Caregivers' effects of augmented cognitive-behavioural therapy for post-stroke depressive symptoms in patients

Citation for published version (APA):

Kootker, J. A., van Heugten, C. M., Kral, B., Rasquin, S. M., Geurts, A. C., & Fasotti, L. (2019). Caregivers' effects of augmented cognitive-behavioural therapy for post-stroke depressive symptoms in patients: secondary analyses to a randomized controlled trial. *Clinical Rehabilitation*, 33(6), 1056-1065. [269215519833013]. <https://doi.org/10.1177/0269215519833013>

Document status and date:

Published: 01/06/2019

DOI:

[10.1177/0269215519833013](https://doi.org/10.1177/0269215519833013)

Document Version:

Publisher's PDF, also known as Version of record

Document license:

Taverne

Please check the document version of this publication:

- A submitted manuscript is the version of the article upon submission and before peer-review. There can be important differences between the submitted version and the official published version of record. People interested in the research are advised to contact the author for the final version of the publication, or visit the DOI to the publisher's website.
- The final author version and the galley proof are versions of the publication after peer review.
- The final published version features the final layout of the paper including the volume, issue and page numbers.

[Link to publication](#)

General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal.

If the publication is distributed under the terms of Article 25fa of the Dutch Copyright Act, indicated by the "Taverne" license above, please follow below link for the End User Agreement:

www.umlib.nl/taverne-license

Take down policy

If you believe that this document breaches copyright please contact us at:

repository@maastrichtuniversity.nl

providing details and we will investigate your claim.

Caregivers' effects of augmented cognitive-behavioural therapy for post-stroke depressive symptoms in patients: secondary analyses to a randomized controlled trial

Clinical Rehabilitation
2019, Vol. 33(6) 1056–1065
© The Author(s) 2019
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/0269215519833013
journals.sagepub.com/home/cre

Joyce A Kootker¹ , Caroline M van Heugten^{2,3}, Bart Kral⁴, Sascha MC Rasquin^{5,6}, Alexander C Geurts^{1,4} and Luciano Fasotti^{7,8}

Abstract

Objective: To investigate the concomitant effects of two patient-directed interventions for post-stroke depressive symptoms on caregivers' well-being.

Design: Secondary analyses of the results of a randomized controlled trial.

Subjects: Fifty caregivers of stroke patients receiving outpatient rehabilitation.

Interventions: Stroke patients and their caregivers were randomly allocated to either cognitive-behavioural therapy augmented with movement or occupational therapy ($n=23$) or computerized cognitive training ($n=27$) to alleviate depressive symptoms in patients.

Main measures: Emotional burden (Involvement Evaluation Questionnaire), practical burden (Caregiver Strain Index), mental health (General Health Questionnaire) and emotional complaints (Hospital Anxiety and Depression Scale).

Results: Caregivers of patients who received cognitive-behavioural therapy reported significantly higher mental health levels (mean difference (MD)=1.78, 95% confidence interval (CI)=0.43–3.13, $P=0.01$) and less worrying about patients' well-being (MD=1.9, 95% CI=0.56–3.24, $P<0.01$). In addition, there were positive time effects on the Involvement Evaluation Questionnaire for Brain Injury, particularly the subscales Worrying, Supervision and Tension.

¹Department of Rehabilitation, Donders Institute for Brain, Cognition and Behavior, Radboud University Medical Center, Nijmegen, The Netherlands

²Department of Neuropsychology and Psychopharmacology, Faculty of Psychology and Neuroscience, Maastricht University, Maastricht, The Netherlands

³Department of Psychiatry and Neuropsychology, Faculty of Health, Medicine and Life Sciences, School for Mental Health and Neuroscience, Maastricht University, Maastricht, The Netherlands

⁴Sint Maartenskliniek, Nijmegen, The Netherlands

⁵Adelante Rehabilitation Center, Hoensbroek, The Netherlands

⁶Department of Rehabilitation Medicine, CAPHRI, Maastricht University Medical Center, Maastricht, The Netherlands

⁷Klimmendaal, Rehabilitation Center, Arnhem, The Netherlands

⁸Donders Institute for Brain, Cognition and Behavior, Radboud University, Nijmegen, The Netherlands

Corresponding author:

Joyce A Kootker, Department of Rehabilitation, Donders Institute for Brain, Cognition and Behavior, Radboud universitair medisch centrum, Postbus 9101, 6500 HB Nijmegen (898), Reinier Postlaan 4 (route 932), Nijmegen, The Netherlands.
Email: joyce.kootker@han.nl

Conclusion: The results suggest that augmented cognitive-behavioural therapy aimed at improving patients' emotional, behavioural and social functioning positively affects some aspects of caregivers' well-being.

Keywords

Stroke, caregivers, depression, randomized controlled trial, secondary analyses

Date received: 4 October 2017; accepted: 31 January 2019

Introduction

Stroke survivors are frequently left with lasting problems in the chronic phase of their illness. Their spouses are often obliged to adopt a caregiver role, as the patients may still need support in several domains of daily life. The psychological sequelae of stroke, such as depressive symptoms in the stroke patient, appear to be a 'significant challenge' for caregivers' emotional stability.¹ Such a challenge may lead to high prevalence rates of depression, anxiety and lower life satisfaction in caregivers.²⁻⁴ Moreover, caregivers often experience high levels of emotional burden, such as concern, worries and feelings of responsibility for the patients' well-being.¹ Also, restrictions in their societal participation occur that may lead to social isolation and limited support from family and friends.⁵ Conversely, the well-being of caregivers may also influence the well-being of patients. Research even showed that depressive symptoms in caregivers may worsen the post-stroke depressive symptoms in patients and negatively affect patients' rehabilitation and well-being.^{6,7}

A small number of studies have investigated the effect of interventions specifically aimed at the caregivers of patients with stroke,⁸ but there are no clinical practice guidelines yet.^{9,10} In their Brain Integration Programme study, Geurtsen et al.¹¹ showed that interventions for patients with acquired brain injury can have a concomitant positive effect on caregivers' emotional burden and mental health.

We recently studied the effects of an augmented cognitive-behavioural therapy compared to computerized cognitive training for post-stroke depressive symptoms in a randomized controlled trial.¹² The cognitive-behavioural therapy was aimed at ameliorating patients' emotional burden, their

behavioural as well as their social limitations, and was complemented ('augmented') with activity-oriented goal attainment supported by a movement of occupational therapist.¹³ Interestingly, both patient groups showed an equal reduction of depressive symptoms over time. As opposed to computerized cognitive training, cognitive-behavioural therapy was directed at cognitive and behavioural change, which may benefit caregivers' well-being as well.¹ Therefore, we investigated if caregivers would report differences in well-being after each of the interventions, providing directions for the clinical application of either one of the interventions. We present secondary analyses from the randomized controlled trial, regarding caregivers' practical and emotional burden, mental health and emotional complaints. We expected that caregivers of stroke patients receiving the augmented cognitive-behavioural therapy would show a higher level of well-being.

Methods

Caregivers of patients experiencing depressive symptoms post stroke and participating in a randomized controlled trial, as part of the Restore4Stroke study in the Netherlands (Clinical Trial Registration: NTR2999, Dutch Trial Register), were eligible for participation. For methodological details of the study design, we refer to a previous publication.¹⁴ Patients were randomly assigned either to the experimental augmented cognitive-behavioural therapy or to computerized cognitive training (Cogniplus) as a control intervention. For details of the augmented cognitive-behavioural treatment protocol, we refer to another publication.¹⁵ Both interventions lasted four months.

Caregivers were considered eligible if they had a relationship with the patient at the moment of inclusion, were at least 18 years old, and had adequate knowledge of the Dutch language. In the present study, all participants were patients' spouses.

Stratified block randomization (block size 4) was performed by a randomization programme to randomize patients and caregivers to each group.¹⁴ After every patient assessment session, caregivers received questionnaires in hardcopy booklets which they returned by post. If necessary, they were reminded by phone in case the booklets were not returned within two weeks. All data were collected by a blinded research assistant.

Socio-demographic data were collected at inclusion: caregivers' age, gender, education level, marital status and financial situation. In addition, caregivers answered questions about the type of relationship and frequency of contact with the patient, and about the presence of children in their household. Caregiver outcome data were collected at the same time points as patient outcome data were obtained at enrolment (T0: before randomization), directly after the intervention (T1: after four months) and at four (T2) and eight months follow-up (T3). The study was approved by the Committee on research involving Human Subjects, Nijmegen, The Netherlands, and by the local committees of all participating institutes. Written informed consent was collected from all caregivers at enrolment.

Emotional burden was measured with the Involvement Evaluation Questionnaire for Brain Injury (IEQ-BI).^{9,16} This scale is a 31-item self-report questionnaire in Dutch, covering four subscales: Tension, Supervision, Worrying and Urging.¹⁶ All subscales were scored on a five-point Likert-type scale. Lower scores indicate lower levels of caregiver burden. The Involvement Evaluation Questionnaire has shown good internal consistency, discriminant validity and responsiveness.¹⁷

The General Health Questionnaire (GHQ) is a 12-item self-report instrument and was used for the measurement of mental health with a Likert-type-scoring method.¹⁸ Lower scores indicate that caregivers experience lower mental health problems.¹⁹

This scale has shown good internal consistency¹⁹ and test-retest reliability.²⁰

The Caregiver Strain Index (CSI) was used as a brief instrument to identify strain on caregivers.²¹ It contains 13 items measuring the levels of stress experienced by caregivers. Questions can be answered with yes (1) or no (0). A score ≥ 7 indicates the existence of caregiver strain. The CSI has shown good internal consistency²¹ and test-retest reliability.²²

Depressive and anxiety symptoms in caregivers were measured with the Hospital Anxiety and Depression Scale (HADS) which consists of 14 items. Seven items constitute the subscale Depression (HADS-D), while the other seven items form the subscale Anxiety (HADS-A).²³ All items were rated on a four-point scale ranging from 0 to 3. A score 3 indicates the highest experienced level of emotional distress. The HADS has shown good internal consistency²⁴ and good test-retest reliability.²⁵

To analyse group differences for each of the outcome measures, we used linear mixed models for repeated measures with adjustment for baseline values.^{12,14} Analyses were performed using the intention-to-treat principle. The dependent variables were the outcome measures (i.e. Involvement Evaluation Questionnaire total; subscales Supervision, Tension, Worrying and Urging; CSI; GHQ; Hospital anxiety and Depression Subscale Depression and subscale anxiety). The independent variables were Treatment (cognitive-behavioural therapy versus computerized cognitive training) and Time (four time points, T0–T3). Treatment and Time effects are presented as mean differences (MDs) with 95% confidence intervals (CIs). The level of significance was set at 0.05. Analyses were performed with SAS 9.2 for Windows and IBM SPSS Statistics 20 for Windows. Data analysis was performed by an independent statistician who was blinded for group allocation.

Results

Caregivers of 50 patients were included in the present study, of whom 23 were related to a patient who received cognitive-behavioural therapy. A

Figure 1. Flow chart of caregivers who participated in the randomized controlled trial.

flow chart is presented in Figure 1. The socio-demographic and psychological characteristics at baseline are displayed for each group in Table 1. Due to patient dropout, the data of four caregivers at four-month follow-up and of seven caregivers at eight-month follow-up were lost. The post-treatment data of six other caregivers were lost, either because their partners did not complete the treatment or because they were unwilling to continue. Table 2 shows the observed mean values (SD) for each of the outcome measures for both treatment groups at the four time points.

Table 3 shows the overall treatment effects on all outcome measures as well as the post hoc analyses per point of measurement corrected for baseline values. The cognitive-behavioural therapy group showed better scores compared to the computerized cognitive training on the GHQ (see Supplemental Figure 1). Post hoc analyses showed significant group differences directly post-treatment and at four months post-treatment, but no longer at eight months follow-up (see Table 3). As for the IEQ-BI, the cognitive-behavioural therapy

showed better scores than the computerized cognitive training on the subscale Worrying (see Figure 2 for observed means). Post hoc analyses showed significant group differences only at eight months post-treatment (see Table 3). No significant treatment effects were found for any of the other outcomes.

Both groups improved over time on the IEQ-BI on its total score (MD=3.55, 95% CI=0.38–6.72, $P=0.03$), the subscales Supervision (MD=0.54, 95% CI=0.01–1.08, $P=0.05$), Worrying (MD=1.18, 95% CI=0.11–2.24, $P=0.03$) and Tension (MD=1.71, 95% CI=0.43–3.00, $P=0.01$). The other parameters did not show any significant time effects.

Discussion

This study showed that caregivers reported improved standards of mental health and lower levels of worrying when their spouses received cognitive-behavioural therapy compared to computerized cognitive training. Yet, the mechanisms explaining

Table 1. Caregivers' demographics and baseline characteristics.

Characteristics	Cognitive-behavioural therapy		Computerized cognitive training	
	N	Mean (SD)/n (%)	N	Mean (SD)/n (%)
Sex	23		27	
Men		8 (34.8)		10 (37)
Women		15 (65.2)		17 (63)
Age (years)	23	59.8 (12.5)	27	59.6 (10.2)
Educational level ^a	23		27	
High		9 (39.1)		2 (7.4)
Low		14 (60.9)		25 (92.6)
IEQ-BI				
Total (0–108)	22	20.6 (11.4)	24	21.1 (11.1)
Tension (0–36)	24	7.5 (4.7)	23	7.2 (3.9)
Supervision (0–24)	24	1.7 (2.2)	23	2.0 (2.4)
Worrying (0–24)	27	6.6 (4.3)	22	6.7 (3.6)
Urging (0–32)	24	6.7 (4.7)	23	7.3 (5.6)
GHQ (0–12)	26	3.8 (3.7)	23	2.7 (3.3)
CSI (0–13)	27	6.8 (3.0)	23	6.0 (3.2)
HADS				
Depression (0–21)	27	5.1 (3.8)	23	4.6 (3.1)
Anxiety (0–21)	27	6.3 (4.1)	23	6.9 (3.5)

IEQ-BI Total: Involvement and Evaluation Questionnaire–Brain Injury Total (0–108); IEQ-BI Tension: Involvement and Evaluation Questionnaire–Brain Injury Tension subscale (0–36); IEQ-BI Supervision: Involvement and Evaluation Questionnaire–Brain Injury Supervision subscale (0–24); IEQ-BI Worrying: Involvement and Evaluation Questionnaire–Brain Injury Worrying subscale (0–24); IEQ-BI Urging: Involvement and Evaluation Questionnaire–Brain Injury Urging subscale (0–32); GHQ: General Health Questionnaire (0–12); CSI: Caregiver Strain Index (0–13); HADS: Hospital Anxiety and Depression Scale.

^aBased on education system of Verhage.

this result are not fully understood. The findings suggest that an intervention for reducing depressive symptoms post stroke may indeed be able to influence caregivers' well-being.^{1,26} Although these effects were small, they are remarkable since the results from this trial did not show differential intervention effects in terms of patient-related outcomes. That is, depressive symptoms of patients decreased over time regardless of the type of intervention they had received.¹²

Why does it appear that caregivers benefit if their spouse received the cognitive-behavioural therapy intervention? The lack of group differences in patient-related outcomes let us question whether we had found a non-specific (e.g. Hawthorne) effect, although both interventions brought about a similar level of 'attention'.¹²

Indeed, the two interventions were similar in that they were weekly administered to the patient

by a therapist or assistant in a rehabilitation centre.^{12,13} Yet, the interventions differed in their content. Whereas the cognitive-behavioural therapy group received a psychological treatment (complemented by a behavioural intervention in which patients worked on their activity-oriented goals with a movement or occupational therapist¹³), the computerized cognitive training group merely received supervised cognitive training modules on a computer. Another difference between interventions was that the cognitive-behavioural therapy augmented with specific goal attainment led to a vast amount of homework, which was not the case for computerized cognitive training.

Although the caregivers were not directly addressed in either intervention, a potential reason for the differential effects on caregivers in the present study may be related to interaction in the home situation. Having a partner that commits to homework to

Table 2. Observed means (SD) of the caregiver outcomes by point of measurement by group.

Outcomes	Baseline		Post-treatment		Four-month follow-up		Eight-month follow-up	
	N	Mean (SD)	N	Mean (SD)	N	Mean (SD)	N	Mean (SD)
IEQ-BI Total								
CBT	22	20.6 (11.4)	17	17.9 (15.5)	14	17.3 (15.5)	15	11.0 (17.9)
CCT	24	21.08 (11.1)	24	18.7 (12.8)	20	17.9 (13.9)	15	15.9 (13.4)
IEQ-BI Tension								
CBT	23	7.5 (4.7)	18	6.9 (6.7)	15	5.7 (6.8)	16	5.1 (4.9)
CCT	24	7.2 (3.9)	24	7.1 (5.2)	20	6.6 (5.4)	15	5.3 (4.7)
IEQ-BI Supervision								
CBT	23	1.7 (2.2)	18	1.3 (1.8)	15	1.4 (2.4)	16	0.9 (1.2)
CCT	24	2.0 (2.4)	24	1.5 (1.7)	20	1.3 (1.3)	15	0.7 (1.0)
IEQ-BI Worrying								
CBT	22	6.6 (4.3)	18	4.9 (4.8)	16	4.8 (4.8)	16	3.6 (3.1)
CCT	27	6.6 (3.6)	24	6.2 (4.3)	21	6.1 (4.8)	16	5.1 (3.8)
IEQ-BI Urging								
CBT	23	6.7 (4.7)	17	6.3 (5.4)	15	7.3 (5.8)	16	3.8 (2.5)
CCT	24	7.3 (5.6)	24	5.8 (4.7)	20	5.8 (5.8)	15	6.3 (6.1)
GHQ								
CBT	23	3.8 (3.7)	17	2.9 (3.7)	15	2.3 (2.6)	17	2.3 (2.6)
CCT	26	2.7 (3.3)	22	4.3 (4.0)	21	4.7 (4.5)	16	3.3 (3.6)
CSI								
CBT	23	6.8 (3.0)	20	5.5 (3.9)	19	5.1 (3.9)	17	5.8 (3.4)
CCT	27	6.0 (3.2)	24	6.1 (3.2)	21	5.8 (3.1)	16	5.6 (3.1)
HADS-D								
CBT	23	5.1 (3.8)	18	5.4 (3.8)	16	4.9 (4.0)	17	5.1 (4.1)
CCT	27	4.6 (3.1)	24	5.9 (4.3)	21	5.9 (3.7)	16	4.9 (3.7)
HADS-A								
CBT	23	6.3 (4.1)	18	6.6 (4.5)	16	6.0 (4.4)	17	5.6 (4.3)
CCT	27	6.9 (3.5)	24	6.9 (4.7)	21	7.1 (4.4)	16	6.2 (3.9)

IEQ-BI Total: Involvement and Evaluation Questionnaire–Brain Injury Total (0–108); CBT: Cognitive–Behavioural Therapy; CCT: Computerized Cognitive Training; IEQ-BI Tension: Involvement and Evaluation Questionnaire–Brain Injury Tension subscale (0–36); IEQ-BI Supervision: Involvement and Evaluation Questionnaire–Brain Injury Supervision subscale (0–24); IEQ-BI Worrying: Involvement and Evaluation Questionnaire–Brain Injury Worrying subscale (0–24); IEQ-BI Urging: Involvement and Evaluation Questionnaire–Brain Injury Urging subscale (0–32); GHQ: General Health Questionnaire (0–12); CSI: Caregiver Strain Index (0–13); HADS-D: Hospital Anxiety and Depression Scale–Depression subscale (0–21); HADS-A: Hospital Anxiety and Depression Scale–Anxiety subscale (0–21).

achieve activity-oriented goals may have had concomitant positive effects on the caregiver. As providing such homework can easily be added to any type of psychological intervention, future research should take into account the concomitant effects of patient-directed interventions on caregivers' well-being, particularly when such interventions include homework to achieve activity-related goals. Caregivers may

also play a supportive role in the implementation and effect of home-based interventions.

The chronicity of patients' impairments following stroke may play a role in the absence of other effects on the caregivers.²⁷ Although emotional complaints of patients improved after treatment, their physical and cognitive impairments following stroke were still the same. These remaining impairments

Table 3. Estimated MDs (95% CIs) between groups at all time points using linear mixed model for repeated measurements while adjusting for baseline values.

Outcomes	Post-treatment		Four-month follow-up		Eight-month follow-up		Overall	
	MD (95% CI)	P	MD (95% CI)	P	MD (95% CI)	P	95% CI	P
IEQ-BI Total								
CBT	2.11 (−3.02 to 7.23)	0.41	1.40 (−3.92 to 6.71)	0.60	5.11 (−0.84 to 1.06)	0.09	3.11 (−1.3 to 7.37)	0.74
CCT	Reference		Reference		Reference		Reference	
IEQ-BI Tension								
CBT	0.25 (−2.65 to 3.14)	0.86	0.46 (−2.46 to 3.37)	0.76	0.61 (−1.83 to 3.06)	0.62	0.35 (−2.02 to 2.71)	0.77
CCT	Reference		Reference		Reference		Reference	
IEQ-BI Supervision								
CBT	0.30 (−0.45 to 1.06)	0.42	−0.07 (−1.03 to 0.89)	0.89	0.31 (−0.39 to 1.00)	0.38	0.28 (−0.24 to 0.80)	0.59
CCT	Reference		Reference		Reference		Reference	
IEQ-BI Worrying								
CBT	1.60 (−0.22 to 3.42)	0.08	1.25 (−0.42 to 2.93)	0.14	2.64 (0.83 to 4.45)	<0.01	1.90 (0.56 to 3.24)	0.01
CCT	Reference		Reference		Reference		Reference	
IEQ-BI Urging								
CBT	0.42 (−1.38 to 2.22)	0.64	−0.30 (−2.51 to 1.91)	0.79	1.14 (−1.72 to 4.00)	0.43	0.55 (−1.05 to 2.16)	0.80
CCT	Reference		Reference		Reference		Reference	
GHQ								
CBT	1.82 (0.20 to 3.44)	0.03	2.60 (0.34 to 4.87)	0.02	1.59 (−0.25 to 3.43)	0.09	1.78 (0.43 to 3.13)	0.01
CCT	Reference		Reference		Reference		Reference	
CSI								
CBT	1.18 (−0.29 to 2.66)	0.11	1.04 (0.65 to 2.72)	0.22	0.47 (−1.22 to 2.16)	0.58	0.91 (−0.38 to 2.19)	0.16
CCT	Reference		Reference		Reference		Reference	
HADS-D								
CBT	0.93 (−0.62 to 2.48)	0.23	1.27 (−0.28 to 2.82)	0.11	0.87 (−0.75 to 2.49)	0.29	1.04 (−0.23 to 2.30)	0.11
CCT	Reference		Reference		Reference		Reference	
HADS-A								
CBT	0.10 (−1.72 to 1.93)	0.91	0.03 (−2.06 to 2.12)	0.98	0.28 (−1.38 to 1.94)	0.74	0.20 (−1.4 to 1.89)	0.96
CCT	Reference		Reference		Reference		Reference	

MDs: mean differences; CIs: confidence intervals; IEQ-BI Total: Involvement and Evaluation Questionnaire–Brain Injury Total (0–108); CBT: Cognitive-Behavioural Therapy; CCT: Computerized Cognitive Training; IEQ-BI Tension: Involvement and Evaluation Questionnaire–Brain Injury Tension subscale (0–36); IEQ-BI Supervision: Involvement and Evaluation Questionnaire–Brain Injury Supervision subscale (0–24); IEQ-BI Worrying: Involvement and Evaluation Questionnaire–Brain Injury Worrying subscale (0–24); IEQ-BI Urging: Involvement and Evaluation Questionnaire–Brain Injury Urging subscale (0–32); GHQ: General Health Questionnaire (0–12); CSI: Caregiver Strain Index (0–13); HADS-D: Hospital Anxiety and Depression Scale–Depression subscale (0–21); HADS-A: Hospital Anxiety and Depression Scale–Anxiety subscale (0–21).

Figure 2. IEQ Worrying score (0–24). Differences between caregivers in cognitive-behavioural therapy group and computerized cognitive training group: T0=at inclusion, T1= post-treatment, T2= four-month post-treatment and T3= eight-month post-treatment.

continued to limit patients in the performance of daily activities and to restrict them in their social participation. Hence, caregivers retained a ‘caregiver role’ and their practical burden remained unchanged. This is a relevant consideration, as particularly the CSI is sensitive to practical burden which may explain why it did not show any change. Our pattern of results is congruent with the notion of Geurtsen et al.⁸ and Davis et al.²⁸ that practical burden, mental health and emotional burden are different constructs.^{11,29}

Limitations

This study has several limitations. First, the analyses that were performed were pre-planned and secondary to the patient trial. Therefore, the analyses were not adjusted for multiple testing.¹² Pre-planning of these analyses reduced the potential risk of an accidental finding. Second, the relatively small number of participants was due to the fact that this was a secondary analysis as well. Therefore, our results should be interpreted with caution and need replication including caregiver well-being as a primary outcome. Third, the absence of any effects

on caregivers’ emotional complaints could be a consequence of using the HADS which was originally developed as a questionnaire for use in patients with somatic co-morbidity. As a consequence, the items of this questionnaire have not been validated to identify and monitor emotional complaints in a ‘healthy’ caregiver group.³⁰

Implications for clinical practice and future research

Our results suggest that augmented, activity-oriented cognitive-behavioural therapy aimed at improving stroke patients’ emotional, behavioural and social functioning may positively influence relevant aspects of caregivers’ well-being.

An alternative, current perspective on alleviating caregiver burden is to focus interventions directly on the problems and needs of the caregivers themselves.²⁹ Therefore, future intervention studies directed at the improvement of the emotional consequences after stroke need to take into account the caregivers as relevant targets for assessment, irrespective of whether the intervention itself is primarily aimed at patients or their caregivers. These studies should then

focus on practical burden, mental health and emotional burden when impact on caregivers is assessed. Evidence for the effectiveness of specific interventions primarily directed at caregivers of stroke patients is still lacking.^{8,29} Currently, the effects of an intervention for caregivers of stroke survivors, taking into account both practical burden and mental health, are being investigated.⁹

Clinical message

- Caregivers may also experience benefits in terms of well-being when their spouse receives cognitive-behavioural therapy for depressive symptoms after stroke.

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The Restore4Stroke project was funded by VSB Fund/ZonMw (#98000004).

Supplemental material

Supplemental material for this article is available online.

ORCID iD

Joyce A Kootker <https://orcid.org/0000-0002-8717-2352>

References

- Cameron JI, Cheung AM, Streiner DL, et al. Stroke survivor depressive symptoms are associated with family caregiver depression during the first 2 years poststroke. *Stroke* 2011; 42(2): 302–306.
- Gillen R, Tennen H, Affleck G, et al. Distress, depressive symptoms, and depressive disorder among caregivers of patients with brain injury. *J Head Trauma Rehabil* 1998; 13(3): 31–43.
- Mintz MC, van Horn KR and Levine MJ. Developmental models of social cognition in assessing the role of family stress in relatives' predictions following traumatic brain injury. *Brain Inj* 1995; 9(2): 173–186.
- Smeets SM, van Heugten CM, Geboers JF, et al. Respite care after acquired brain injury: the well-being of caregivers and patients. *Arch Phys Med Rehabil* 2012; 93(5): 834–841.
- McCullagh E, Brigstocke G, Donaldson N, et al. Determinants of caregiving burden and quality of life in caregivers of stroke patients. *Stroke* 2005; 36(10): 2181–2186.
- Carnwath TC and Johnson DA. Psychiatric morbidity among spouses of patients with stroke. *Br Med J (Clin Res Ed)* 1987; 294(6569): 409–411.
- Scholte op Reimer WJ, de Haan RJ, Pijnenborg JM, et al. Assessment of burden in partners of stroke patients with the sense of competence questionnaire. *Stroke* 1998; 29(2): 373–379.
- Visser-Meily A, van Heugten C, Post M, et al. Intervention studies for caregivers of stroke survivors: a critical review. *Patient Educ Couns* 2005; 56(3): 257–267.
- Krieger T, Feron F and Dorant E. Developing a complex intervention programme for informal caregivers of stroke survivors: the caregivers' guide. *Scand J Caring Sci* 2017; 31(1): 146–156.
- Legg LA, Quinn TJ, Mahmood F, et al. Non-pharmacological interventions for caregivers of stroke survivors. *Cochrane Database Syst Rev* 2011(10): CD008179.
- Geurtsen GJ, van Heugten CM, Martina JD, et al. Three-year follow-up results of a residential community reintegration program for patients with chronic acquired brain injury. *Arch Phys Med Rehabil* 2012; 93(5): 908–911.
- Kootker JA, Rasquin SM, Lem FC, et al. Augmented cognitive behavioral therapy for poststroke depressive symptoms: a randomized controlled trial. *Arch Phys Med Rehabil* 2017; 98(4): 687–694.
- Kootker JA, Rasquin SM, Smits P, et al. An augmented cognitive behavioural therapy for treating post-stroke depression: description of a treatment protocol. *Clin Rehabil* 2015; 29(9): 833–843.
- Kootker JA, Fasotti L, Rasquin SM, et al. The effectiveness of an augmented cognitive behavioural intervention for post-stroke depression with or without anxiety (PSDA): the Restore4Stroke-PSDA trial. *BMC Neurol* 2012; 12: 51.
- Van Wijngaarden B, Schene AH, Koeter M, et al. Caregiving in schizophrenia: development, internal consistency and reliability of the Involvement Evaluation Questionnaire – European Version. EPSILON Study 4. European psychiatric services: inputs linked to outcome domains and needs. *Br J Psychiatry Suppl* 2000; 177(39): s21–s27.
- Geurtsen GJ, Martina JD, Van Heugten CM, et al. A prospective study to evaluate a new residential community reintegration programme for severe chronic brain injury: the Brain Integration Programme. *Brain Inj* 2008; 22(7–8): 545–554.

17. Geurtsen GJ, Meijer R, van Heugten CM, et al. Experienced emotional burden in caregivers: psychometric properties of the Involvement Evaluation Questionnaire in caregivers of brain injured patients. *Clin Rehabil* 2010; 24(10): 935–943.
18. Goldberg D. Use of the General Health Questionnaire in clinical work. *Br Med J (Clin Res Ed)* 1986; 293(6559): 1188–1189.
19. Politi PL, Piccinelli M and Wilkinson G. Reliability, validity and factor structure of the 12-item General Health Questionnaire among young males in Italy. *Acta Psychiatr Scand* 1994; 90(6): 432–437.
20. Piccinelli M, Bisoffi G, Bon MG, et al. Validity and test-retest reliability of the Italian version of the 12-item General Health Questionnaire in general practice: a comparison between three scoring methods. *Compr Psychiatry* 1993; 34(3): 198–205.
21. Robinson BC. Validation of a Caregiver Strain Index. *J Gerontol* 1983; 38(3): 344–348.
22. Ugur O and Fadiloglu C. ‘Caregiver Strain Index’ validity and reliability in Turkish society. *Asian Pac J Cancer Prev* 2010; 11(6): 1669–1675.
23. Zigmond AS and Snaith RP. The Hospital Anxiety and Depression Scale. *Acta Psychiatr Scand* 1983; 67(6): 361–370.
24. Mykletun A, Stordal E and Dahl AA. Hospital Anxiety and Depression (HAD) scale: factor structure, item analyses and internal consistency in a large population. *Br J Psychiatry* 2001; 179: 540–544.
25. Spinhoven P, Ormel J, Sloekers PP, et al. A validation study of the Hospital Anxiety and Depression Scale (HADS) in different groups of Dutch subjects. *Psychol Med* 1997; 27(2): 363–370.
26. Marsh NV, Kersel DA, Havill JH, et al. Caregiver burden at 1 year following severe traumatic brain injury. *Brain Inj* 1998; 12(12): 1045–1059.
27. Wolfe CD. The impact of stroke. *Br Med Bull* 2000; 56(2): 275–286.
28. Davis LC, Sander AM, Struchen MA, et al. Medical and psychosocial predictors of caregiver distress and perceived burden following traumatic brain injury. *J Head Trauma Rehabil* 2009; 24(3): 145–154.
29. Brereton L, Carroll C and Barnston S. Interventions for adult family carers of people who have had a stroke: a systematic review. *Clin Rehabil* 2007; 21(10): 867–884.
30. Herrmann C. International experiences with the Hospital Anxiety and Depression Scale – a review of validation data and clinical results. *J Psychosom Res* 1997; 42(1): 17–41.