

The Effects of a Psychosocial Intervention among Dutch Informal Caregivers of Persons with
Dementia: A Cluster, Randomized Controlled Trial

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Master thesis Clinical Neuropsychology

Course code: P_ MTHNEUR

May 2021

Word count: 8541

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Abstract

Psychosocial interventions aimed at improving the sense of competence and mental health of the informal caregiver, can delay institutionalization of the person with dementia. The current study examined the association between resource utilization, sense of competence of and depressive symptoms in the caregiver and possibly improve sense of competence of and alleviate depressive symptoms in the caregiver after a psychosocial intervention. The study was performed as a cluster randomized controlled trial design. One-hundred-and-eight dyads were allocated to the intervention or the control group. The short psychosocial intervention entailed psychoeducation, practical suggestions for activities, and peer support. Outcome measures were The Center for Epidemiologic Studies Depression scale and the Short Sense of Competence Questionnaire. Outcomes were measured at baseline and three- and six-month follow-up. At baseline, only time spent on instrumental activities of daily living (a facet of resource utilization) and sense of competence were associated with depressive symptoms. Furthermore, there was an indirect effect of total hours spent on care on depressive symptoms through sense of competence. The intervention did not increase sense of competence of or fewer depressive symptoms in the caregiver at follow-up in comparison to the control group. Nevertheless, creating more sense of belonging and relief for caregivers with help of support groups seems to be fruitful. Further research with larger sample sizes is needed to investigate the efficacy of the current psychosocial intervention.

Keywords: dementia, caregiving, psychosocial intervention, mental health

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The Effects of a Psychosocial Intervention among Dutch Informal Caregivers of Persons with Dementia: A Cluster, Randomized Controlled Trial

The number of people who suffer from dementia was estimated to be around 270.000 in 2016 in the Netherlands (Alzheimer Nederland, 2018). The World Health Organization (WHO, 2020) stated that the amount of people with dementia (PwD) globally was estimated at around 50 million in 2015. Furthermore, the number of PwD could nearly double every 20 years (Alzheimer's Disease International [ADI], 2015). Dementia is a debilitating and a progressive disease that can lead to memory impairments, changes in mood or behaviour, and difficulties in performing familiar tasks (ADI, 2013). Dementia interferes with activities of daily living for the person affected, eventually leading to institutionalization (Kolb & Wishaw, 2015).

However, adequate care for people with dementia can prevent early institutionalization (Ying et al., 2018). Formal care is based on the personal needs of the PwD. Generally, a casemanager dementia is involved, forming a tailored care plan where healthcare specialists are consulted if needed. Complementing formal care, informal care forms an important aspect for PwD. Informal care is unpaid caregiving, commonly provided by a spouse, another family member, or a friend (Haex, Thoma-Lürken, Beurskens, & Zwakhalen, 2019). Nonetheless, dementia not only affects the PwD, but family or friends surrounding the PwD are affected as well. The impact can be physical, emotional, or even financial and causes stress to families and caregivers (WHO, 2020). As the disease progresses, the support that the PwD needs increases and therefore the strain on the informal caregiver can increase (Haex et al., 2019).

Consequently, informal caregivers become more prone to developing psychological disorders, e.g., major depression, anxiety disorders, and so forth (WHO, 2012). Caregivers who dedicate a substantial part of their personal life to taking care of a PwD, show more psychological complaints and experience a reduced quality of life in comparison to caregivers who dedicate less time of their personal life to taking care of a PwD (Riedijk, Duivenvoorden,

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Van Swieten, Niermeijer, & Tibben, 2009). For example, caregiving intensity was associated with a decreased mental health of the caregiver in western European countries (Bremer et al., 2015). Van der Lee, Bakker, Duivenvoorden, and Dröes (2014) complement this finding in a systematic review and conclude that a higher caregiver burden was associated with a decreased mental health. Furthermore, caregivers who experienced a high subjective burden were more prone to commit their relatives with dementia into a mental healthcare facility than caregivers who experienced a lower subjective burden (Gaugler, Kane, Kane, Clay, & Newcomer, 2003).

Improving and maintaining the mental health of informal caregivers and thereby alleviating burden and depressive symptoms, can delay institutionalization of the PwD (ADI, 2011; Dickinson et al., 2017; Pinquart & Sorensen, 2006; Van der Lee et al., 2014; Wu et al., 2019). However, it is not solely of high social importance to support informal caregivers by reducing depressive symptoms, but of high economic importance as well (Dickinson et al., 2017; Van der Lee et al., 2014; Wu et al., 2019). In the Netherlands, dementia has the highest healthcare costs among other diseases, accounting for 9.30 billion euros in 2017 alone. This is about 10 percent of the total healthcare costs in the Netherlands (Alzheimer Nederland, 2018).

Several factors have been associated with caregiver burden. For example, PwD increasingly experience problems with executing activities of daily living (ADL) as the dementia advances (Kang et al., 2014). Time spent on helping the PwD with ADL is part of the resource utilization of the caregiver, measuring formal and informal healthcare use (Wimo et al., 2013). ADL is further differentiated into time spent on personal ADL (PADL), instrumental ADL (IADL), and supervision time. Examples of PADL are the need to assist in bathing or eating. Examples of IADL are the need to assist in doing groceries or aiding in managing financial matters for the PwD. When studying mental well-being in a cohort of European caregivers who perform informal care at home for a PwD, the amount of care provided by the informal caregiver in the form of PADL, IADL, and supervision time were all

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negatively associated with caregiver well-being (Lethin et al., 2016). However, studies investigating the relationship between the different facets of resource utilization and caregiver well-being remain scarce.

Further vital factors that are not only associated with caregiver burden, but also for determining early institutionalization of the PwD were, among others, the sense of competence of the caregiver and the dementia severity of the PwD (Spijker et al., 2011). Sense of competence is a personal resource that affects the mental health of the caregiver and can be defined as the feeling of being able to care for the PwD (Vernooij-Dassen et al., 1999). Having a lower sense of competence seemed to be related to a lower quality of life of the caregiver (Riedijk et al., 2009). Additionally, caregivers that showed a high sense of competence felt more qualified for their role in giving care and experienced fewer depressive symptoms (Ying et al., 2018). However, in a review by Ying et al. (2018), examining the sense of competence of caregivers, it was argued that most studies included did not include a control group and it was unclear if the results could be generalized. Correspondingly, an increased sense of competence was associated with better mental health and predicted more subjective fulfilment in life (Borsje et al., 2016; Quinn, Clare, & Woods, 2012). Another potent factor that influences caregivers' well-being is the severity of the dementia of the person they are taking care of (Spijker et al., 2011; Ydstebø, Benth, Bergh, Selbæk, & Vossius, 2020). In particular, problems that accompany the severity of the dementia, for example behavioral or cognitive problems, predicted a higher burden and earlier institutionalization of the PwD (Gaugler et al., 2003).

Investigating the relationship between resource utilization, sense of competence, and depressive symptoms could result in manageable parameters for future therapeutic interventions. A large systematic review stated that the most effective interventions to improve subjective well-being of the caregiver should incorporate therapeutic and educational components (Dickinson et al., 2017). More particular, early and multi-component

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interventions seemed to help the PwD by delaying their institutionalization and reduce depressive symptoms in their caregivers. Herein, group therapy was favored instead of individual therapy (Dickinson et al., 2017). Regarding sense of competence, psychoeducational interventions in the form of psychoeducation, social support, and behavioral cognitive therapy appeared useful to increase sense of competence of caregivers in comparison to a control group (Gossink et al., 2018). Complementary, in a meta-analysis, psychosocial and behavioral interventions seemed beneficial for caregivers to improve their sense of competence and decrease depressive symptoms (Jütten, Mark, Wicherts, & Sitskoorn, 2018). More specific, educational programs yielded the best results (Jütten et al., 2018). However, studies investigating the effects of psychosocial interventions were inconclusive and the association between these factors still needs further scientific clarification (Dickinson et al., 2017; Jütten et al., 2018).

Future interventions should be aimed at improving sense of competence of the caregiver so that meaning can be found in the caregiving role. Sense of competence of the caregiver can potentially protect the caregiver from the negative effects of time spent on care on their mental health. Van der Lee et al. (2014) states that the confidence of the informal caregiver was associated with decreased burden. Informal caregivers may benefit from interventions aimed to increase self-efficacy and thus decreasing depressive symptoms (Gonyea, O'Connor, Carruth, & Boyle, 2005).

An important, additional factor that could potentially influence caregivers' outcomes is adherence to intervention sessions. Evaluating adherence to intervention sessions could pose a valuable research aspect to take into account during analyses to optimize intervention benefits (Chee, Gitlin, Dennis, & Hauck, 2007). Caregivers who followed a psychosocial intervention and were more therapeutically engaged showed greater benefits (e.g., less depressive symptoms) after the intervention, than caregivers who were less therapeutically engaged (Nguyen, Nguyen, Pham, Nguyen, & Hinton, 2018). Also, it seemed that caregivers

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with higher mental well-being adhered better to treatment sessions and thus benefitted more from the intervention (Chee et al., 2007). A possible explanation proposed by Chee et al. (2007) is that caregivers with low adherence to intervention sessions were less open to change. Wu et al. (2019) carried out a systematic review investigating the efficacy of psychosocial interventions for improving quality of life of the caregiver. Unfortunately, nearly all studies included failed to report adherence to intervention sessions after the intervention (Wu et al., 2019). Secondly, adherence to intervention sessions is not always included in statistical analyses.

In conclusion, evidence for psychoeducational interventions to reduce depressive symptoms in caregivers has been inconclusive (Gossink et al., 2018; Joling et al., 2012). Also, most studies did not include control groups, generalization forms a challenging aspect regarding external validity and adherence to intervention sessions is not always taken into account during analyses (Wu et al., 2019; Ying et al., 2018).

The current study aimed to examine the association between resource utilization, sense of competence of the caregiver, and depressive symptoms in the caregiver. First, it was investigated whether the three facets of resource utilization had different influences on the mental health of the caregiver. It was expected that the different facets of resource utilization were positively correlated with depressive symptoms in the caregiver. Secondly, it was investigated whether the sense of competence of the caregiver had a protecting influence on the expected negative association between the hours spent on providing care (resource utilization) and the mental health of the caregiver. It was expected that sense of competence of the caregiver had a mediating influence on the relationship between resource utilization and depressive symptoms of the caregiver, where a higher sense of competence results in fewer depressive symptoms. Thirdly, it was investigated whether a psychosocial intervention could improve the sense of competence and mental health of the caregiver after a three- and six-month follow-up in comparison to the control group. It was expected that a psychosocial

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intervention will result in a decrease in depressive symptoms in the intervention group in comparison to the control group after a three- and a six-month follow-up. Also, it was expected that the psychosocial intervention resulted in an increase in sense of competence in the intervention group in comparison to the control group after a three- and a six-month follow-up. To conclude, it was investigated if adherence to intervention sessions had an influence on the intervention outcomes (formed by the sense of competence and mental health) of the caregiver after a three- and six-month follow-up in comparison to the control group. It was expected that a higher adherence to intervention sessions would result in a higher change in sense of competence of and depressive symptoms in the caregiver than having a low adherence to intervention sessions after a three- and a six-month follow-up in comparison to the control group.

Methods

Participants

One-hundred-and-eight dyads were included in the current study. The mean age of the persons with dementia in the sample was 79.66 ($SD = 7.13$) and the mean age of the caregivers was 70.53 ($SD = 10.83$). Alzheimer's disease was the most prevalent type of dementia among the PwD (38.90%), followed by vascular dementia (21.30%). Frontotemporal dementia, mild cognitive impairment and Lewy body dementia were represented relatively low (each 2.10%). A part of the PwD stated their type of dementia as 'other' or unknown (33.50%); An official diagnosis was not always present. Most PwD were coresidential with the caregiver (76.90%). Most caregivers were spouses (73.10%) or a friend of the PwD (25.0%). Further demographic characteristics of the study sample can be found in Table 1. For hypothesis three and four, dropouts and participants with missing data were removed and a subset of participants was used from the main study sample ($n = 69$). The subset of participants did not differ significantly from the main study sample.

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Inclusion of the informal caregiver depended on the following criteria: The informal caregiver was a spouse, family member, or a friend of the PwD. The caregiver provided care for at least three days per week without receiving a financial compensation.

Inclusion of the PwD depended on the following criteria: The PwD had a diagnosis of a dementia type or there was a strong suggestion that the cognitive impairment was linked to dementia. The PwD had to live at home. The PwD was excluded if the PwD had started medication specifically for dementia in the six months prior to the study, because it could influence outcomes of interest of the current study by serving as bias.

Furthermore, it was important that both the caregiver and the PwD did not have other physical or mental conditions that could impede their participation to the study. Finally, the dyads could not participate in other intervention studies during the current study.

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Table 1

Characteristics study sample

Characteristic	PwD	Caregiver
Age in years		
<i>M (SD)</i>	79.66 (7.13)	70.53 (10.83)
Sex		
Male	64 (59.30%)	28 (25.90%)
Female	43 (39.80%)	80 (74.10%)
Education level*		
1-3	20 (18.87%)	11 (10.18%)
4-5	67 (63.21%)	75 (69.44%)
6-7	19 (17.92%)	22 (20.37%)

Note. N = 108. *Education level is coded with help of the classification of Verhage (1964): 1 = less than lower school/did not finish lower school, 2 = finished lower school, 3 = finished lower school and had further education for less than two years, 4 = lower than MULO/MAVO-level (e.g.: LTS), 5 = MULO/MAVO, 6 = HAVO/HBS/HBO, 7 = VWO/university.

Materials

Multiple questionnaires were administered; the current study only described outcomes of interest. During every measurement, general information and demographic characteristics were collected with help of different forms, one for the PwD and one for the caregiver.

Resource Utilization in Dementia Instrument-Lite version (RUD-Lite).

The RUD-Lite (Wimo & Winblad, 2003) was used to determine the hours spent on care. The RUD-Lite measures informal care time and use of health services among older adults with dementia and their caregivers. The RUD-lite is based on the original RUD

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questionnaire and has a baseline version and a follow-up version (Wimo, Wetterholm, Mastey, & Winblad, 1998). The RUD is administered as an interview with the caregiver and has several distinct parts. Part one assesses the caregiver, including general information (e.g.: age in years), caregiver time (e.g.: ‘On a typical care day during the last 30 days, how much time per day did you spend supervising the patient?’). The outcome measures were time spent on PADL, time spent on IADL, supervision time, and total time spent on care. The variables were measured in hours and are continuous. Total time spent on care was calculated by adding time spent on PADL to time spent on IADL. Supervision time was not taken into account, because adding supervision time to the equation culminated in a score above 24 hours. The internal consistency of time spent on PADL (Cronbach’s alpha = .82) and supervision time (Cronbach’s alpha = .81) was good among 20 institutionalized PwD (Wimo & Nordberg, 2007). The internal consistency of total time spent on care was acceptable (Cronbach’s alpha = .78). The internal consistency of time spent on IADL was not acceptable (Cronbach’s alpha = .33). The validity (correlations) was strong for time spent on PADL, supervision time, and total time spent on care, but low for time spent on IADL (Wimo & Nordberg, 2007).

The Center for Epidemiologic Studies Depression scale (CES-D).

The CES-D (Radloff, 1977) was used to assess depressive symptoms in the caregiver. The Dutch version of the CES-D was used in the current study (Hanewald, 1987). Answers are given by the caregiver on a four-point Likert scale and are based on how the caregiver felt in the past week. Scoring options were 0 (rarely or none of the time/less than 1 day), 1 (some or a little of the time/1-2 days), 2 (occasionally or a moderate amount of time/3-4 days) or 3 (all of the time/5-7 days). The questionnaire contains 20 items. An example of a question is: ‘This last week, I felt sad’. The minimum score is 0, the maximum score is 60, and a higher score indicates a higher amount of depressive symptoms. Construct validity was moderate ($r = .56$; Hanewald, 1987). Furthermore, the CES-D had a satisfactory criterion validity for

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detecting a major depressive disorder in an older population in the Netherlands ($N = 487$; Beekman et al., 1997). The internal consistency was excellent in a non-institutionalized cohort in the United Kingdom among adults between 24 and 74 years old (Cronbach's $\alpha = .90$; Cosco, Prina, Stubbs, & Wu, 2017). The internal consistency with respect to time was acceptable at baseline (Cronbach's $\alpha = .74$) and good at three- and six-month follow-up among a sample of 302 elderly above 65 years old in the Netherlands (Cronbach's $\alpha = .82$; Van de Rest, Van der Zwaluw, Beekman, De Groot, & Geleijnse, 2009).

The Short Sense of Competence Questionnaire (SSCQ).

The SSCQ (Vernooij-Dassen et al., 1999) was used to determine the caregivers' beliefs in their own functioning. The SSCQ is administered as an interview with the caregiver and contains seven items. The first four items are scored on a five-point Likert scale (1 = yes, agree very strongly, 2 = yes, agree, 3 = yes/no, neutral, 4 = no, disagree, 5 = no, disagree very strongly). The last three items are scored on a three-point Likert scale (1 = yes, agree, 2 = neutral, 3 = no, disagree). An example question is: 'I wish that my spouse/friend [relationship to PwD] and I had a better relationship'. The scores on all items were added and a total score was calculated, where a higher score indicated a higher sense of competence. The reliability was acceptable (Cronbach's $\alpha = .76$) and the SSCQ had a high construct validity comparing the Pearson correlation between the original SCQ and the SSCQ ($r = .88$) among 141 community-living caregivers of people with dementia (Vernooij-Dassen et al., 1999).

Global Deterioration Scale (GDS).

The stage of dementia was estimated with help of the GDS (Reisberg, Ferris, De Leon, & Crook, 1982). The GDS was administered as a semi-structured interview with the caregiver. The scale ranges from one to seven and measures the stage of the dementia and the magnitude and severity of cognitive decline. The stage was determined by the interviewer with help of prescribed criteria (clinical characteristics) per stage of dementia. Stage 1 is 'no cognitive decline' and is characterised by absent subjective complaints and memory deficits.

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Stage 2 is ‘very mild cognitive decline (age-associated memory impairment)’ and is characterised by subjective complaints of memory deficits, but no objective evidence of memory deficits. Stage 3 is ‘mild cognitive decline (mild cognitive impairment)’ and is characterised by earliest clear-cut deficits, such as word- and name-finding deficits or denial beginning to manifest. Stage 4 is ‘moderate cognitive decline (mild dementia)’ and is characterised by clear-cut deficits in different areas, for example decreased knowledge of current and recent events and an inability to travel to familiar locations. Stage 5 is ‘moderately severe cognitive decline (moderate dementia)’ and is characterised by the patient no longer being able to survive without assistance during ADL. Stage 6 is ‘severe cognitive decline (moderately severe dementia)’ and is characterised by forgetfulness, unawareness of events, needing assistance with ADL and including personality and/or emotional changes. Stage 7 is ‘very severe cognitive decline (severe dementia)’ and is characterised by loss of verbal abilities, loss of motor skills, rigidity, and so forth. The GDS was initially validated at the time with help of biomarkers attained via positron emission tomography (PET) scans (Ferris et al., 1980). There were medium to strong correlations of the GDS scores with a lower metabolic rate in several brain areas, i.e., the caudate nucleus, thalamus, and temporal areas ($r = .69-.83$). Areas where glucose utilization (metabolic rate) was less efficient indicated worse functional activity in that brain area corresponding with higher GDS scores. The interrater reliability was high, as found in several studies ($ICC = .87-.97$; Herndon, 2006).

Adherence to intervention sessions.

Adherence to the intervention was measured with help of the general information questionnaires, administered after the intervention took place during the measurement at three-month follow-up. The score ranged from one to six intervention sessions.

Design

Approval of the Medical Ethical Review Committee from the Vrije Universiteit Medisch Centrum was obtained. The current study used a cluster, randomized controlled trial

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design. Outcomes were obtained from two groups of participants, i.e.: a control group, receiving usual care, and an intervention group. Outcome measures were assessed at three occasions; at baseline (before the start of the intervention if placed in the intervention group), at three months from baseline and at six months from baseline. If centres (meeting centres, day-care facilities for PwD, and so forth) agreed to partake in the study, they were randomly allocated to either the intervention group or the control group. If multiple locations of the same organisation or centre were interested, each location was allocated to a group individually to prevent cross-contamination of information between locations.

Procedure

Centres for the elderly in different parts across the Netherlands were invited to take part in the study. Emails were sent to contact persons of eligible centres, containing background information of the study. If centres were interested, a meeting was set up to get acquainted. Healthcare professionals at the centres searched for eligible dyads and sent information packages. Participants enrolled when interested. Potential participants were then called by research assistants to explain the background of the study and to control eligibility based on the inclusion and exclusion criteria. If participants were still interested, a first measurement was planned. Prior to the first measurement, both the caregiver and the PwD gave informed consent. If the PwD was not able to sign the informed consent form, the caregiver was authorized to sign in their name. Participants received a copy of the informed consent.

Measurements took approximately an hour and a half. Different orders of administering the questionnaires were used to prevent order effects. A measurement took place at the home of the PwD or caregiver or at their affiliated centre where they received care. The research assistant was blind to the participants' group allocation. Participants in the intervention group were asked to fill out an evaluation form about the intervention and manual after three and six months. Forms were filled out anonymously. An example question

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is: 'Did you find the intervention sessions useful?'. Arrangements were made to ensure participants in the control group could receive the intervention or the manual after the last measurement, if desired.

The Intervention.

The caregivers of the dyads who were allocated to the intervention group, received a psychosocial training entailing multiple components. If placed in the intervention group, centres could compose groups of four to eight caregivers to partake in the intervention. The intervention was arranged by a health care professional from the meeting centre and the intervention sessions were held at the centre. Usually, this was a dementia casemanager. The health care professional leading the intervention received a training (appr. two hours) from the project leader from the Vrije Universiteit Amsterdam. The health care professional received instructions on how to arrange the intervention sessions and what to discuss with the recipients, e.g., to give enough space for the caregivers to talk to each other about the consequences of caregiving. At the start of the intervention, all caregivers in the intervention group received a manual. With help of the manual, different themes were subsequently discussed, i.e.: educating the caregivers about (the effects of) dementia and its types, teaching effective communication with the PwD, and coping with behavioural changes, teaching ways to cope with the burden of caregiving and maintaining a healthy lifestyle and suggestions for activities with the PwD. The intervention consisted of six sessions, each session taking approximately one hour, covering two months. Attendance was listed by the health care professional. In the first three sessions (given once every week), educational subjects were discussed. The final three sessions (given once every two weeks) focussed on sharing experiences. A home visit took place between session five and six (preferably) to ensure treatment fidelity (adherence to the intervention and the intervention sessions) and to help with initiating activities at home.

Statistical Analyses

IBM SPSS Statistics 24 was used to analyse the results (IBM Corp., 2016). Outliers were checked by calculating z -scores. If the z -score deviated more than three standard deviations, the data was checked for abnormalities, for example items missing.

For hypothesis one, a multiple regression was performed. The assumption of linearity was evaluated with a normal probability plot and the assumption of homoscedasticity with a residual plot. To evaluate the assumption of normality, the Kolmogorov-Smirnov test was used. Multicollinearity was evaluated using VIF-values. The independent variables consisted of the different facets of resource utilization (PADL, IADL, supervision time) and the total score on the SSCQ. The dependent variable consisted of the total score on the CES-D. The stage of dementia was controlled for and was used as a covariate. The different stages were translated into dummy variables with three levels (stages of dementia GDS one, two and seven were absent at baseline, creating the need for three dummy variables).

For hypothesis two, a simple mediation analysis was performed using the PROCESS macro for SPSS 24 developed by Hayes (2018), to investigate if a mediation was present between total sum of hours spent on care (PADL & IADL) and the total score on the CES-D through the total SSCQ score.

For hypothesis three, a three-way repeated measures MANOVA was performed. The assumption of normality was assessed with histograms. For the assumption of sphericity, Mauchly's test was used. The independent variables consisted of time (three levels; i.e., t0, t1, t2) and group allocation (two levels; i.e., intervention or control group). The dependent variables consisted of the total SSCQ and total CES-D scores. Baseline stage of dementia was used as a covariate, taken into account as a factor during analyses. The score on the GDS was divided into two groups, i.e., GDS low (stages three and four) and GDS high (stages five and six).

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For hypothesis four, a four-way repeated measures MANOVA was performed. The independent variables consisted of time (three levels) and group allocation (two levels). The dependent variables consisted of the total SSCQ and total CES-D scores. The stage of dementia and adherence to intervention sessions were used as covariates. Adherence to intervention sessions was divided into two groups, i.e.: intervention-low (one till five intervention sessions followed) and intervention-high (all sessions followed).

To reduce the type 1 error rate when conducting multiple comparisons after the repeated measures MANOVA's, a multiple-comparison post hoc correction (Bonferroni adjustment) was applied to all variables.

Results

Before performing the analyses, the data was checked for outliers. Fourteen participants were deleted from further analyses. Three outliers were removed from further analyses, exceeding 24 hours of given care per day on the total hours spent on care variable. The other 11 participants were removed because of missing values on the questionnaires. Based on VIF values, there was no concern for multicollinearity (all VIF values were below 10). Linearity was checked through scatterplots. Normal distributed residuals were checked with a normal P-P plot and indicated an approximately normal distribution of errors. A scatterplot of residuals was investigated and revealed that the homoscedasticity assumption was not violated for all independent variables. Descriptive statistics of the variables of interest at baseline are reported in Table 2.

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Table 2

Descriptive statistics of the dependent and independent variables at baseline

Measure	<i>N</i>	Minimum	Maximum	<i>M</i>	<i>SD</i>
PADL	108	0.00	9.00	1.27	1.95
IADL	108	0.00	16.00	2.92	2.49
Supervision time	108	0.00	24.00	7.21	8.06
Sum PADL & IADL	108	0.00	16.00	4.19	3.64
Total SSCQ	108	7.00	28.00	20.63	4.73
Total CES-D	108	0.00	44.00	11.18	8.27

Note. PADL = personal activities of daily living. IADL = instrumental activities of daily living. SSCQ = Short Sense of Competence Questionnaire. CES-D = Center for Epidemiological Studies Depression scale.

Multiple regression

A multiple linear regression was conducted to evaluate the prediction of the total score on the CES-D based on hours spent on PADL, hours spent on IADL, hours spent on supervision, and total score on the SSCQ, after controlling for scores on the GDS; see Table 3 below. In the first model, the GDS score was added, explaining 5.84% of the variance in the total CES-D score, $F(3, 104) = 2.15, p = .098$. In the second model, the score on the GDS, the hours spent on PADL, hours spent on IADL, and hours spent on supervision were added, explaining 16.46% of the variance in the total CES-D scores, $F(6, 101) = 3.32, p = .005$. The second model explained 11% more variance in total CES-D scores compared to model 1, R squared change = .11, F change (3, 101) = 4.28, $p = .007$. Of individual predictors, in the second model, only IADL reached statistical significance, indicating a positive association, $b(se) = 0.80(0.34), t(101) = 2.32, p = .022, r^2_{partial} = .23$. In the third model, the score on the GDS, the hours spent on PADL, hours spent on IADL, hours spent on supervision, and the

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total SSCQ score were added, explaining 26.87% of the variance in the total CES-D scores, $F(7, 100) = 5.25, p < .001$. The third model explained 10% more variance in total CES-D scores compared to model 2, R squared change = .10, F change (1, 100) = 14.24, $p < .001$. Of individual predictors, in the third model, only total SSCQ score reached statistical significance, indicating a negative association, $b(se) = -0.61(0.16), t(100) = -3.77, p < .001, r^2_{partial} = -.35$.

Table 3

Hierarchical multiple regression, dependent variable: total CES-D score

Variable	Model 1		Model 2		Model 3	
	<i>B</i>	<i>SE</i>	<i>B</i>	<i>SE</i>	<i>B</i>	<i>SE</i>
GDS=4 ^a	3.89	2.41	1.70	2.42	0.09	2.32
GDS=5	5.70*	2.25	3.58	2.32	2.18	2.21
GDS=6	4.07	3.11	2.80	3.11	1.76	2.94
PADL			-0.58	0.43	-0.53	0.40
IADL			0.80*	0.34	0.56	0.33
Supervision			0.20	0.10	0.17	0.10
Total SSCQ					-0.61**	0.16
<i>Adjusted R²</i>	.03		.12		.22	
<i>R² change</i>			.11*		.10**	

Note. $N = 108$. ^aIn the sample, only GDS levels 3 to 6 were present, creating the need for three dummy variables. * = $p < .05$. ** = $p < .001$.

Mediation analysis

A simple mediation analysis was performed to examine the relationship between total sum of hours spent on care (PADL & IADL) and total score on the CES-D through the total

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SSCQ score, using the PROCESS macro for SPSS 24.0, developed by Hayes (2018) and bootstrapping methods (5000). There was a significant, positive and indirect effect of total hours spent on care on the total score on the CES-D scores through the total SSCQ score, $ab = 0.21$, 95% C.I. [0.01, 0.47], see Figure 1 below. The direct effect of hours spent on care on total score on the SSCQ was negative and significant, $b(se) = -0.30(0.12)$, $p = .018$. The direct effect of hours spent on care on total score on the CES-D was not significant, $b(se) = 0.29(0.21)$, $p = .151$. The direct effect of the total SSCQ score was negative and significant, $b(se) = -0.71(0.16)$, $p < .001$.

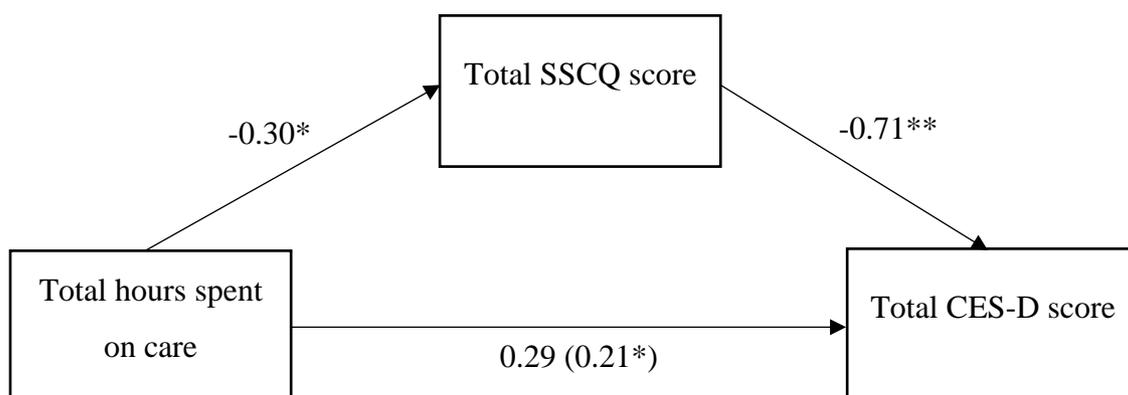


Figure 1. The unstandardized coefficients of the relationship between total hours spent on care and total CES-D score as mediated by total SSCQ score. Between brackets is the indirect effect of total hours spent on care on total score CES-D (as mediated by total SSCQ score).

* = $p < .05$. ** = $p < .001$.

Three-way Repeated Measures MANOVA

A three-way repeated measures MANOVA was conducted to determine whether there were significant differences in CES-D and SSCQ scores after a three- and six-month follow-up in comparison to a control group, taking baseline GDS score into account ($n = 69$).

Five participants were removed from further analyses because of missing values on the questionnaires. Mauchly's test of sphericity was not violated. A Box's M test was performed to test for multivariate homogeneity of variances and covariances, where a

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significance level of .001 was used ($p = .009$). The Shapiro-Wilk test was used to assess the assumption of normality and was violated for participants in the control group on the SSCQ for t0 and t2. The assumption for normality was violated for participants in the control group on the CES-D for t1. The assumption for normality was violated for participants in the low GDS group on the SSCQ for t0 and t1. The assumption of normality was violated for participants in the low GDS group on the CES-D for t1 and t2 and for participants in the high GDS group violated for t0, t1, and t2. For descriptive statistics and sample sizes of the different groups, see Table 4.

Table 4

Descriptive statistics three-way Repeated Measures MANOVA

Measure	Group	GDS	t0		t1		t2		n
			M	SD	M	SD	M	SD	
CES-D	Control	Low	8.57	5.98	10.50	11.53	11.00	8.17	14
		High	9.06	7.04	9.06	6.93	9.00	6.06	17
	Intervention	Low	11.67	7.93	9.94	8.17	13.17	11.46	18
		High	12.10	8.44	11.85	8.70	12.55	9.80	20
SSCQ	Control	Low	21.00	5.31	22.00	2.57	21.43	3.27	14
		High	21.35	4.65	20.94	4.28	20.41	5.33	17
	Intervention	Low	21.28	5.71	20.83	6.53	19.39	6.53	18
		High	19.20	4.16	19.95	4.06	19.85	3.72	20

Note. Participants were either in the control group or in the intervention group. Secondly, people with dementia had either a GDS score (stage of dementia) of 3 or 4 (GDS low) or a GDS score of 5 or 6 (GDS high).

There were no statistically significant changes over time in the combined outcome variables (total CES-D and total SSCQ scores), taking baseline GDS score into account, Pillai's Trace = .03, $F(4, 62) = 0.49$, $p = .747$, partial $\eta^2 = .03$, there was no significant interaction effect between time and group (based on control or intervention group) on the

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combined outcome variables, Pillai's Trace = .03, $F(4, 62) = 0.40$, $p = .809$, partial $\eta^2 = .03$, and no significant interaction effect between time and group allocation, taking baseline GDS score into account on the combined outcome variables, Pillai's Trace = .09, $F(4, 62) = 1.48$, $p = .220$, partial $\eta^2 = .09$.

There was no significant main effect of time on the combined outcome variables, Pillai's Trace = .07, $F(4, 62) = 1.16$, $p = .337$, partial $\eta^2 = .07$, no significant main effect of group allocation on the combined outcome variables, Pillai's Trace = .03, $F(2, 64) = 0.89$, $p = .418$, partial $\eta^2 = .03$, and no significant main effect of GDS score group allocation on the combined outcome variables, Pillai's Trace = .01, $F(2, 64) = 0.45$, $p = .642$, partial $\eta^2 = .01$.

Four-way Repeated Measures MANOVA

A four-way repeated measures MANOVA was conducted to determine whether there were significant differences in CES-D and SSCQ scores after a three- and six-month follow-up in comparison to a control group, taking adherence to intervention sessions and baseline GDS score into account ($n = 69$).

Mauchly's test of sphericity was not violated. A Box's M test was performed to test for multivariate homogeneity of variances and covariances ($p = .004$). For descriptive statistics and sample sizes of the different groups, see Table 5.

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Table 5

Descriptive Statistics four-way Repeated Measures MANOVA

Measure	Group & adherence	GDS	t0		t1		t2		n
			M	SD	M	SD	M	SD	
CES-D	Control	Low	8.57	5.98	10.50	11.53	11.00	8.17	14
		High	9.06	7.04	9.06	6.93	9.00	6.06	17
	Intervention-low	Low	9.44	8.81	8.44	8.03	8.11	6.62	9
		High	15.56	9.88	13.33	7.48	11.33	8.86	9
	Intervention-high	Low	13.89	6.72	11.44	8.50	18.22	13.34	9
		High	9.27	6.13	10.64	9.76	13.55	10.83	11
SSCQ	Control	Low	21.00	5.31	22.00	2.57	21.43	3.27	14
		High	21.35	4.65	20.94	4.28	20.41	5.33	17
	Intervention-low	Low	23.33	4.00	23.67	5.41	22.56	5.79	9
		High	17.56	3.97	19.56	3.09	18.56	3.54	9
	Intervention-high	Low	19.22	6.61	18.00	6.58	16.22	5.87	9
		High	20.55	3.98	20.27	4.84	20.91	3.67	11

Note. Participants were divided based on their participation in the control group or in the intervention group. Intervention-low = one to five meetings followed of the intervention. Intervention-high = all meetings followed of the intervention. Secondly, people with dementia had either a GDS score of 3 or 4 (GDS low) or a GDS score of 5 or 6 (GDS high).

There were no statistically significant changes over time in the combined outcome variables, taking baseline GDS score into account, Pillai's Trace = .06, $F(4, 60) = 0.90$, $p = .427$, partial $\eta^2 = .06$. There was no statistically significant interaction effect between time and group allocation based on control or intervention group and intervention sessions followed on the combined outcome variables, Pillai's Trace = .18, $F(8, 122) = 1.50$, $p = .164$, partial $\eta^2 = .09$. There was no significant interaction effect between time and group allocation based on control or intervention group and intervention sessions followed on the combined outcome variables, taking baseline GDS score into account, Pillai's Trace = .12, $F(8, 122) = 0.97$, $p = .461$, partial $\eta^2 = .06$.

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There was no statistically significant main effect of time on the combined outcome variables, Pillai's Trace = .08, $F(4, 60) = 1.30$, $p = .281$, partial $\eta^2 = .08$, no significant main effect of group allocation on the combined outcome variables, Pillai's Trace = .06, $F(4, 126) = 0.89$, $p = .472$, partial $\eta^2 = .03$, and no significant main effect of GDS score group allocation on the combined outcome variables, Pillai's Trace = .01, $F(2, 62) = 0.43$, $p = .652$, partial $\eta^2 = .01$.

Intervention evaluation

After the intervention concluded, caregivers in the intervention group were asked to fill out an evaluation questionnaire. From the 33 participants (60%) who returned the questionnaire, 27 caregivers (82%) rated the meetings relatively useful or very useful. Only four caregivers rated the meetings as somewhat useful and only one caregiver did not find the meetings to be useful at all. All caregivers were positive about the experiences and advice that could be exchanged during meetings. Amongst the reactions were: 'I have more patience and insight', 'I now know how to respond to confusing moments of the person with dementia' and 'You are more conscious about how to handle and cope with dementia'. Most caregivers (76%) still used tips and advices learned during the meetings, especially when taking care of themselves. All participants would recommend the intervention to other people and think that most caregivers would benefit from this kind of intervention.

Discussion

Improving and maintaining the mental health of informal caregivers and thereby alleviating burden of and depressive symptoms in the caregiver, can delay institutionalization of the PwD. Psychosocial interventions aimed at increasing the sense of competence can possibly alleviate depressive symptoms and has economic and societal benefits. The aim of the current study was to evaluate the effects of a psychosocial intervention on caregivers' outcomes of sense of competence and depressive symptoms after a three- and six-month follow-up and to shed light on the relationship between resource utilization, sense of

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competence, and depressive symptoms. First, only the hours spent on care in the IADL facet of resource utilization was significant and positively associated with depressive symptoms. Time spent on PADL and supervision time were not significantly associated with depressive symptoms. Sense of competence of the caregiver was significantly and negatively associated with depressive symptoms. Secondly, there was a mediation effect of total hours spent on providing care on depressive symptoms in the informal caregiver, through the sense of competence of the caregiver. The sense of competence had a negative influence on depressive symptoms where a higher level of sense of competence was correlated with fewer depressive symptoms. However, there was no direct effect of total hours spent on care on depressive symptoms. Thirdly, the psychosocial intervention did not decrease depressive symptoms in and did not improve sense of competence of caregivers after a three- and six-month follow-up in comparison to a control group receiving usual care. Also, there were no significant differences between the intervention and control group and between the groups based on the stages of dementia severity. Fourthly, taking adherence to intervention sessions into account did not alter these results.

In line with the first and second hypothesis, the present study confirmed that participants who showed a lower level of sense of competence experienced more depressive symptoms. This is in line with findings that the sense of competence of the caregiver was negatively associated with depressive symptoms in the caregiver (Borsje et al., 2016; Ying et al., 2018). Looking at the personal construct of sense of competence, it is apparent that caregivers with a higher feeling of competence were more confident in their functioning as a caregiver. These participants felt more qualified for their caregiving role, which most likely reduced the experienced burden and improved their coping with the mental aspects of managing informal caregiving (Ying et al., 2018). Therefore, sense of competence possibly forms a protective factor of the effects of hours spent on care. A higher sense of competence seemed to positively affect the resilience of the caregiver, possibly decreasing caregiver

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burden. Furthermore, a higher sense of competence was associated with staying positive and using a problem-focused coping-style, improving resilience (Joling et al., 2016).

In contrast with the first hypothesis, the different facets of resource utilization were not associated with depressive symptoms in the caregiver. However, only the distinct facet time spent on helping the PwD with IADL (e.g., doing groceries or laundry) of resource utilization was positively associated with depressive symptoms while taking dementia severity into account. This finding verified the correlation found by Lethin et al. (2018), who investigated the different facets of resource utilization among informal caregivers in a longitudinal design. It seemed that providing support with IADL was associated with a higher risk of disabilities for the caregiver later in life (Chan, Anstey, Windsor, & Luszcz, 2011). Although there was no significant association between time spent on helping the PwD with PADL and depressive symptoms in the caregiver, the possibility exists that time spent on PADL does not affect burden of the caregiver. Caregivers have a personal relationship with the PwD and form a large source of emotional support for the PwD. Time spent on helping the PwD with PADL possibly weakened the association between stress and psychological well-being of the caregiver later in life, because caregivers experienced gratitude from providing PADL (Chan et al., 2011).

Another possible explanation for not finding a significant influence of time spent on caregiving on mental well-being is explained in a study Bremer et al. (2015). After controlling for the dementia severity and living conditions, the influence of hours spent on providing care on health outcomes weakened and behavioral problems from the PwD emerged as a stronger predictor of a diminished subjective health of the caregiver than time spent on providing care. Complementing the findings from Bremer et al. (2015), is the finding by Lethin et al. (2017) that fewer neuropsychiatric symptoms in the PwD was an associated factor for caregiver psychological well-being and a predicting factor for increased caregiver psychological well-being. The fact that behavioral and/or neuropsychiatric symptoms of the PwD had a negative

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influence on caregiver well-being and dependency in ADL's, may prove an interesting factor to explore in future research, investigating the relationship between ADL, subjective well-being of the caregiver, and neuropsychiatric symptoms in the PwD even further and possibly explaining the varying results and findings in literature and in the current study. The current study took dementia severity into account, possibly weakening the influence of hours spent on care on health outcomes of the caregiver.

Contrary to expectations, the psychosocial intervention did not increase the sense of competence of the caregiver at follow-ups. Secondly, there were no differences in sense of competence between the intervention and control group. Furthermore, taking dementia severity and adherence to intervention sessions into account did not alter these outcomes. In the meta-analysis performed by Jütten et al. (2018), it was concluded that the sense of competence of the caregiver was higher in intervention groups than control groups at follow-up, contradicting the results of the current study. However, most studies included did not yield significant results and effect sizes for sense of competence were small (Jütten et al., 2018). Gossink et al. (2018) also stated an increased sense of competence in the intervention group. However, comparing the control and intervention groups after follow-up did not produce significant differences. A possible explanation for the discrepancy between the findings in the current study and in literature, could be found in a personal attribute of the caregiver. Educating caregivers about coping skills was successful in individual sessions when caregivers used an emotion-oriented coping style (Olazaran et al., 2010). The finding was replicated multiple times in literature, stating that improving sense of competence was especially effective when an emotion-based coping style was reduced to lighten the experienced burden in caregiving (Chiu, Wesson, & Sadavoy, 2013). Maintaining a supporting and adaptive caregiving coping strategy among caregivers, was associated with a higher sense of competence among caregivers (Stansfeld et al., 2018). Associated factors regarding sense of competence, like coping strategy at baseline could be taken into account in

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future research, shedding light on the possibly more complex connection between sense of competence and depressive symptoms in the caregiver.

Also contrary to expectations, the psychosocial intervention did not ameliorate depressive symptoms in the caregiver at follow-ups. Outcomes were not altered by taking dementia severity or adherence to intervention sessions into account. Moreover, there were no differences in outcomes between the intervention and control group. It was concluded that it is difficult to distinguish large enough effects in depressive symptoms among caregivers over time (Gossink et al., 2018). However, many studies did find a significant result pre- versus post-intervention, in comparison to a control group (Gaugler, Reese, & Mittelman, 2015). First, the possibility exists that in the current study, the sample sizes of the individual groups were too small to attain a good statistical power to detect differences, while controlling for covariates. Secondly, a systematic review concluded that the most effective interventions not only incorporated an educational component, but also a therapeutic component, e.g., cognitive behavioral therapy, where interventions delivered in a support group yielded the best results (Dickinson et al., 2017). The current study used an intervention mainly focused on psychoeducation. Future studies could examine different types of interventions to determine the most effective way to help informal caregivers.

Although the current study did not find significant effects of the psychosocial intervention on the outcome measures, it is informative to look retrospectively at other measures among caregivers. When examining the data from the evaluation forms, filled out after the intervention, it is encouraging to read that most participants still meet other participants and continued with the meetings in an informal way after the official intervention had ended. Maintaining a social network had a positive effect on ameliorating depressive symptoms among caregivers (Van der Lee et al., 2013). Improving knowledge of dementia through learning from fellow informal caregivers creates a sense of belonging, ameliorating the negative impact of stressful events with respect to caregiving (Carter, Monaghan, &

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Santin, 2020). Possibly, psychosocial interventions did not have an effect on the examined mental health outcomes in the current study, but these kind of interventions may help caregivers build a support group which leads to improving satisfaction with providing care and reducing stress (Elvish, Lever, Johnstone, Cawley, & Keady, 2013).

The current study had several limitations: Because of the many levels of the independent factors in the repeated measures MANOVA's, the sample sizes of the individual groups were small, therefore creating little statistical power to detect significant differences between groups. Future studies could focus on including enough dyads to make analyses with large enough groups to detect reliable effects. Secondly, during the data acquisition it was decided that question eight of the CES-D questionnaire ('I felt hopeful about the future') would not be asked to participants anymore. The experience was that most participants rated question eight of the CES-D negatively or could not answer it properly, because participants became emotional because of the degenerative nature of the disease. Therefore, item eight was deleted from further analyses of the questionnaire. This resulted in a total score of the CES-D with less clinical importance and needs to be carefully approached. Future studies could possibly look at different questionnaires for measuring depressive symptoms among caregivers (e.g.: The Beck Depression Inventory; Beck, Ward, Mendelson, Mock, & Erbaugh, 1961). Thirdly, only baseline dementia severity was taken into account during analyses. The scores on the GDS at follow-ups were not taken into account. However, changes in the severity of dementia could possibly varied between participants and had different influential changes on scores of the questionnaires if taken into account. Future studies would benefit from measuring it at a continuous level, for example, make use of the Mini-Mental State Examination (Kok & Verhey, 2002) for measuring dementia severity at scale level and including it in analyses as a control variable.

A strength of the current study was the recruitment of participants across the Netherlands, which culminates in a higher external validity and higher generalizability than

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recruitment in only one part or district. Secondly, although the intervention did not elicit significant improvements regarding the outcome measures, the intervention was very valuable and informative according to ratings by the participants. Thirdly, the importance of adherence to intervention sessions is understated in the current literature (Wu et al., 2019; Ying et al., 2018). Investigating the current psychosocial intervention while taking adherence to intervention sessions into account is an addition to the current state of the literature concerning interventions for improving subjective well-being of informal caregivers.

The results from the current study have potential implications for clinical practice. Training caregivers with respect to sense of competence, making them less vulnerable to the strain of subjective burden and creating more time for themselves, could pose as a valuable short intervention to improve personal managing skills. Secondly, in particular more time spent on helping the PwD with IADL by the caregiver was associated with more depressive symptoms among caregivers. Dementia case managers can be trained to detect and address the caregivers at risk for developing depressive symptoms because of high burden regarding IADL. These caregivers could be eligible for a short psychosocial intervention to address their needs and benefit from support groups and peer support.

Overall, the current study presents itself as one of a kind in the Netherlands by investigating the effects of a psychosocial intervention among a vulnerable group of participants across the Netherlands suffering from a debilitating and progressive disease longitudinally. The distinction made in resource utilization and the fact that sense of competence is a construct of interest in the future, proves helpful for creating clinical and practical implications. Although the current intervention did not elicit significant improvements in the investigated outcomes regarding the psychosocial intervention, the positive feedback with respect to the intervention sessions received from participants sounds promising. While a cure for dementia is still not in sight in the near future, creating more

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sense of belonging and relief for caregivers with help of support groups and peer support seems to be a fruitful and practicable temporary solution.

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