



## Review

## Factors determining the impact of care-giving on caregivers of elderly patients with dementia. A systematic literature review

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## ABSTRACT

**Introduction:** Dementia caregivers suffer a considerable care burden. More than in comparable groups of caregivers or peers, they are confronted with feelings of depression and decreased physical health. Although many studies are set up to determine the link between the stressors in dementia care-giving and the impact on the family caregiver, the results remained inconclusive. Others, depression in caregivers remains the main cause of a premature or acute ending of home care.

**Method:** The aim of this systematic literature review was to analyse what factors determine the development of depression in caregivers of elderly patients with dementia. Depression was taken as primary outcome as it is shown to be the main reason for caregivers to abandon home care.

**Results:** Depression occurs in one in three of caregivers and it occurs more frequently in those who care for patients with dementia than in caregivers of patients with other chronic illnesses.

**Conclusion:** Caregiver characteristics rather than objective care needs of the patients tend to be responsible for the onset of depression. Future research should concentrate on demonstrating links between negative feelings in caregivers and the way the care situation evolves. This can have important implications in home care support.

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## 1. Introduction

Caring for elderly patients in their home environment seriously burdens all persons involved [1]. Caregivers of home-dwelling elderly patients with dementia report more physical and psychosocial burden than their peers of the same age and in the same living circumstances. Research shows that these caregivers suffer from depression more often, perceive their workload as heavier and are in less good health, taking more medication than their peers. Moreover, caregivers report feeling isolated and experiencing pressure on their socio-economic life.

At the root of this psychosocial and physical burden lies the invasive character of dementia. The disease not only has an invasive effect on the patient, but when a member of the family shows signs of dementia role patterns and relationships in the patient's home environment are also thoroughly shaken and rearranged [2,3].

The aim of this systematic literature review was to analyse what factors determine the development of depression in caregivers of elderly patients with dementia. Depression was taken as primary outcome as it is shown to be the main reason for caregivers to abandon home care [4,5].

## 2. Methods

### 2.1. Literature

We searched for studies using Medline and Embase, Psyclit, Cinahl, EBM Reviews (Cochrane Database of Systematic Reviews, American College of Physicians Journal Club, Database of Abstracts of Reviews of Effects, Cochrane Controlled Trials Register) and publications from the grey circuit (primarily graduate theses and policy reports). Because society has undergone important changes both in ways that people live together and in professional care provision over the last few decades, the search was limited to the publications of the last 15 years (1990–2009). We consulted the table of contents of important local journals in psychiatry, neurology, internal medicine, sociology and nursing over the same period (*Acta Neurologica Belgica*, *Archives of Public Health*, *HANU*, *Huisarts en Wetenschap*). Lists of references from the articles retained were screened for additional material.

### 2.2. Definitions

The search for relevant literature was hampered from the start due to the lack of a clear-cut definition of 'caregiver' [6]. A first batch of articles resulting from a search on 'primary caregiver' appeared to contain studies with informal carers of a residential elderly patient with dementia, formal volunteers caring for home-dwelling elderly with dementia, and professional family help. The term 'home nursing/care' yielded similar results.

From a summary of the literature, the Flemish Home Care Decree 1998 and field experience we distilled the following definition: a caregiver is any person who cares for a needy person in his or her direct environment on a regular basis and more or less as a matter of course. The caregiver is related (family, friends, neighbours, ...) to the person receiving care and is not a professional caregiver.

It was decided to limit the review to caregivers who met the criteria in this definition.

### 2.3. Selection of articles

The study population consisted of caregivers and their family member with dementia. The type of publication was restricted to intervention studies and observational research including cross-sectional studies. For a study to be included, the primary outcome 'depression' had to be measured by means of validated tools. Depending on the subgroup analysis we used socio-demographic characteristics and the presence of 'subjective workload' as independent variables. To be included in our analyses, subjective workload in a study also had to be measured by means of validated tools.

We used the following search and Mesh terms: dementia, home care, family caregiver, home nursing. Search terms were truncated for "home care\*" and "home nurse\*".

### 2.4. Quality judgment

The collected data were systematically described and qualitatively assessed according to the Delphi criteria without statistical analysis [7]. This checklist, developed by the Delphi Consensus Group, contains a list of generic criteria to assess the quality of randomized controlled trials. Although not fully appropriate for using in cross-sectional or follow up studies, this checklist was considered to be of best value as guideline for quality assessment.

All articles were evaluated on the basis of the following items: formulation of outcome measures, study design, population and source. Articles were coded on date of publication, authors, sample size and features, rating scales and presentation of the final results.

When the quality of a report was debatable, a discussion between several independent reviewers was conclusive for inclusion or exclusion of the concerned article.

### 2.5. Analysis

The meta-analysis was carried out by means of Review Manager Software version 4.2. Because of the high heterogeneity of the study population we opted for subgroup analyses. A meta-regression analysis was not possible because the variation in outcome measures was too high.

Study and control population were grouped on the basis of the proposed subgroup analyses. In these analyses odds ratios with confidence intervals and mean values with standard deviations were indicated. Where necessary, any missing values were added by means of conversion tables for *t*-values or with manual calculations. Odds ratios were fed into Review manager in logarithmic values via the "generic inverse method". With this method, effect size can be calculated with effect estimates and standard error. Mean values were converted into estimates with their standard error and then analysed together with odds ratios.

Where odds ratios were available, only bivariate outcomes were used and not the controlled odd ratios. Studies of which only regression coefficients were known were not included in the analyses.

Heterogeneity was tested by means of the  $I^2$ -score. A score higher than 50% was considered as an analysis with important heterogeneity. For statistical pooling a fixed effect model was used in analyses with homogeneous outcomes. To measure heterogeneity a random effect model was used.

**Table 1**  
Search strategy and outcome.

Search terms	Source	Limits	Amount of inclusions/total
Dementia, caregivers	All EBM reviews	No	343
	Ovid Medline 1990–2009	CT, CCT, evaluation studies, multicenter study, RCT, validation studies	300
Dementia, home care	All EBM reviews	No	57
	Ovid Medline 1990–2009	CT, CCT, evaluation studies, multicenter study, RCT, validation studies	36
Dementia, home nursing	All EBM reviews	No	41
	Ovid Medline 1990–2009	CT, CCT, evaluation studies, multicenter study, RCT, validation studies	30
Dementia, mantelzorgers	Doctoral thesis	No	7
Handsearching demencie, mantelzorgers	Acta Neurologica Belgica, Archives of Public Health, HANU, Huisarts en Wetenschap	No	3

**3. Results**

3.1. Characteristics of the individual studies

3.1.1. Selection of articles

Table 1 gives an overview of the initial batch of articles (n = 817) resulting from a search for which there was only a limitation on publication date (1990–2009) and on type of publication (interventional study, observational study).

After selecting articles based on title and abstract and after removing doubles we retained a total of 207 articles from the databases consulted (Fig. 1).

A manual search through reference lists and journals yielded an extra 10 studies, of which only 1 was new. In an additional search reviews (n = 26) and meta-analyses (n = 1) were checked manually for missing publications. Of the 207 articles retained for our review, 30 were eligible for inclusion (Table 2). For this meta-analysis only 14 articles appeared to contain sufficient and usable data.

Depression, quantified by means of a validated tool, was described in all articles included as a depressed state of mind and emotional stress. Recruitment and inclusion of patients and caregivers occurred in various ways. Most researchers used an existing database for epidemiological or intervention studies. Participants

were mainly recruited from (semi) professional contexts such as memory clinics, day care centers, self-help groups and via the local press or via carers.

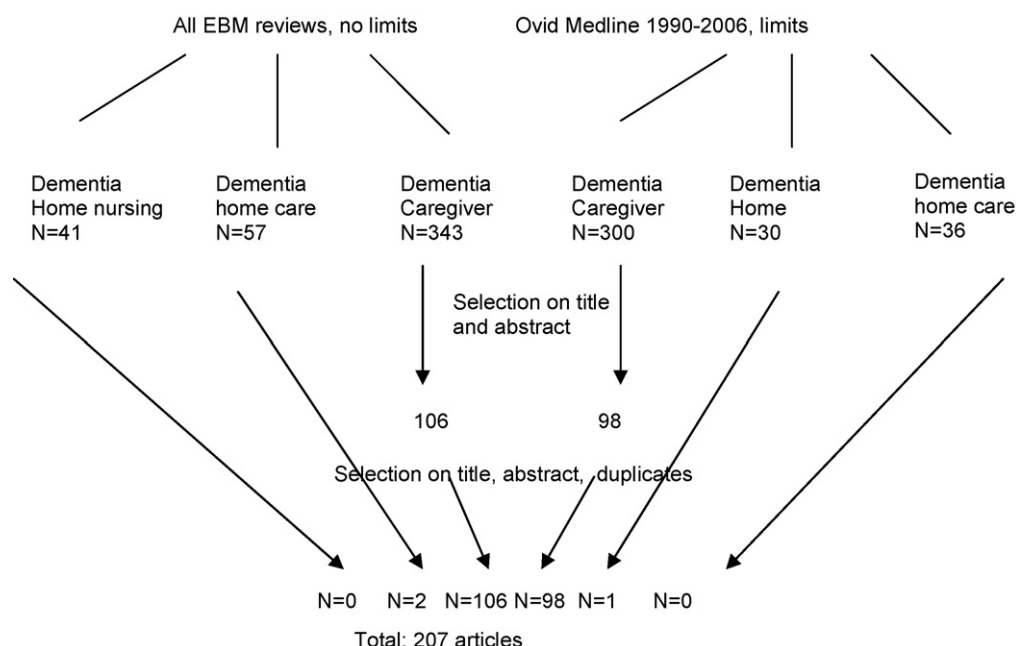
A number of criteria for inclusion of the index patient were used consistently. Dementia was usually described as a positive score on the Mini Mental State Examination (MMSE), the Cambridge Examination of Mental Disorders (Camdex) or the Clock Drawing Test. A number of studies included patients without requiring any other inclusion criteria than the report of a social worker or caregiver that the patient had dementia.

3.2. Impact of care-giving

The prevalence of depression in caregivers of elderly patients with dementia is significantly higher than in socio-demographically comparable groups of non-caregivers and than in caregivers of patients with non-dementia related chronic illnesses or of psychiatric patients [8–13]. Depression rates in caregivers of elderly patients with dementia range from 30% to 80%, depending on the study population and the recruiting method.

3.2.1. Characteristics of caregivers

Depression in caregivers is related to a number of demographic features. Meta-analyses show that women are more frequently



**Fig. 1.** Selection of articles after initial search.

**Table 2**  
Quality control of the studies ( $n = 30$ ).

Title	Study population, design and setting	Outcome depression	Result	Remarks
Bauer et al. [25]	115 spouse caregivers, cross-section from memory clinic, 2 groups patients with dementia based upon MMSE	Depression: CES-D, cut off $\geq 16$	Mean score on CES-D 11.82 en 10.24 at respectively low and high score on MMSE MMSE-score not related to depression	High mean score on MMSE 24.5 No prevalence reported
Baumgarten et al. [48]	218 caregivers of dementia and non-dementia patients, recruitment from geriatric poly-clinic Cross-section	Depression: CES-D, cut off $\geq 16$	Mean score on CES-D for caregivers 15.5 versus 8.2 for control group, significant difference	Caregivers only spouses and off springs Caregivers older in control Group 1/3 refused participation
Brody and Luscombe [18]	193 dementia patients and their caregivers, recruited from memory clinic Alzheimer dementia versus vascular origin versus others	Depression: GHQ 30 item version, scores $< 5$ normal, 5–10 mild symptomatology, $> 10$ moderate to severe	Mean score GHQ 5.4, higher scores in females, spouses, co-habitants, behavioral disturbances and depression in the patient	No clean control group Selection bias: memory clinic is intervention
Clyburn et al. [37]	613 caregivers, cross-section of data base	Depression: CES-D, cut off $\geq 16$	Mean score onop CES-D 6.91 Correlation between burden and depression 0.49 (burden mediates depression) No difference between both groups	Analyses in conceptual frame work: different models of cause-consequence relationship Also caregivers of residential dementia patients included Small study group Only bivariate analyses
Cohen et al. [49]	72 caregivers recruited from memory clinic Cross-section	Depression GHQ-30 item	Mean onore op GHQ for 'low burden' group 4.25 versus 12.31 for 'high burden' group, significant difference	
Covinsky et al. [23]	5627 caregivers, cross-section of database	Depression: GDS-15item, cut off $\geq 6$	Mean score 4.4 on GDS, $\geq 6$ bij 32% Predictors of depression: younger, ADL, behavior, income, relation time investment	No control Group
Donaldson et al. [38]	100 dementia patients and their caregivers recruited from geronto-psychiatric clinic	Depression (distress): GHQ-28 items, score of 4/5 suspicious for depression	52% depression Predictors of depression: depression dementia patient, behavior, cognitive status and gender caregiver	No features of the caregiver in analysis (logistical regression) Selection bias
Edwards et al. [36]	202 caregivers, cross-section of database, employed and unemployed caregivers matched (study and control group)	Depression: CES-D-20 item, cut off $\geq 16$	No difference in depression scores in both groups	Only correlations, no direction No features of the caregiver
Fortinsky et al. [50]	197 dementia patients and caregivers, recruitment from tele-service, cohort study	Depression: CES-D-10 item	Mean depression score 3/10 Depression when low feelings of control, behavioral disturbances and ADL-dependence	Selection bias: tele-service
Gallichio et al. [16]	327 caregivers of database	Depression: CES-D, cut off $\geq 16$	No significant difference in depression prevalence between male and female 23.9% versus 19.7% Depression in spouse and off springs, behavioral disturbances and poorer health in caregiver (log reg)	Broad definition of caregiver Selection bias: strong survivors in long cohort study
Graham et al. [41]	109 dementia patients and caregivers, recruited from memory clinic and home care organization	Depression: Carer Stress Scale	29% depressed More knowledge gives lower depression scores (34 versus 47 mean score)	Direction of correlation unclear
Kurz et al. [51]	207 dementia patients and caregivers, recruited from database	Depression: BDI, mild to moderate depression score 5–15	46.5% dementia caregivers at least mildly depressed versus 33.1% non-dementia caregivers	
Meshefedian 1998 [52]	321 caregivers recruited from database, random sample	Depression: CES-D, cut off $\geq 16$	Mean depression score 8.8, higher scores in spouses and off springs, lower education level, ADL-dependence, disease progression and behavioral disturbances	
Schulz et al. [53]	92 caregivers and dementia patients recruited from memory clinic	Depression: GDS-short form, score $\geq 5$	38% depressed depending on cognitive status, ADL-dependence and behavior	No features of caregivers Selection bias
Waite et al. [54]	72 caregivers, cross-section of day care center and poly-clinic	Depression: GDS-15 item, cut off $\geq 5$	Mean depression score 4.31; significantly higher score in co-habiting caregivers and in depressed caregivers (log reg)	Selection bias; recruitment from support organization Broad definition of caregiver

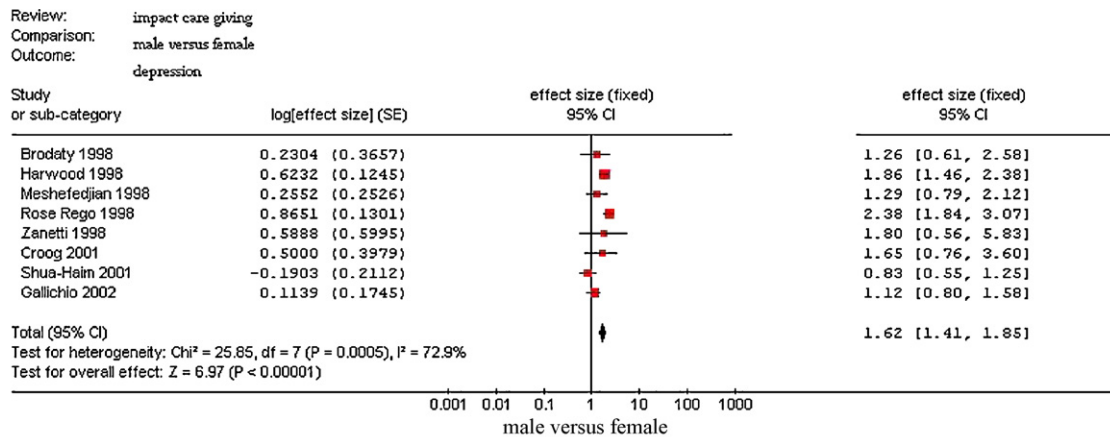
Table 2 (Continued)

Title	Study population, design and setting	Outcome depression	Result	Remarks
Harwood et al. [19]	Caregivers recruited from memory clinic, screened on the presence of depression, patients screened on dementia with MMSE $\leq 23$ Cross-section	Depression: CES-D, cut off $\geq 16$	254 (39%) of the caregivers is depressed, in particular spouses and daughters, latino's Influence of patients' features related to race of caregiver	Selection bias; recruitment from support organization Only depressed caregivers recruited
Alspaugh et al. [55]	189 caregivers: study Group recruited from intervention, control group via local media Cohort study 12 months	Depression: CES-D, cut off $\geq 16$	68 caregivers depressed on T1, 68% stable pattern over 1 year, 40 caregivers remain depressed, 75 caregivers end up depressed Burden is trigger for depression	No base line for co-variables: cause-consequence for depression unclear
Rinaldi et al. [22]	419 caregivers and patients recruited from geriatric clinic Cross-section	Depression: BSI-d	Mean score of 5.8 on BSI-d In group 'high burden, stress, depression and anxiety' mean depression score of 10.29 versus 2.61 in group with 'low profile' ADL-dependence and behavioral disturbances responsible for profile caregiver	Unclear analyses; control group composed after analyses
Zanetti et al. [24]	Caregivers recruited from research center, cross-section	Depression: BDI	32% mild depression (10–18), 21.4% moderate depression (19–29), 8.7 severe depression (score $>30$ ) Depression correlated with spousal relationship, poorly estimated health and competence	No control group Direction of correlation unclear
Williams [20]	720 caregivers recruited from database, comparison between black and white Cross-section	Depression: CES-D, cut off $\geq 16$	Mean depression score high in both groups (score 14 versus 13) Inverse relation between depression and income, behavioral and cognitive disturbances, social network, caregiver age, perceived health Black caregivers experience more positive care aspects	Limited analysis reporting
O'Rourke et al. [56]	382 caregivers recruited from epidemiological research via screening with MMMSE (score $<78/100$ ) Cohort study of 5 jaar	Depression: CES-D, cut off $\geq 16$	Positive relation between physical health and depression	Under- and over reporting of morbidity: morbidity: only 'perceived health' registered
Croog et al. [17]	$n = 199$ caregivers from clinical trial Cross-section	Depression: general Well Being Adjustment Scale	Mean depression score 14.9, higher in female and younger male caregivers and related to behavioral disturbances	Only age and gender of the caregiver included in analysis
Colantonio et al. [57]	$n = 148$ caregivers via Alzheimer association, Telephone interviews Cross-section	Depression: CES-D, cut off $\geq 16$	Mean depression score 10.6	Heterogeneous study group (age, race, time spent care-giving)
Shua-Haim et al. [15]	$n = 92$ caregivers recruited from memory clinic Cross-section	Depression: GDS-15 item, cut off $\geq 5$	38% depressed caregivers, related to patients' depression, ADL $< 12$ , hallucinations	Drop out of 16% No features of caregivers
Goode et al. [43]	$n = 197$ caregivers recruited from memory clinic, Cohort study	Depression: CES-D, cut off $\geq 16$	Mean depression score 14.8 on t1 and 14.13 on t2 no significant difference, depression related to stress in the caregiver	Drop out of 75 caregivers
Rose-Rego et al. [58]	$n = 99$ dementia care-giving spouses, participating in ADRC-study versus non-caregivers	Depression: CES-D, cut off $\geq 16$	Mean depression score female caregivers 16.64 versus male 9.31 versus control group female 4.31 and male 4.30	Mix of control group
Bertrand et al. [26]	$n = 349$ caregivers of dementia versus non-dementia caregivers Cross-section recruited from osteoporosis study	Stress: perceived stress scale	Higher stress in dementia caregivers, more behavioral disturbances and ADL-dependence related to 'Role captivity'	Bias in study population: cross-section of 65 plus females who after $>10$ years of follow up end in study

Table 2 (Continued)

Title	Study population, design and setting	Outcome depression	Result	Remarks
Coen et al. [59]	n = 72 caregivers and dementia patients recruited from memory clinic	GHQ-30 item	Quality of life lower in caregivers experiencing a high burden	No regression analysis Selection bias
Thomas et al. [27]	n = 100 caregivers and dementia patients, cross-section from psycho-geriatric center	Depression: QOL	Half of caregivers is depressed, related to depression in patient, to behavioral disturbances and progression of care process	No control group, no follow up Selection bias
Livingston et al. [12]	n = 118 caregivers of dementia patients, depressed and physically disabled patients	Depression: validated semi-structured interview	Caregivers more depressed than other relatives	

ADL: Activities of Daily Living; BDI: Beck Depression Inventory; BSI: Brief Symptom Inventory; GDS: Geriatric Depression Scale; CES-D: Center for Epidemiological Studies Depression Scale; GHQ: General Health Questionnaire; MMSE: Mini Mental State Examination.



Legendum

- Effect size: size of the effect expressed in standardized mean difference between both groups
- Log effect size: logarithmic scale
- $I^2$ : measure for heterogeneity
- Z: spreading of the effect

Fig. 2. Effect of the variable 'gender' on depression. Effect size: size of the effect expressed in standardized mean difference between both groups. Log effect size: logarithmic scale.  $I^2$ : measure for heterogeneity. Z: spreading of the effect.

depressed than men (effect size 1.62, 95% confidence interval (CI) 1.41–1.85) [13–20] (Fig. 2).

The difference in depression prevalence in age class above and under 65 years is not significant (effect size 1.30, 95% CI 0.96–1.74) [14–16]. One study was not included in the analysis because it was too incongruent with the other studies. This study revealed a non-significant difference in depression rates between age classes [17]. This study only included (older) caring partners of patients with dementia (Fig. 3).

Spouses have a higher risk of depression than other caregivers (effect size 2.25, 95% CI 1.95–2.58) [14,16,18] (Fig. 4).

Caregivers of Latin-American or of Black African origin feel less depressed than their white colleagues. However, the difference in depression score was not significant (effect size 1.18, 95% CI 0.87–1.59) [19,20] (Fig. 5).

The appraisal of a higher workload by the caregiver is related to a higher prevalence of depression (effect size 2.43, 95% CI 2.33–2.53) [21,22] (Fig. 6).

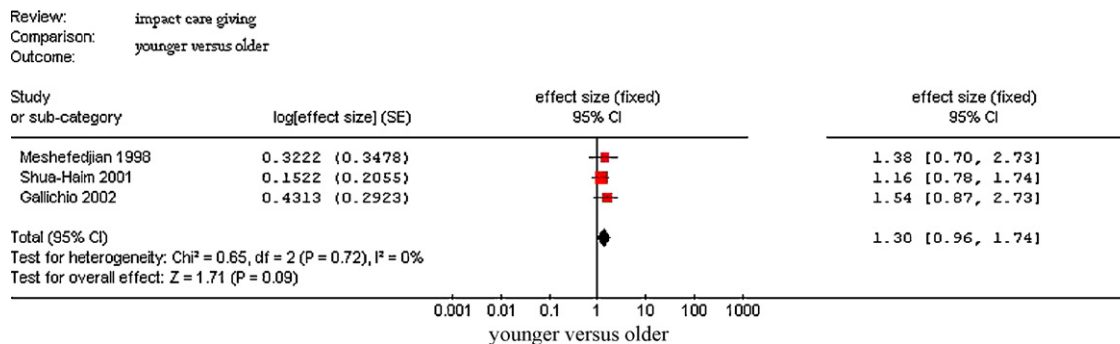


Fig. 3. Effect of the variable 'age' on depression.

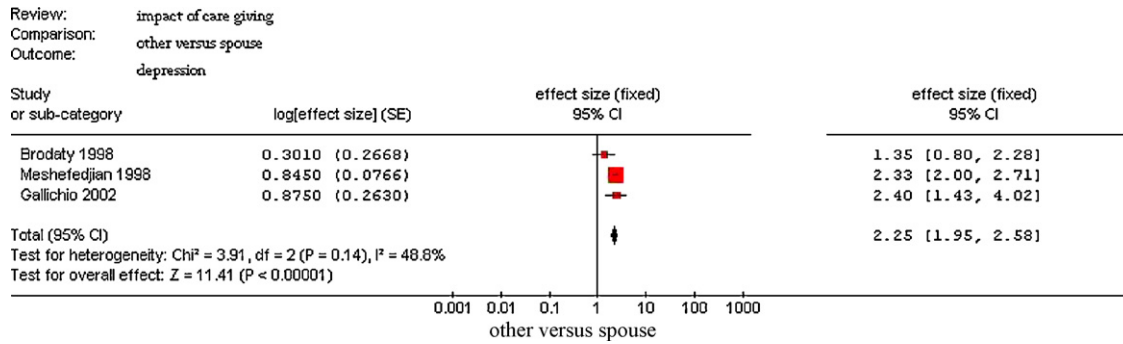


Fig. 4. Effect of the variable 'relation' on depression.

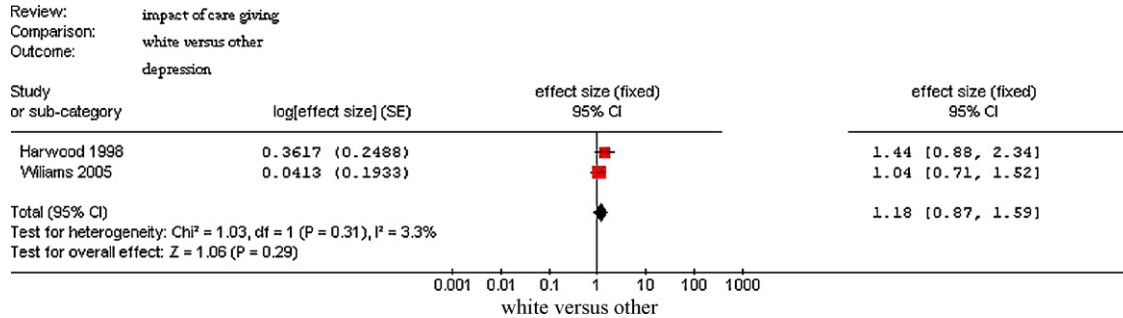


Fig. 5. Effect of the variable 'race' on depression.

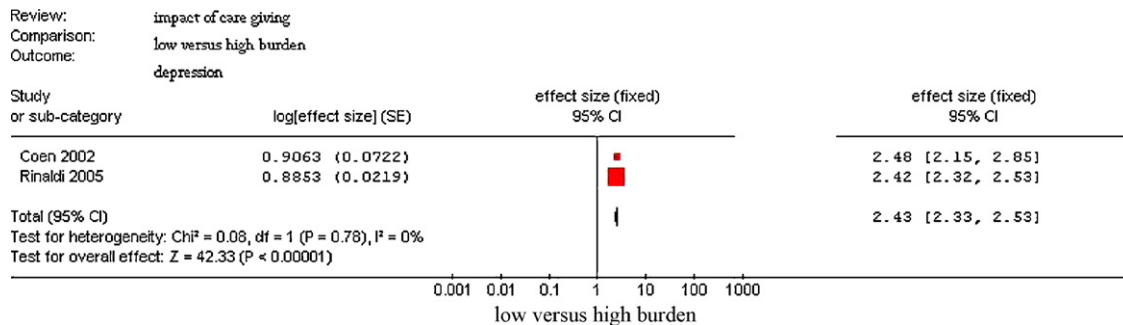


Fig. 6. Effect of the variable 'subjective workload' on depression.

3.2.2. Characteristics of patients with dementia

A higher care need in patients with dementia is related to more depression in caregivers (effect size 1.50, 95% CI 1.40–1.62) [14–16,23] (Fig. 7).

One study was not included in the analysis because it was too incongruent with the other studies [24]. One study was not

included in the analysis because it was too incongruent with the other studies [17]. This study showed an inverse but non-significant relation between depression of the caregiver and dependence of the patient. Adding this study to the analysis would have made the model too heterogeneous with an  $I^2$  of 97%. A random effect model with all three studies was not feasible either.

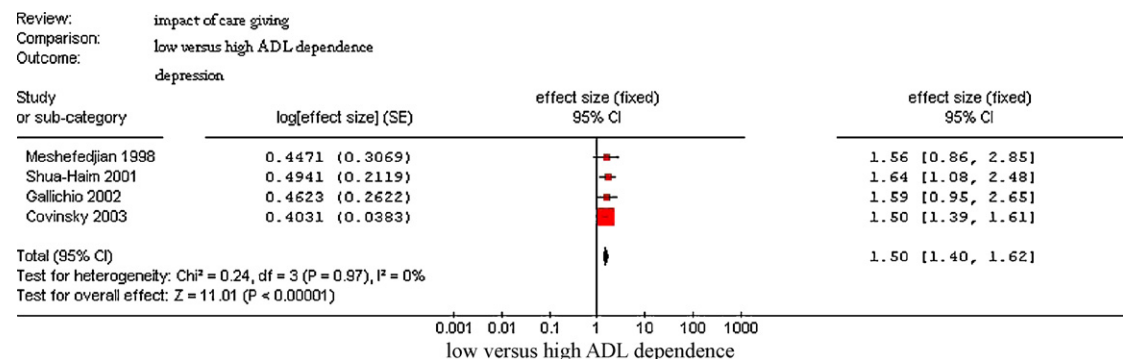


Fig. 7. Effect of the variable 'ADL-dependence' on depression.

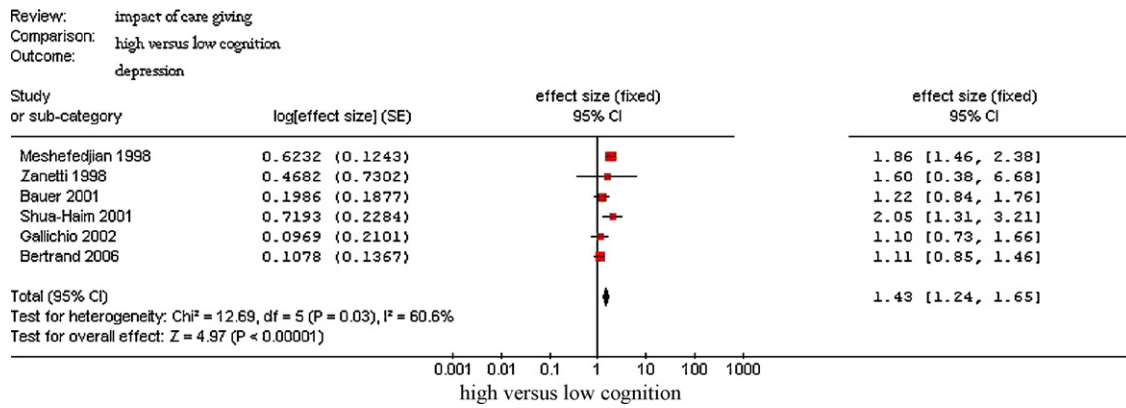


Fig. 8. Effect of the variable ‘cognitive functioning’ on depression.

Caregivers of patients with dementia who have better cognitive functions experience less depression than caregivers of patients with more severe dementia (effect size 1.43, 95% CI 1.24–1.65) [14–16,24–26] (Fig. 8).

Caregivers of patients with dementia showing behavioral disturbances are more often depressed than caregivers of patients who do not have these problems (effect size 1.59, 95% CI 1.43–1.77) [15,16,24,27] (Fig. 9).

4. Discussion

4.1. Summary of main findings

A lot of research has been devoted to the impact of care-giving to home-dwelling elderly patients with dementia. Because studies in this field are hard to fit in an experimental design, they often show much incongruence among them [6,28].

Depression occurs in one in three of caregivers and it occurs more frequently in those who care for patients with dementia than in caregivers of patients with other chronic illnesses. Changing role patterns, the continuous mourning process of the caregiver for a relative with dementia and the uncontrollable nature of the illness render caring for a patient with dementia into an exceptional situation. Prevalence rates for depression vary widely, mainly due to selection bias and heterogeneous study groups.

4.2. Methodological issues

To allow for a more refined literature review, the definition of ‘caregiver’ has been formulated more strictly. It should be noted that this definition cannot be implemented in just any culture or

in any health system. The definition of ‘caregiver’ as we found it in studies was mostly kept vague and low-threshold in order to simplify recruitment. In our definition the emphasis has deliberately been put on the lack of a formal network in which the caregiver provides care.

The population of patients with dementia appears to be more homogeneous. All studies used the same validated screening instruments to indicate the presence of cognitive disturbances. The diagnostic value of these instruments is debatable but research shows that the presence of cognitive disturbances present sufficient proof for caregivers’ higher subjective workload [29–31].

Most researchers recruited from (semi) professional contexts such as memory clinics, day care centers, self-help groups or via care providers. A likely selection bias in this is that caregivers who are available for participation in a study or who receive professional support already experience less stress [32].

Most studies were designed as cross-sectional studies, with or without follow-up over a relatively short period (3–6 months). Follow-up is usually difficult to ensure due to the extra burden it puts on the care situation. But, it is also possible that caregivers experience the interviews as a welcome change in their daily routine of caring for their relative [33]. Besides, it is assumed that because of a certain social pressure most caregivers answer questions more positively [28,32]. It can therefore be assumed that the quantitative data in this study underestimate the real impact of care-giving.

4.3. Carer characteristics

Female caregivers are more often depressed than men and this corresponds with data from general demographic studies. On the

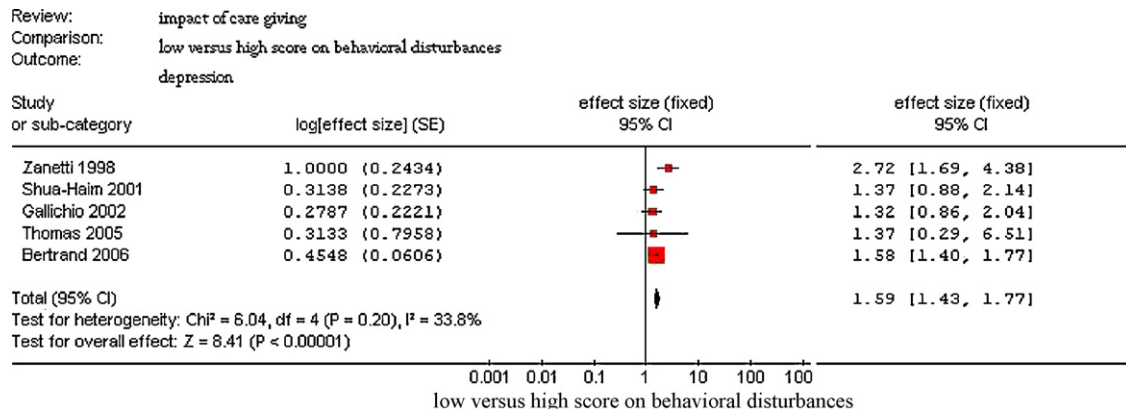


Fig. 9. Effect of the variable ‘behavioral disturbances’ on depression.



one hand it is more often women who take care of an ill relative [34]. On the other hand the extra household burden for female caregivers is usually heavier than that of their male colleagues.

The considerable heterogeneity in the meta-analysis of the variable 'gender' can be explained by the variation in the study groups. Indeed, the relationship between caregiver and patient was not taken into account. Spouses are significantly more often depressed than other caregivers. Social isolation, mourning the progressive loss of their partner and continuous care burden make them more vulnerable [3].

Older caregivers are also more often depressed than their younger colleagues although meta-analysis did not show any significant difference [35]. For older caregivers the burden of care is often heavier due to their own physical limitations and the fear of having to leave their relative behind when they die. Younger caregivers become depressed because of the combination of their social position (job, family, friends) with caring for a relative with dementia [36].

The socio-cultural background appears to render white caregivers more susceptible for depression than their coloured colleagues although the difference is not significant. The African and Latin-American caregivers recruited in these studies were mainly immigrants who still live in close-knit and supportive communities.

Finally, particularly caregivers who feel heavily burdened are susceptible to depressive feelings [37,38]. Perceived lack of support and understanding cause caregivers to feel dejected and stressed.

#### 4.4. Patient characteristics

Strong Activities of Daily Life (ADL)-dependence in a patient is related to the development of depressive feelings in the caregiver. Both the objective care burden and the confrontation with physical deterioration are determining factors in this. Incontinence in the patient might cause extra stress [39]. Caregivers' feelings of being misunderstood often surface in this context.

A patient with dementia with serious cognitive deficits causes more negative feelings in the caregiver. However, the analysis shows important heterogeneity due to the difference in study population (partners versus mixed group of caregivers) Partners appeared more sensitive to the mental deterioration than other caregivers. Moreover, caregivers experience the different phases of dementia as stressful to varying extents. For some caregivers caring for a restless patient with beginning dementia is stressful, whereas for others caring for a bedridden terminal patient is stressful [23].

Behavioral disturbances in the patient are strongly related to negative feelings and depression in the caregiver. Especially the uncontrollable and unpredictable character of these disturbances might be responsible for the stressful effect of this observation [40].

#### 4.5. Implications for future research

There are strikingly few data available on coping strategies in the caregiver. The development of negative feelings in the care situation is determined by a complex interaction of factors. Not one of these factors separately is sufficient condition for the negative feelings to develop. Moreover, the severity of objective problems in the care situation does not correspond with the stress experienced by the caregiver. Although in most studies the focus is on the association between the objective care need of the patient with dementia and the general wellbeing of the caregiver, in reality it appears that it is more often the specific characteristics of the caregiver that are responsible for the negative feelings [24,41,42]. Different profiles of caregivers can be distinguished according to the way a caregiver copes with problems in the care situation. Caregivers who feel involved and supported in the care situation and who look for

solutions to problems in a reasonable way appear to cope best with the negative impact of a care situation [43–45].

Future research should concentrate on demonstrating links between negative feelings in caregivers and the way the care situation evolves. This can have important implications in home care support. A caregiver who feels adequately supported but who has also learned how to solve problems in an involved and efficient way will be more successful in giving care and in persevering with the care-giving commitment.

## 5. Conclusion

In accordance with other reviews on this topic, also our results on the impact of care-giving remained inconclusive [1,46,47]. A substantial population bias is likely to be responsible for this observation. Remarkably, the impact of care-giving is strongly related to the characteristics of the population included. Both physically and psychosocially caregivers are less healthy than their peers or than colleague-caregivers of a chronically ill, non-dementia relative. However, a further meta-regression according to the caregiver and the patient characteristics was not feasible. The data sets were insufficiently or inappropriately reported to design a reliable model.

The implication of coping as the disclosed link between the impact of care-giving and depression in the caregiver can be promising in the daily practice of home care. A further exploration between the positive aspects of care-giving and the onset of depression in the caregiver is required.

Considering the caregiver as the indispensable link in the dementia care chain, could be important in organizing home care.

## Contributors

The authors declare that they participated in the co-writing of the manuscript and that they have seen and approved the final version.

## Competing interests

This study was funded by the National Social Security Board in the framework of a population based survey on the needs of community dwelling dementia patients and their carers. The project was by public tender assigned to the Academic Centre of General Practice of the Catholic University of Leuven and the Department of Clinical Psychology in Aging of Liege. The authors and researchers were not involved in any competing interests. The medical Ethical Board of the Medical School of the Catholic University of Leuven approved the study.

## Ethical adherence

The medical Ethical Board of the Medical School of the Catholic University of Leuven granted formal permission for this trial on 27 January 2005.

## Provenance and peer review

Commissioned and externally peer reviewed.

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