and the relationship between informal caregiver and person with dementia (**Chapter 9**). The process evaluation offered possible explanations for not finding any significant results in the RCT, including the fact that not all participants used the e-mail contacts, online videos and e-bulletins. It was also noted that nurses involved often only provided the first two steps of the 5A model (‘Assessing’ and ‘Advising’).

REFLECTIONS ON THE FINDINGS

Support the Informal Caregiver

Nursing staff appear only partially to fulfill their role of supporting informal caregivers of community-dwelling people with dementia. Our studies indicate that nurses see informal caregivers as the main partners in providing self-management support to the person with dementia but that they are less aware that informal caregivers might also need support (**Chapter 4**).

Support for informal caregivers is very important for maintaining the informal care for the relative with dementia at home. As the population ages, the number of people with dementia living in their own homes with support from their own network will increase. Informal caregivers have a significant role in caring for their relative with dementia as the well-being of both the informal caregiver and person with dementia depends substantially on the balance between the needs of the person with dementia and the informal caregiver's abilities to fulfill them [12].

However, caring for a loved-one with dementia at home can be extremely demanding and help from nurses, friends, and family is needed to support them in this [2]. Nurses must pay attention to informal caregivers and realize that support is needed for various aspects and care tasks, including how to deal with symptoms of dementia in everyday life [13, 14]. It is essential that nurses realize that being acknowledged by health professionals and friends is very important for informal caregivers (**Chapter 6**) [15]. Receiving appreciation and acknowledgement for the everyday tasks makes informal caregivers feel they are sharing the care. Nurses should therefore focus not only on illness-related tasks and so-called 'everyday life work' but also on making sure that informal caregivers feel acknowledged [16]. This requires a holistic approach from nurses, including support for informal caregivers, in aspects related to the health and wellbeing of the relative with dementia as well as supporting the self-management tasks of the informal caregiver.

Personalized Self-Management Support

The research described in this thesis indicates that it is beneficial to use interventions that target individual personal needs (**Chapter 3**). It must be taken into account here that the needs of informal caregivers are often diverse, as they are confronted with multiple tasks including taking care of their relative with dementia as well as having to deal with caregiving-related stress and their own health (**Chapter 5**).

Some informal caregivers may find ways to self-manage adequately; others may need support in this regard. There may be differences between informal caregivers in terms of e.g. the self-management strategies used (**Chapter 5**), their needs (**Chapter 6**), competencies, and readiness to use self-management strategies [17]. Also, some informal caregivers have limited options for dealing with their numerous tasks due to their advanced age, low educational level, low income or multiple morbidity [18-20]. These informal caregivers are less likely to self-manage their own health and the consequences of dementia of their relative in their daily lives [21].

To ensure that informal caregivers have opportunities to deal with their multiple tasks, nurses must be aware of the needs of informal caregivers. Common support needs of informal caregivers were described in **Chapter 6**, such as information about dementia and its symptoms, tips and advice, and opportunities to discuss experiences and feelings. However, needs may vary between informal caregivers and might for example be different in the initial stages than in subsequent stages of the dementia of the relative [13]. Because every situation and how people deal with it can be so different, personalized and tailored support is needed. In order to provide personalized support, nurses always have to identify the needs of informal caregivers. A systematic approach, such as that provided by the 5A model (see **Chapter 7**), might be helpful in this regard.

Using eHealth as a Tool for Self-Management Support

This thesis shows that eHealth offers opportunities for self-management support but does not meet all needs and challenges of individuals with dementia and their informal caregivers. For instance, eHealth (in this thesis also often referred to as 'online interventions') can offer accessible digital information and the possibility of sharing experiences, asking advice online for, and having personal e-mail contact with a health professional (**Chapter 6**).

Policymakers consider increased use of eHealth to be a necessity because western health systems are under severe budgetary constraints from the ageing population and rising healthcare costs. More frequent use of eHealth interventions is considered to be a way forward for increasing the self-management of patients and informal caregivers and controlling healthcare costs [22-24]. The combination of eHealth, relevant health information, and support would make people better able to make decisions on how to organize their care and wellbeing.

Nevertheless, eHealth may not always be an appropriate tool in all regards. Firstly, in the study described in **Chapter 6**, informal caregivers stressed that eHealth cannot entirely replace face-to-face contact. Support through eHealth was often seen as impersonal as it is often not geared to personal situations. According to the informal caregivers, face-to face support from health professionals is needed in order to provide tailored support and overcome potential communication issues (**Chapter 6)**. This finding is consistent with the findings from a recent review [25] that suggests that face-to-face contact is required for effective decision making.

Secondly, eHealth is not always used as fully as possible. For instance, in our online self-management support intervention, not all informal caregivers made use of all opportunities: 78% of the participants made use of the opportunity for personal e-mail contact with a dementia nurse, 80% watched an online video and only 37% clicked the e-bulletin that was offered (**Chapter 9**). This finding is similar to the findings of other e-mail support interventions in which high levels of non-use were also found [26, 27]. Non-use of online interventions is a known issue among people facing dementia, as well as other target groups [28-30]. To interpret and potentially increase usage rates, it is important to get a better understanding of how online interventions may benefit informal caregivers and how their usage can be increased [31].

Thirdly, not all health professionals have the required competencies to support people via eHealth yet. The use of eHealth, for instance in the form of personal e-mail contact with patients or informal caregivers, requires different competencies and skills from the healthcare professionals than providing face-to-face care. When using eHealth, health professionals are asked to give the same quality of care online as they would in a traditional face-to-face mode. Nurses in the study described in **Chapter 8** reported some difficulties in providing online support via e-mail, such as difficulties in assessing the personal situation and needs at a distance, finding ways to communicate with the informal caregiver and not knowing if information and advice was being understood. This last finding was also noted in a recent study by Brandt *et al.* [32]. Lack of direct interactions impacted nurses' ability to see the patient's reaction to their advice or questions [32, 33].

Finally, specifically for patients with dementia, increasing cognitive constraints seem to make eHealth less useful: eHealth appeals to both digital skills and language skills, which are often less present in people with dementia than in the general population. The informal caregivers who were questioned in the online focus groups (**Chapter 6**) clearly indicated that they find eHealth useful to some extent for themselves, but not for their relative with dementia.

Considering the above-mentioned limitations of eHealth, there is still a gap between the benefits postulated by policymakers on the one hand and care users' actual experience and views about eHealth. Although it is stressed that online support should be tailored, accessible, and understandable for everyone [34], some people will benefit and some will not [27, 35]. Studies on eHealth often include younger and computer-literate participants [36, 37], whereas many people caring for a relative with dementia are older with less experience in using computers and in eHealth [25]. Span *et al.* [38] stated that participants aged over 70 need more time, learning to access the Internet and send messages. Related to that, participants recruited in studies evaluating eHealth interventions are often not representative in all regards and form a selection of the target group. This was also the case in our study presented in the **Chapters 8 and 9**, where relatively well-educated and not very elderly informal caregivers participated. However, in the future more and more seniors will be well acquainted with the Internet [39]. Considering the enhanced access and everyday use, it is likely that adoption of eHealth will increase in the future. Acknowledging both the potential benefits and the limitations of eHealth, a better picture is needed of what can be done online and what has to be done offline in what kind of specific subgroups of patients and informal caregivers. In addition, further investments can be made in making online support more personal and tailored, increasing the compliance of use of available eHealth interventions, and improving nurses' competences in providing online support [33, 40].

Competence of Nurses to Provide Self-Management Support

This thesis has shown that nursing staff consider self-management support as part of their job but often do not find themselves sufficiently skilled in performing the corresponding role (**Chapter 4**). This finding is consistent with other studies from different settings [32, 41, 42]. This thesis also showed that self-management support included (combined) elements such as information, psychological education, skills training and/or coping strategies (**Chapters 2 and 3**). It is known that self-management support goes beyond delivering information and traditional patient education [43, 44]. Setting realistic goals, anticipating barriers and developing personalized action plans are crucial actions in self-management [45]; this is also in line with the 5A model [10] that was used as the starting point in the online intervention evaluated in the **Chapters 8 and 9**. However, Duprez *et al.* [46] found that nurses in general rarely make shared decisions, set goals, or organize follow-up care. Most nurses adopt a traditional role in which patients (and informal caregivers) have to follow nurses' instructions [41]. This may explain the finding in this thesis that nurses often provided only the first two steps of the 5A model ('Assessing' and 'Advising') [10] (**Chapter 8**).

Training in competencies, which is already in basic nursing education, is needed to equip nurses to provide self-management support to people with dementia and their informal caregivers [47]. Van Hooft *et al.* [48] categorized the required competencies of nurses according to the steps in the 5A model [10]: competencies to Assess, Advise, Agree, Assist and Arrange [10, 48]. In addition to training, Van Hooft *et al.* [48] argue that not only nurses' competencies but also their self-efficacy to perform self-management support should be enhanced. The belief among nurses that they have the capability to support self-management may not always be reflected in actual practice [48]. In the study described in **Chapter 4** of this thesis, it was found that 66.5% of nursing staff think their own knowledge and skills are sufficient to deliver self-management support. It is important for this group that they also use this knowledge and skills (correctly) in daily practice.

GENERAL METHODOLOGICAL CONSIDERATIONS

Reflections on methodological strengths

This thesis combined a variety of quantitative and qualitative studies, including systematic meta-reviews, a cross-sectional survey, interviews, online focus groups, and an RCT. The mixed method approach enhanced the validity of the results [49] and helped create an in-depth understanding of self-management and self-management support in dementia care.

The intervention protocol for the online contacts evaluated in the RCT (**Chapter 7**) was developed and evaluated in close cooperation with dementia nurses in order to ensure relevance to practice and implementation in dementia care [50]. In addition, the online videos and e-bulletins used were developed in close collaboration with representatives of informal caregivers.

In addition, the fact that the RCT was combined with a process evaluation has major advantages. The process evaluation gave an in-depth picture of the context of the RCT and was highly important in elucidating the implementation process and giving explanations for the findings of the RCT.

Reflections on methodological limitations

Participants involved in our empirical studies (**Chapters 5, 6, and 9**) are not in all regards representative of the population of informal caregivers of people with dementia. Most informal caregivers were well-educated and computer-literate informal caregivers, which represents only 59% of informal caregivers of people with dementia [51]. This seems to have resulted in a sample of informal caregivers who already had a lot of information and knowledge about how to support a relative with dementia and challenging behavioral and mood changes. They may therefore already have found ways to adequately self-manage with dementia and the consequences in daily life. Nevertheless, these informal caregivers too may have needs that require nurses' support, given that the needs may change throughout the illness process [13].

In addition, informal caregivers were only involved in parts of the development of the intervention (**Chapter 7**), namely in the development of the videos and e-bulletins and (for practical reasons) not in the intervention protocol for the e-mail contact with the dementia care nurse. However, as we also evaluated the e-mail contacts among informal caregivers (in the process evaluation, **Chapter 8**), they were involved, albeit not from the initial stages. Ideally, end-users have to be engaged throughout the entire development process in order to achieve better adherence [52].

In addition, we saw limited use of some elements of the online intervention (particularly the use of the e-bulletins) in our RCT, which may have biased the results (**Chapters 8 and 9**). Because not all informal caregivers used all elements of the intervention, the contrasts between the three intervention arms became less. Non-use is a methodological known difficulty in online intervention research [28, 29]. To gain insight better picture of this issue, a set of recommendations on how to conduct and report research on eHealth was described by Eysenbach [53] in the CONSORT-EHEALTH statement (Consolidated Standards of Reporting Trials of Electronic and Mobile HEalth Applications and onLine TeleHealth). Although limited use of the online self-management support intervention may have biased our results, we reported on these issues according to recommendations in the CONSORT-EHEALTH statement. This meant, for instance, that we clearly described which online components were used, how these components were used, and that we reported on typical limitations in the eHealth trial (**Chapters 8 and 9**). This allows researchers and other disciplines to interpret the findings and also lets them classify and summarize the findings of our RCT in future systematic reviews [53].

IMPLICATIONS FOR PRACTICE, EDUCATION, AND POLICY

1. Support the informal caregiver in self-management

This thesis showed that nursing staff consider informal caregivers as partners in the care for the relative with dementia, but they stated that they were less aware that informal caregivers might need support themselves (**Chapter 4**). All healthcare professionals in dementia care should be aware of the significant role of informal caregivers of people with dementia living at home. Most importantly, nurses have to realize that receiving appreciation and acknowledgement for the everyday care is very important for informal caregivers in enabling them to deal with daily challenges (**Chapter 6**). Nurses have to give informal caregivers the feeling that they are being seen and heard. Nurses can also point informal caregivers towards informal resources such as peer support in Alzheimer cafes. This might also be an element of self-management support.

What needs addressing at this moment is that it is difficult for nurses to offer structural self-management support to informal caregivers in daily practice. Care organizations sometimes do not have policies on self-management support, which makes it difficult for nurses to provide support for it. This thesis found attention to the issue of self-management support in the policy of the care organization to be a facilitator for the provision of support for people with dementia and informal caregivers (**Chapter 4**). We therefore recommend that care organizations should have a clear policy on self-management (and support for it) in dementia care to let nurses give proper support to informal caregivers of people with dementia.

2. Provide a personal approach

Among other things, this thesis describes how, in cases of behavioral changes in the person with dementia, informal caregivers often know what to do in theory but are not always able to put it into practice (**Chapter 5**). As a result, informal caregivers are not always able to deal with the behavioral changes of their relative adequately in daily life. Nurses should therefore tailor support to suit informal caregivers’ needs and use appropriate interventions that target those needs (**Chapter 2**). To provide tailored support, nurses need to be aware of the changing needs of informal caregivers. Nurses together with the informal caregivers need to continuously examine what informal caregivers can do themselves and what kind of support is needed (such as information, tips/advice, peer support, professional support). In these recurring conversations, informal caregivers should be made more self-reliant, for example by pointing out where they can find the necessary information, as well as giving them self-confidence in how they are coping.

One way to offer personalized self-management support is to use the steps of the 5A model. In this model, the wishes and needs of the person are central to self-management support [54]. Nurses can use this model for structuring self-management support. Our studies showed how personalized support according to the 5A model can be given online (**Chapters 7, 8, and 9**).

Finding ways to provide personalized support online is important, as the number of people with dementia (and informal caregivers) will rise [55, 56], whereas the number of nurses is not expected to increase [13]. One of the strategies for providing personalized support to informal caregivers at home cost-effectively may be eHealth. However, some informal caregivers said eHealth is impersonal and that personal advice in specific situations requires face-to-face contact (**Chapter 6**). In addition, they did not consider the use of eHealth to be appropriate for their relative with dementia. Better insights are therefore needed into which elements can be done online and which elements require offline support and for what kind of people in order to offer personalized support.

3. Recommendations for the use of the intervention protocol

Based on the findings of the process evaluation (**Chapter 8**), in which both informal caregivers and nursing professionals were involved, we have added two specific recommendations for use of the intervention protocol. Firstly, the process evaluation showed that the various aspects (e-mail contact, videos, and e-bulletins) were not sufficiently integrated, in the sense that the dementia nurse who had the e-mail contact with the informal caregiver often did not relate her recommendations to the information in the videos and the e-bulletins. Although the intervention protocol (a translated version is displayed in Additional file 1 of this thesis) refers to the use of the videos and e-bulletins, dementia nurses who will be involved in the e-mail contacts have to be better instructed and more aware of the importance of integrating the various aspects in a way that lets them complement each other.

Secondly, the intervention protocol is now structured around a maximum of three e-mail contacts. Outside the context of the RCT, the intervention can be spread over more e-mail contacts. This is important, as most informal caregivers expressed their feelings of burden and stress in the first e-mail contact instead of finding ways to self-manage their situations. Actual improvements in self-management skills may require more e-mail contact than the three e-mail contacts that were offered in the context of the RCT.

4. Raise awareness and train nurses in providing self-management support

Based not only on this thesis (**Chapters 4 and 8**) but also as found in other studies, nurses often do not feel sufficiently skilled to perform the role of self-management support [42, 47]. Nurses need to have the skills to provide self-management support. To achieve this, training is recommended, which should also be part of basic nursing education. This training is needed to equip nursing staff and nursing students with the knowledge and skills for supporting both the informal caregiver and the person with dementia in their home environment. The training may be based on the 5A model [10, 11]. However, as there is a knowledge gap about how best to train nurses, more theory-driven training interventions are recommended that focus on nurses' attitudes and organizational support [47].

Nurse training colleges also have to prepare students by equipping them with knowledge and skills for providing self-management support in daily practice. This is very important as previous studies found that nursing students – who represent the future nursing workforce – are often not sufficiently well educated in providing self-management support [57, 58]. Extra effort is therefore needed to integrate the comprehensive set of self-management support activities into the nursing curricula in order to prepare nursing students better for adequately supporting people's self-management [47].

5. Improve the knowledge and skills of nurses in providing online support.

This thesis has shown that providing online support requires other competencies and skills from nurses than face-to-face support (**Chapter 8**). Given that more people will need self-management support and eHealth offers opportunities to ensure the quality of care, nurses should be prepared to provide support (at least partially) online. Nurses need to have the skills to give online support about how to live with dementia, caregiving at home, and dealing effectively with behavioral changes. Communication by e-mail in an understandable and tailored way to the person with dementia and their informal caregivers is new challenge for most nurses. Healthcare institutions should recognize that eHealth will increasingly become part of care provision within an organization. To support and guide this development, we recommend that they promote a clear organizational policy on the use of online interventions and facilitate training opportunities for nursing staff. It must be possible for nurses to be trained in continuing education courses if they are asked to provide online support. They also should be aware of the online possibilities and resources they can use in daily practice in addition to the traditional face-to-face care they provide.

IMPLICATIONS FOR FUTURE RESEARCH

1. Self-management support for informal caregivers who might be underrepresented in our research.

Most informal caregivers in the studies described in this thesis were relatively highly educated and computer-literate (**Chapters 5, 6, 8, and 9**), so they only represent a proportion of the informal caregivers of people with dementia. The level of education and digital skills may also be related to the extent to which people are able to apply self-management. Not everyone is able to self-manage adequately. Every situation is unique and every person's capacities differ. More research is therefore warranted into how and what kind of online and other self-management support could be provided to informal caregivers with lower educational levels and poorer digital skills and to people with less adequate self-management capacities (**Chapter 6**).

2. Self-management support of people with dementia

The meta-review (**Chapter 2**) indicates that active involvement of a person with early-stage dementia in self-management strategies is possible. However, more research is needed into developing interventions aimed at supporting self-management of people with dementia. Determination of the factors affecting the extent to which people with dementia (and informal caregivers) can be actively involved in (online) self-management support interventions is also an important insight for designing such interventions. When doing so, account must also be taken of the fact that the possibilities for people with dementia to use of eHealth are probably limited because of the decreasing cognitive skills. Especially for people with dementia, traditional face-to-face contact might remain irreplaceable.

3. Online self-management support for informal caregivers of people with dementia

This thesis indicates that online self-management support intervention proved suitable for providing tailored information and advice in a way that meant informal caregivers felt acknowledged (**Chapter 8**). Future research should continue with developing tailored and online self-management support interventions for informal caregivers of people with dementia. In the development of future online interventions, more in-depth research should be based on which parts of support can be done online and have to be done offline.

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ADDITIONAL FILE 1. INTERVENTION PROTOCOL

Online self-management support for informal caregivers for managing behavioral changes in their relative with dementia

INTERVENTION PROTOCOL

Developed by: Amsterdam UMC (VUmc), Dutch Alzheimer's society, NIVEL,
The Geriant Foundation, Trimbos Institute.

February 2017

1. For whom is this intervention protocol intended?

This intervention protocol has been written for nursing staff who will be in e-mail contact with informal caregivers during online self-management support.

These nurses must be specialized in guidance of people living at home with dementia and their informal caregivers. They could for instance be nursing staff whose daily practice involves working as a case manager. This requires extensive knowledge about providing assistance for informal caregivers when there are behavioral changes in their relatives.

2. To whom is online self-management support offered?

The intervention is intended for informal caregivers who meet the following criteria:

- they are a family member of a person diagnosed with dementia (all subtypes are possible)
- and they are in contact with the relative with dementia at least once a week
- they are aged 18 or over
- they have access to the Internet and are able to use the Internet and e-mail themselves

3. What are the objectives of online self-management support?

Online self-management support will give informal caregivers options for dealing effectively with behavioral changes in their relatives. The ultimate objectives are that the informal caregiver will feel better capable of coping with the changed behavior, that it will help improve the relationship between the informal caregiver and the person with dementia, and that behavioral changes will be reduced.

4. What are the elements of the online self-management support?

The online self-management support intervention consists of three parts: offering personal e-mail contact with the nurse, online videos, and e-bulletins. Each of those elements is explained below:

a. Offering an opportunity for **personal e-mail contact** with a nurse, spread over a period of 12 weeks. Please refer to the paragraph “What do the e-mail contacts involve?” The nurse will instigate a total of at most three e-mail contacts within a period of twelve weeks overall. E-mail contacts are only made after the videos and e-bulletins have been offered (see b and c).

b. Offering **online videos** about dealing with behavioral changes in dementia. A total of six videos (approximately 15 minutes) are available about dependent behavior, aggressive behavior, suspicious behavior, apathetic behavior, restlessness at night, and masking behavior respectively. In each of the videos, an informal caregiver speaks about the changing behavior of their relative with dementia. Examples are also given. There is an explanation of what causes the behavior and what exactly it comprises, as well as tips focusing on what the informal caregiver can do to deal with that specific behavior. Finally, the informal caregiver is asked to examine what the possible causes could be of their relative's behavior and what potential ways the informal caregiver can think up that might improve the situation. In the context of the study, an informal caregiver is predominantly offered one specific video. This is the video that, according to the informal caregiver, fits best with the behavioral change that the informal caregiver is experiencing the most problems with. This has been stated by the informal caregiver in the questionnaire. The other five videos are then shown below it with less emphasis. The informal caregiver can watch these as well.
c. Mail messages with an **e-bulletin** about dealing with behavioral changes in dementia. This e-bulletin provides practically oriented information about the various behavioral changes in dementia and how the informal caregiver can cope with them. The behavioral changes are the same as in the videos (dependent, aggressive, suspicious, apathetic, restless at night, and masking behavior). The e-bulletin is a summary of the points addressed in the video.

5. What do the e-mail contacts involve?

5.1 Practical aspects of the e-mail contacts

The nurse:

- answers e-mails from the informal caregiver using the 'Reply' functionality. This means that all the e-mails will be grouped together.
- always responds within two working days to an e-mail from an informal caregiver.

These are personal e-mail messages from the informal caregiver that the nurse will not share with third parties. For the purposes of the study, the nurse does however record a number of data items during the research period, such as:

- the number of contacts that there have been for each informal caregiver;
- whether the informal caregiver has filled in their response to the video. If the informal caregiver does not do this, the nurse will not receive an e-mail from the informal caregiver. For that reason, the nurse sends a standard e-mail to the informal caregiver if no response has been received after one week.

5.2 First personal e-mail from the nurse

Situation:

The informal caregiver has received one of the six videos about changed behavior in their relative with dementia. The informal caregiver is then asked to answer four questions:

- Would you please describe your informal caregiving situation briefly?
- What kind of <type> behavior have you noticed in your relative?
- What could be causing this?
- How do you deal with this behavior?

The nurse receives an e-mail with the answers that the informal caregiver supplies to these questions.

Content and focus:

In the e-mail, the nurse:

- introduces themselves to the informal caregiver, if the informal caregiver has not received a standard e-mail);
- responds to the informal caregiver's answers and attempt to use them to give a list of experiences and requirements;
- provides information about contacting the nurse by e-mail.

The first mail from the nurse emphasizes 'Assessing' and 'Advising,' i.e. the first two steps of the 5A model for self-management support[1].

Assessing: Make an inventory of and then explore the experiences of the informal caregiver with behavioral changes in their relative with dementia, including their knowledge, expectations, and convictions, and how they cope with the illness and its consequences.

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[1] The 5A model provides caregivers with a structure for self-management support, based on what the care user themselves (in this case the informal caregiver) believes to be important and required. The steps in the 5A model are

A	Assessing the state of behavior, beliefs, and motivation;
A	Advising based upon personal health risks;
A	Agreeing on a realistic set of goals;
A	Assisting in anticipating barriers and developing a specific action plan;
A	Arranging follow-up.

The 5A model is explained further in the national module for self-management (CBO, 2014).

Advising: Respond to and explain the informal caregiver's findings, providing tailored information that fits in with the information that came to the fore during the Assessing stage.

5.3 Second personal e-mail from the nurse

Situation:

The informal caregiver has provided a response to the first e-mail contact from the specialist nurse.

Content and focus:

The nurse:

- gives individual feedback (a compliment, tip, or additional information) about the actions that the informal caregiver initiated and how they progressed;
- gives an answer/feedback to exactly what the informal caregiver has said they want to know, with references to other sources of assistance if needed;
- reiterates what the informal caregiver says that they would like to achieve;
- asks the informal caregiver what they think is most important;
- gives feedback to assist the informal caregiver in choosing realistic and feasible objectives. (It is important to be able to achieve successes, no matter how small they may seem. The goals must answer questions such as: What do you want to achieve? And why is that important for you? The goals must also provide motivation for the informal caregiver, as well as something to hold on to when the going gets tough. Formulate specific actions in terms of behavior: "What exactly are you going to do?")
- creates a picture of potential obstacles and thinks up problem-solving techniques and strategies that the informal caregiver may be able to use;
- If the intended goals are not achieved, or not achieved in full, it is important to discuss any negative feelings the patient may have (particularly about guilt and failure), to reinforce positive actions, and to get the patient to commit to the objectives once again.

This e-mail contact focuses on the third and fourth A's of the 5A model: Agreeing and Assisting. Agreeing should be seen in the sense of clarifying the personal objectives and support requirements of the informal caregiver. Assisting, in the sens of identifying possible barriers and support needs in achieving the goals.

5.4 Third personal e-mail from the nurse

Situation

This is the final e-mail contact. The informal caregiver has provided a response to the second e-mail contact from the specialist nurse.

Content and focus:

The final e-mail contact will above all emphasize the final two A's of the 5A model, Assisting and Arranging (see also the second e-mail, Section 5.3). However, depending on the informal caregiver's responses, attention can also be paid to the other A's, Assessing, Advising, and Agreeing.

The nurse:

- gives individual feedback about the actions that the informal caregiver initiated and how they progressed;
- records the 'agreements' by listing the points that have been discussed in the previous e-mail contacts;
- formulates the goals and activities (allowing the informal caregiver to see if they have achieved the objectives);
- gives further ideas for if it does not work. Is a one-time recommendation enough? Or is more extensive advice, a number of follow-up appointments, specialist help, or intensive guidance required? Is a referral therefore needed?
- emphasizes that it is important that the informal caregiver saves the e-mail conversations somewhere themselves, so that the information is visible to the informal caregiver and can be retrieved easily;
- makes clear that this is the concluding e-mail.

5.5 What does the nurse have to do if an informal caregiver does not respond?

<u>Before the start of the e-mail contacts</u>

After an informal caregiver has been registered for the e-mail contacts, the idea is that the nurse should receive a response by e-mail from the informal caregiver within a week. If the nurse does not receive a response, the nurse sends a reminder e-mail to the informal caregiver. If the informal caregiver does not respond to this either, the nurse does not have to do anything further.

<u>After the first/second e-mail contact</u>

It is also possible that there will be no response from the informal caregiver after a personal e-mail from the nurse (the first or second e-mail). In that case, the nurse should do the following:

- The nurse sends an e-mail reminder to the informal caregiver. If the informal caregiver responds to this, the e-mail contacts can be continued.
- If the informal caregiver does not respond to the reminder, the nurse does not have to do anything further. If the informal caregiver makes contact a long time after the reminder, the contacts can be continued again.

Nederlandse samenvatting
Dankwoord
Portfolio
List of publications
About the author

NEDERLANDSE SAMENVATTING

In dit promotieonderzoek is onderzocht hoe verpleegkundigen een effectieve bijdrage kunnen leveren aan zelfmanagement van mensen met dementie en hun mantelzorgers. Daarnaast is ook gekeken naar de rol van e-health bij zelfmanagementondersteuning door verpleegkundigen. In deze samenvatting wordt een overzicht gegeven van de belangrijkste resultaten.

1. Wat voor wetenschappelijk bewijs bestaat er voor de effectiviteit van verschillende soorten professionele zelfmanagementondersteuning voor (a) mensen met dementie en (b) de mantelzorgers van mensen met dementie?

Een veel gebruikte definitie van zelfmanagement is "*het vermogen van een individu om te kunnen omgaan met de symptomen, behandelingen, fysieke en psychologische gevolgen en veranderingen in de levensstijl die worden veroorzaakt door een chronische aandoening*" [1]. Zelfmanagement is voor mensen met dementie niet vanzelfsprekend. Ze hebben hierbij mogelijk hulp nodig.

Om inzicht te krijgen in de effecten van zelfmanagementondersteuningsinterventies voor mensen met dementie, is er een systematische literatuurstudie van bestaande systematische reviews uitgevoerd (**Hoofdstuk 2**).

Zeven systematische reviews voldeden aan de inclusie criteria. Het was op basis van deze systematische reviews niet mogelijk om duidelijke conclusies te trekken over de effecten van zelfmanagementondersteuning voor mensen met dementie. Dit komt voornamelijk doordat de meeste zelfmanagementondersteuningsinterventies deel uitmaakten van uitgebreide interventieprogramma's waarbij ook sprake was van andere interventies, zoals cognitieve stimulatietherapie. Hierdoor kon de afzonderlijke invloed van zelfmanagementondersteuning niet worden bepaald.

De systematische literatuurstudie leverde echter wel interessante informatie en relevante aanbevelingen op voor toekomstig onderzoek. Uit de literatuurstudie bleek dat de huidige zelfmanagementondersteuningsinterventies voor mensen met dementie uit verschillende elementen bestaan en voornamelijk zijn gericht op het psychologische welzijn van de persoon met dementie. De systematische literatuurstudie heeft ook aangetoond dat deze zelfmanagementondersteuningsinterventies hoofdzakelijk werden uitgevoerd door psychologen, ergotherapeuten en psychiaters. Verpleegkundigen (de deskundigen die het meest intensief contact hebben met personen met dementie) speelden maar een kleine rol bij dit soort interventies.

Naarmate de dementie vordert, komen de zelfmanagementtaken steeds meer in de handen van mantelzorgers terecht. Dit kan een zware last zijn voor de mantelzorgers [2], waardoor ze mogelijk hulp nodig hebben van familie, vrienden of hulpverleners. Er is een tweede systematische literatuurstudie van bestaande systematische review uitgevoerd. Deze richtte zich op de effectiviteit van zelfmanagementondersteuning voor mantelzorgers (**Hoofdstuk 3**). Er zijn tien relevante systematische reviews gevonden die van hoge methodologische kwaliteit waren.

De resultaten zijn geordend op basis van de categorisatie van zelfmanagement voor mensen met dementie geformuleerd door Martin *et al.* [3]. Deze categorisatie omvat 1) de relatie met de familie behouden, 2) een actieve levensstijl behouden, 3) psychologisch welzijn behouden, 4) omgaan met veranderingen in het geheugen en 5) informatie over dementie verkrijgen [3]. De systematische literatuurstudie toonde aan dat er wetenschappelijk bewijs bestaat voor de effectiviteit van professionele zelfmanagementondersteuning waarbij de focus ligt op het psychologische welzijn van de mantelzorgers van mensen met dementie. Effectieve interventies die zijn gericht op het psychologische welzijn bestaan voornamelijk uit steungroepen voor mantelzorgers en ‘cognitieve reframing’. Er is ook bewijs voor de effectiviteit van professionele zelfmanagementondersteuning, gericht op het informeren over dementie.

2. *Wat zijn de meningen en ervaringen van verpleegkundigen of verzorgenden die in de thuiszorg of in een verpleeg- of verzorgingshuis werken met betrekking tot zelfmanagementondersteuning voor mensen met dementie en hun mantelzorgers?*

Verpleegkundigen en verzorgenden zijn geschikt om zelfmanagementondersteuning te verlenen, aangezien ze tijdens de dagelijkse zorg nauw contact hebben met de patiënten [4-7]. Er is echter weinig onderzoek gedaan naar de meningen van verpleegkundigen over zelfmanagementondersteuning en de manier waarop zij deze ondersteuning bieden in de dagelijkse praktijk. Daarom werd in dit onderzoek gekeken naar de meningen van verpleegkundigen en verzorgenden over zelfmanagementondersteuning bij dementie en hun vaardigheden bij het verlenen van dit soort ondersteuning (**Hoofdstuk 4**). Hiervoor is gebruikgemaakt van verschillende methoden, waarbij cross-sectionele kwantitatieve vragenlijstgegevens van 206 Nederlandse verpleegkundigen en verzorgenden zijn gecombineerd met kwalitatieve interviews met twaalf verpleegkundigen en verzorgenden.

Uit het kwantitatieve onderzoek bleek dat de grote meerderheid van de verpleegkundigen en verzorgenden vond dat zelfmanagementondersteuning voor mensen met dementie deel uitmaakt van hun werk. Daarnaast gaf de meerderheid aan in de toekomst meer tijd te willen besteden aan zelfmanagementondersteuning. Verpleegkundigen en verzorgenden in de thuiszorg gaven dat vaker aan dan degenen die in verpleeg- of verzorgingshuis werkten.

Enkelen zeiden tijdens de interviews dat zelfmanagementondersteuning geen term was die ze vaak gebruikten. Ze dachten bij deze term aan het helpen van mensen om controle over hun leven te behouden door hen te betrekken bij beslissingen tijdens de dagelijkse zorg. Zij zagen daarnaast mantelzorgers als de belangrijkste personen om zelfmanagementondersteuning te verlenen aan mensen met dementie. Ze waren zich er echter niet altijd van bewust dat mantelzorgers zelf mogelijk ook hulp nodig hebben in het omgaan met de zware zorgtaak.

Verder bleek uit het kwantitatieve onderzoek dat slechts 66,5% van de ondervraagde verpleegkundigen en verzorgenden zichzelf ervaren genoeg vond om zelfmanagementondersteuning te verlenen. Anderen gaven aan dat ze over te weinig vaardigheden en kennis beschikten met betrekking tot zelfmanagementondersteuning voor mensen met dementie en hun mantelzorgers. Verpleegkundigen en verzorgenden vonden voldoende tijd en training belangrijke factoren om goede zelfmanagementondersteuning te kunnen verlenen. Ten slotte is uit dit onderzoek gebleken dat verpleegkundigen en verzorgenden in de thuiszorg meer mogelijkheden voor zelfmanagementondersteuning zagen dan degenen die werkten in een verpleeg- of verzorgingshuis.

3. Wat zijn (a) de zelfmanagementstrategieën en (b) de behoeften aan zelfmanagementondersteuning van mantelzorgers wanneer ze te maken krijgen met veranderingen in het gedrag en de stemming van de persoon met dementie?

Het is voor mantelzorgers lastig om om te gaan met veranderingen in het gedrag en de stemming van mensen met dementie (zoals onrust, apathie, agressie, depressie of angst) [8, 9]. In **Hoofdstuk 5** wordt aandacht besteed aan de stressfactoren en de zelfmanagementstrategieën die worden ingezet wanneer mantelzorgers te maken krijgen met veranderingen in het gedrag en de stemming van hun naaste. Hiervoor zijn vier online focusgroepen gehouden met in totaal 32 mantelzorgers van mensen met dementie, waaronder partners, kinderen en schoonkinderen. Uit dit onderzoek werd duidelijk dat mantelzorgers veel stress ervaren bij veranderingen in het gedrag en de stemming van de persoon met dementie. Met name de volgende stressfactoren werden genoemd: 1) constant moeten schakelen tussen reacties, 2) de persoon met dementie continu moeten bezighouden en afleiden, 3) het feit dat anderen de problematiek van hun naaste als minder ernstig ervaren en 4) in theorie weten wat te doen, maar dit niet in praktijk kunnen brengen.

Mantelzorgers passen verschillende strategieën toe om om te gaan met veranderingen in het gedrag en de stemming van de persoon met dementie, zoals 1) kalm blijven om te voorkomen dat het gedrag escaleert en 2) de persoon met dementie stimuleren en afleiden. Kalm blijven, gaat samen met zich aanpassen aan de gemoedstoestand van de persoon met dementie om te zorgen voor minder spanning of onrust. Mantelzorgers stimuleren en leiden de persoon met dementie af door bijvoorbeeld verhalen te vertellen, humor te gebruiken, positief te zijn of activiteiten voor te stellen.

Naast het omgaan met veranderingen in gedrag en stemming van de naaste, moeten mantelzorgers ook omgaan met hun eigen stress of andere emoties. Mantelzorgers gaven aan dat ze in dat soort situaties afleiding zoeken, zoals hobby's of afspreken met familie of vrienden. Een andere strategie die mantelzorgers toepassen om met stress om te gaan en de zorg te kunnen volhouden, is regelmatig uitrusten om 'de batterij weer op te laden'. Daarnaast hebben mantelzorgers de behoefte om hun gevoelens en last te delen met vrienden, familie of hulpverleners. Op die manier kunnen ze ook hun eigen dagelijkse stress verminderen.

Het is essentieel om een duidelijk beeld te hebben van de behoefte aan zelfmanagementondersteuning van mantelzorgers. Zo kunnen ze professionele ondersteuning ‘op maat’ krijgen. In **Hoofdstuk 6** wordt besproken hoe en door wie mantelzorgers geholpen willen worden bij veranderingen in het gedrag en de stemming van hun naaste. Er is ook gekeken naar de meningen van mantelzorgers over het gebruik van e-health als hulpmiddel bij zelfmanagementondersteuning.

Er zijn online focusgroepen gehouden om de onderzoeksvragen voor hoofdstuk 6 te beantwoorden. Dit waren dezelfde online focus groepen zoals beschreven in hoofdstuk 5. De resultaten tonen aan dat mantelzorgers hulp nodig hebben van hulpverleners, vrienden of familie. Deze hulp bestaat uit 1) informatie over dementie en de gevolgen hiervan, 2) tips en advies om om te gaan met veranderingen in het gedrag en de stemming, 3) de mogelijkheid om ervaringen en gevoelens te bespreken en 4) waardering en erkenning voor hun zorgverlening.

Mantelzorgers vinden e-health nuttig om algemene informatie te verkrijgen over dementie en daarmee samenhangende veranderingen in het gedrag en de stemming, maar ook om ervaringen te delen of hulp te vragen via internet of e-mail. Ze benadrukken echter dat een persoonlijke aanpak erg belangrijk is. Daarom kan e-health in zekere mate worden gebruikt om zelfmanagementondersteuning te verlenen, maar dit mag face-to-face contact niet volledig vervangen.

4. Is een online zelfmanagementondersteuning interventie bestaande uit persoonlijk e-mailcontact met een gespecialiseerde dementieverpleegkundige effectief en wordt het positief beoordeeld ten opzichte van online ondersteuning zonder persoonlijk e-mailcontact?

In **Hoofdstuk 7** wordt het design beschreven van een gerandomiseerd effectonderzoek met drie ‘interventiecondities’ voor online zelfmanagementondersteuning:

1. een 'major' interventie voor zelfmanagementondersteuning die bestaat uit persoonlijk e-mailcontact met een verpleegkundige die is gespecialiseerd in dementiezorg, in combinatie met online video's en elektronische bulletins (e-bulletins);
2. een 'medium' interventie die bestaat uit alleen online video's en e-bulletins; en
3. een 'minor' interventie met alleen e-bulletins.

Een verpleegkundige volgde een interventieprotocol om zelfmanagementondersteuning te bieden via e-mail. Dit protocol is gebaseerd op de vijf stappen van het 5A-model voor zelfmanagementondersteuning [10, 11]:

1. Achterhalen van behoeften, opvattingen en kennis;
2. Adviseren door informatie op maat te geven;
3. Afspreken van realistische doelen;
4. Assisteren bij het omgaan met persoonlijke barrières en inventariseer behoefte aan extra ondersteuning;
5. Arrangeren van een specifiek plan voor (vervolg) ondersteuning.

Met behulp van deze vijf stappen konden verpleegkundigen de online zelfmanagementondersteuning structuur geven binnen een dynamisch proces ‘op maat’.

De online zelfmanagementondersteuning (persoonlijk e-mailcontact, video's en e-bulletins) was ontworpen om mantelzorgers te ondersteunen, waardoor de persoon met dementie indirect ook wordt geholpen. De uitkomstmaten waren zelfeffectiviteit van de mantelzorgers, de aanwezigheid van gedragsveranderingen bij de persoon met dementie, en positieve en negatieve aspecten in de relatie tussen de mantelzorgers en mensen met dementie. De hypothese was dat een hogere zelfeffectiviteit van de mantelzorger een positieve invloed zou hebben op de relatie tussen de mantelzorger en de persoon met dementie, en ook een positieve invloed zou hebben op gedrag bij de persoon met dementie.

Gegevens zijn verzameld op drie momenten: bij de nulmeting (T0), zes weken na de nulmeting (T1) en twaalf weken na de nulmeting (T2). Vervolgens werden de resultaten van de drie interventiecondities met elkaar vergeleken door middel van een mixed-model analyse.

Het gerandomiseerde effectonderzoek met drie interventiecondities met 81 mantelzorgers werd van maart 2017 tot en met augustus 2017 uitgevoerd (**Hoofdstuk 9**). Ook werd een procesevaluatie uitgevoerd om de online zelfmanagementondersteuning te evalueren. In de procesevaluatie zijn kwantitatieve en kwalitatieve methoden gecombineerd. Uit de procesevaluatie (**Hoofdstuk 8**) bleek dat mantelzorgers veel waarde hechtten aan het e-mailcontact met een gespecialiseerde verpleegkundige. Het was voor deze mantelzorgers erg belangrijk om bevestiging van een verpleegkundige te krijgen dat ze het goed deden. De mantelzorgers vonden het e-mailcontact van toegevoegde waarde op de video's en e-bulletins. Ze waardeerden het ook dat de informatie en het advies werden toegespitst op hun specifieke situatie. Dankzij de online zelfmanagementondersteuning ervaarden de mantelzorgers erkenning van de verpleegkundigen.

De positieve resultaten van de procesevaluatie waren echter niet terug te vinden in het gerandomiseerde effectonderzoek, waarin geen statistisch significant verschillen tussen de drie interventiecondities werden gevonden voor de zelfeffectiviteit van de mantelzorger, de gedragsveranderingen in de persoon met dementie en de relatie tussen de mantelzorger en de persoon met dementie (**Hoofdstuk 9**). De procesevaluatie leverde verschillende mogelijke verklaringen voor de afwezigheid van positieve resultaten in het gerandomiseerd effectonderzoek. Een mogelijke verklaring betreft bijvoorbeeld het feit dat niet alle deelnemers gebruikmaakten van het e-mailcontact, de online video's en de e-bulletins. Daarnaast pasten de verpleegkundigen meestal alleen de eerste twee stappen van het 5A-model toe ('achterhalen' en 'adviseren').

In **Hoofdstuk 10** worden de resultaten van dit proefschrift samengevat. Ook worden er aanbevelingen gedaan voor dementiezorg en toekomstig onderzoek.

Uit de resultaten van dit proefschrift kan geconcludeerd worden dat verpleegkundigen en verzorgenden een bijdrage kunnen leveren aan zelfmanagement van mensen met dementie en hun mantelzorgers, bijvoorbeeld wanneer ze te maken krijgen met veranderingen in het gedrag en de stemming van de persoon met dementie. Verpleegkundigen en verzorgenden kunnen mensen met dementie en mantelzorgers helpen door gepersonaliseerde zelfmanagementondersteuning te bieden waarbij de zelfmanagementondersteuning gericht is op zowel de persoon met dementie als de mantelzorger. Deze zelfmanagementondersteuning kan gedeeltelijk online plaatsvinden, maar mag het face-to-face contact niet helemaal vervangen. Dit geldt zeker ook wanneer de online ondersteuning rechtstreeks aan de persoon met dementie is gericht.

Belangrijk voor het bieden van zelfmanagementondersteuning is dat verpleegkundigen en verzorgenden over voldoende vaardigheden beschikken. Dit is echter tot nu toe niet altijd het geval. Extra scholing kan daarom nodig zijn.

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PHD PORTFOLIO

Courses		**Year**
Research skills		
Basiscursus Regelgeving en Organisatie voor Klinisch onderzoekers (BROK-cursus), AMC		2012
Writing in English, Utrecht University		2014
Research Integrity, VUmc Academy		2017
Teaching skills		
Basiskwalificatie Didactische Bekwaamheid (BDB)		2018
(Inter)national conferences	**Oral/ poster presentation**	**Year**
4th International Seminar of the European Palliative Care Research Centre and the European Association for Palliative Care Research Network, Amsterdam	Poster presentation	2014
IPA International Congress, Berlin	Oral presentation	2015
Quest meeting, Amsterdam	Oral presentation	2015
1st annual meeting of Amsterdam Public Health Aging & Later Life Symposium, Amsterdam	Poster presentation	2016
Refereerlunch zelfmanagementondersteuning bij mensen met dementie en hun mantelzorger in de thuissituatie, Amsterdam	Oral presentation	2017
28th Alzheimer Europe Conference, Barcelona	Poster presentation	2018
Refereerlunch zelfmanagement en zelfmanagementondersteuning, Amsterdam	Oral presentation	2019
Teaching	**Organisation**	**Year**
Several education courses on research skills (onderzoekend vermogen), nursing skills (Klinisch Redeneren) and health promotion and prevention (Gezondheidsbevordering)	Inholland university of applied sciences	2016-now
Supervising Bachelor's thesis of several nursing students	Inholland university of applied sciences	2016-now
Media		
'Waardeer de mantelzorger'	V&VN Magazine	2016
'Online contact mag persoonlijk contact niet vervangen'	ZorgenZ...	2017

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Under review

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Huis in het Veld JG, Van Asch IF, Willemse BM, Verkade P, Pot A, Blom MM, Groot Zwaaftink RB, Francke AL. *Process evaluation of online self-management support for family caregivers to deal with behavior changes of a relative with dementia.*

ABOUT THE AUTHOR

Judith Huis in het Veld (1988) studied nursing at the Hogeschool van Amsterdam (HvA) in Amsterdam. After graduating in 2011, she took the pre-master's and master's Health Sciences course (specializing in Prevention and Public Health) at VU University in Amsterdam. During this, she worked as a research nurse at the Academic Medical Center (AMC). Her master's thesis on perspectives on self-care related to age in place among older adults was performed at the Netherlands Organisation for Applied Scientific Research (TNO). After graduation, she commenced her PhD project at the Netherlands Institute for Health Services Research (Nivel) in 2014. She worked on her PhD from 2015-2018 at the end-of-life research group at the VU University Medical Center. In 2016, she worked for 9 months at Verpleegkundigen & Verzorgenden Nederland (V&VN).

After September 2016, she combined her PhD research with teaching for the bachelor of nursing course at Inholland University of Applied Sciences. Furthermore she is involved in the Health & Well-being of Frail Elderly research group of Dr. Robbert Gobbens at Inholland University of Applied Sciences. She completed her PhD in 2019 under the supervision of Prof. Dr. Anneke Francke, Prof. Dr. Berno van Meijel and Dr. Renate Verkaik. She will continue working as a teacher and researcher for the bachelor of nursing course at Inholland University of Applied Sciences.