

The burden of family care giving in dementia

by

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Abstract

Objectives: *This paper reports the results of a descriptive field study in community dwelling elderly and their family caregivers.*

Methods: *As part of a larger field study research was done on the impact on the family caregiver of caring for a community dwelling demented elderly. A sample of caregivers was selected based upon the features of their care needing relative. The information was gathered using validated psychometric instruments. The results were analysed using bivariate models.*

Results: *Taking care of a community dwelling demented elderly reveals higher depression rates and feelings of burden in the family caregiver when compared with colleagues taking care of non demented relatives. An inadequate coping system in the caregiver and behavioral disturbances in the demented are strongly predictive for the negative impact of the homecare.*

Conclusion: *Caregivers of a community dwelling elderly are to be supported in their task in order to lower the psychosocial impact of the homecare situation.*

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Introduction

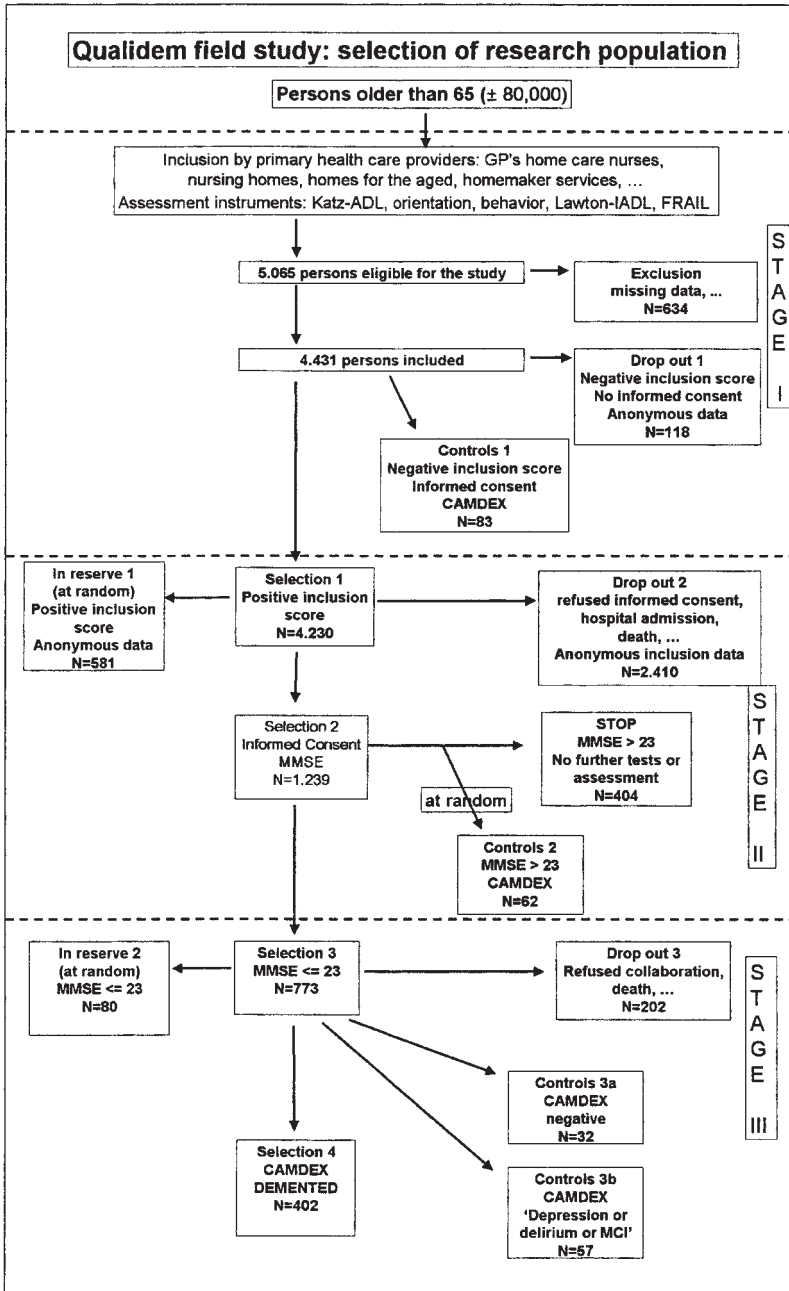
Taking care of a community dwelling demented family member implicates a significant burden on both physical and psychological wellbeing of all persons involved (1-4). Family caregivers of a demented elderly have a higher incidence of depression, feelings of stress en burnout all related to a higher use of medication (5). Beside these findings it appears that family caregivers estimate their general health worse than a comparable population (6). Although a lot of research has been done concerning the typical problems of caring for a demented family member, there is little consistency in the published results (7). Both the unpredictable and the inevitable character of the dementia process as the pre-morbid health status of the caregiver and his relation with the patient are found to be important determinants of the appearance of negative feelings.

A systematic literature review of all reviews and meta-analyses published between 1990 and 2000 concerning this theme was made. The main results were that up to 80% of the caregivers of demented community dwelling elderly suffer of depression en feelings of high burden and that they estimate their general health as poorer than their peers. We therefore studied the impact of family caregiving on the physical and psychological wellbeing of the family caregivers. The central objective in this part of the field study was to develop new or trace existing instruments inventarising the burden of the family caregiver.

Methods

Patients were included in the study population after a process with 4 phases of recruitment and inclusion, with increasing need of care and cognitive deterioration of the involved demented elderly. In the last phase the community dwelling demented elderly and their primary family caregiver were selected. At the beginning of the study 5065 persons older then 65 were entered by several professional caregivers and care providing organizations in the regions of Verviers and Lier. Both regions were selected based upon sociodemographic features. Around Verviers some more elderly were institutionalised though the difference was not significant. In the ongoing of the trial, the share of intramural residing elderly increases up to 78.2% for Verviers and 67% for Lier at the end.

Table 1:
Schedule for recruitment and inclusion.



In the ongoing of the study the participants were conducted to a study- or a control group following their need of care and the fine tuning of the dementia diagnosis. The amount of non-responders from phase 3 to 4 can be interpreted knowing that most participants in these last phases were of very poor physical and mental health with a high profile of vulnerability. Continuing in the field study appeared for these elderly too threatening or too loaded.

The subjects in the study group were all demented following the Camdex-RN. The subjects in the control groups in the last phase were recruited in different stages. Three groups represent control group 1 (no mental disease NMD). One group was considered as a special group because of the very specific problems these elderly perform like depression, delirium or mild cognitive deficit (control group 2, mental disease, MD).

TABLE 2
Study groups – typing of the included patients

Subject	Group
Dement (phase 3): positive score on Camdex-RN	Study group
Not dement, no mental disease: – negative score on inclusion criteria (phase 1) or – negative score on MMSE (phase 2) or – negative score on Camdex-RN (phase 3)	Control group 1 “NMD”
Not dement, mental disease (phase 3): – negative score on Camdex-RN – positive score on delirium, depression or mild cognitive impairment	Control group 2 “MD”

The amounts of participants as mentioned for each phase comprise both the community dwelling elderly and the intramural residing elderly. At the start of the study 60% of the participants resided home, 40% in an institute (2 missing data).

In phase 4 180 community dwelling elderly were left in the study. Each of these participants was accompanied by a family caregiver, being a family member (spouse, child, brother, sister), neighbor or good

friend. Based upon the total of completed depression questionnaires 90 participating family caregivers (response ratio 50%) were invited to collaborate themselves in the study. We met some reluctance in scoring and completing the instruments, probably because of the pre-existing burden of the family caregivers and the degree of difficulty of some instruments. Some of the instruments were not or only partially completed. In order to limit the burden of the interview it was spread over two visits on request of the family caregiver. As a consequence part of the participants dropped out between the first and the second phase of the study.

In order to reduce the burden of the interviews we decided to drop the registration of the Householdbook for a random sample of participants.

In the study group, control group 1 “no mental disease” (NMD) and in control group 2 “mental disease (MD) were respectively 40, 33, and 17 family caregivers included.

Instruments

1. Caregivers

For all caregivers the following instruments and interviews were applied:

- Zung Self Rating Depression Scale (8): a 20 item self scoring instrument, suitable for large population categories. The total score is the sum of the 10 negative and the 10 positive items. Standard cut off point is 60, above this score depression is present.
- Zarit Burden Inventory, short version Hébert 2000: a 12 item self scoring instrument to determine the own perception of workload. The score is a simple sum score. Values above 9 mean high burden with impact on general health.
- Quality of Relation (9): a 14 item self scoring instrument describing the relationship between the family caregiver and the demented elderly. The score is a sum score of the negative and the positive items. Above 42 means a good relationship.
- Ways of Coping Checklist (10): self scoring checklist for determination of the different ways of coping. Exists of 3 subscales corresponding each with a type of coping (emotional, problem solving and supporting). The score is the sum score of each subscale and a higher score on one of the subscales indicates the corresponding coping behavior.

- Household Notebook: an extensive notebook on all financial and socio-economic consequences of homecare. It consists of an interview and a description of direct and indirect costs of homecare (Case Management Project 1996).

2. Study Patients

For all index patients the following instruments were applied:

- Camdex-RN (11): a reference in the diagnosis of dementia. Neuropsychological test battery including physical and psychological health, social situation, cognitive and non-cognitive functions. The result of the test shows a differential diagnosis between not demented, demented, depressed, delirious, mild cognitive impairment.
- CERAD (12): comprehensive behavior observation scale, highlighting different types of behavioral disturbances. The score is a complex integration of all items and subitems.
- Clinical Dementia Rating scale (13): instrument staging dementia on different levels (orientation, behavior, care need, ...)
- Katz, IADL and Frail (14-16): instruments documenting the need of care in activities of daily life and the frailty of the demented elderly.

The primary outcome measure was depression in the family caregiver related to several characteristics of the caregiver and the elderly. The secondary outcome measure was the burden as experienced by the caregiver.

Statistical analysis

SAS version 8.2 was used to analyze the data. The data were submitted to bivariate analysis with stratification for age, sex and need of care where possible. Because of the small numbers of participants per group a regression analysis seemed impossible.

Results (Table 3)

Characteristics of the elderly

Age. The mean age of the community dwelling elderly persons in the last phase is 84 years for the study group and 81.3 years in the controlgroup NMD. The difference between both is not significant.

Regional distribution. The distribution of the community dwelling elderly is equally divided over both regions Verviers and Lier.

Characteristics of the family caregivers (Table 3)

The amount of participating caregivers was based on the depression rating scales. A total of 89 of these scales were fully completed returned. With a initial sample of 180 caregivers, this is a response ratio of 50 %.

Sex. The variable "sex of the primary caregiver" was poorly completed in the files (partly due to the withdrawal of the household notebook for half of the caregivers). As a consequence only few data are available on this parameter. On the other hand the sex of the partner was better completed with a male-female ratio of 3/2 (n resp. 15/11). Considering that in most cases the partner is the primary caregiver, we decided to use this variable in the further analysis. The sex distribution is equal for both groups. Because of the small numbers of participants there's no subdivision made between regions or groups.

Age. The mean age of the partner of the patient is 84 in the study-group and 81.5 in the control group. A T-test showed no significant difference between the groups.

Prevalence of depression. The overall prevalence of depression in participating caregivers is 30%. The prevalence of depression in the study group is higher then in control group NMD (no mental disease, RR 3.6, 95%; CI 1.3-10). The prevalence of depression in the group mental disease is higher then in the group with demented patients (RR 2.9, 95% CI 0.6-13.4). The sex distribution for depression tends to the female caregivers with a ratio of 1/3 (n=16, 8 men, 8 women) in all groups.

The overall mean depression score is 47.9 (n=89). The mean depression score in the study group is 47.8 with higher scores for the female caregivers. The mean depression score in control group MD is significant higher then the mean depression score in de study group en control group NMD.

In region Lier the mean depression scores are remarkable higher then in Verviers (n Lier/Verviers 67/25; T-Test $p < 0.05$).

Depression and experienced workload. The overall mean score on the Zarit burden inventory is 13.3 (n male/female 8/8). There's no significant difference between the workload experienced by male and female caregivers (T-test $p = 0.02$ ns). The mean score in the study group

TABLE 3

Prevalence and relative risks of depression and burden in caregivers.

This table shows the numbers of participants in each group, the corresponding prevalence of burden and depression, the overall amount of caregivers with burden, depression, coping behavior, quality of relation and the number of patients with high/low care need. Corresponding to these values, the relative risk on depression and burden is described.

Variable	N (%)	Depression RR (CI)	Burden RR (CI)
Group	Index + 14 (15.22%), -20 (21.74%) NMD +8 (8.70%), - 41 (44.57%) MD + 6 (6.52%), - 3 (3.26%)	Index vs NMD 3.6 (1.3-10) MD vs Index 2.9 (0.6-13.4)	Index vs NMD 1.1 (0.4-3) MD vs Index 0.4 (0.08-1.7)
Burden	+ 57 (64%) - 32 (35%)	Index 0.9 (0.2-4.2) MD 0.2 (0.01-4.7) NMD 0.9 (0.2-4.2)	
Depression	+ 28 (30%) - 64 (70%)		Index 0.9 (0.2-4.2) MD 0.2 (0.01-4.7) NMD 0.9 (0.2-4.2)
Problem solving coping	+ 33 (34%) - 58 (64%)	0.6 (0.2-1.6)	2.5 (0.8-5.9)
Emotional coping	+ 37 (40%) - 54 (60%)	3.3 (1.3-8.4)	4.1 (1.5-11.1)
Supporting coping	+ 49 (43%) - 51 (57%)	0.9 (0.4-2.4)	3.9 (1.5-10.1)
Quality of relation	+ 149 (92%) - 13 (8%)	0.4 (0.05-3.9)	0.6 (0.5-0.7)
Katz score	+ 46 (11%) - 375 (89%)	0.5 (0.1-1.8)	1.7 (0.5-5.7)
Continence	+ 150 (36%) - 271 (64%)	0.8 (0.3-2)	1.7 (0.7-4.3)
Frailty	+ 273 (65%) - 148 (35%)	1.3 (0.4-4)	1.6 (0.5-4.5)

+ = positive

- = negative

N (%) = amounts and percentage

RR (CI): relative risk and 95% confidence index

Index: demented patients and their caregivers

NMD: patients with no mental disease and their caregivers

MD: patients with mental disease and their caregivers

Sex. In the study group 17% is male, 83% is female. In the control group the distribution is 26% versus 74%. The difference between both is slightly significant but in the analysis this conclusion is not relevant.

is significant higher then in both control groups (T-test NMD and MD resp. $p < 0.005$ and $p = 0.01$). The difference in workload between both control groups is not significant (control group MD slightly higher burden).

The relative risk on a high burden (sum score > 9) in the study group versus the control group NMD is 1.1 (95% CI 0.4-3). In control group mental disease caregivers report less frequently a high burden then caregivers of demented elderly (RR 0.4, 95% CI 0.08-1.7).

The mean score on the burden scale does not differ significantly for depressive or non depressive caregivers (n depressive/n non depressive 64/26, Wilcoxon 0.8 ns).

The overall mean age of the caregivers doesn't reach statistical significance. As a consequence there's no stratification needed for this parameter. Moreover, all caregivers are younger then 75 years and form for this parameter a homogenous group.

Depression and way of coping

1. Problem solving coping behavior

In both control groups (mental disease and no mental disease) we found a higher score on this type of coping behavior then in the study group although the difference does not reach statistical significance (T-test $p > 0.05$). Male caregivers show higher rates of problem solving coping then there female colleagues but the difference is not significant (male/female 8/7, T-test $p > 0.5$). Depressed caregivers show slightly less problem solving coping than their non-depressed colleagues (T-test $p = 0.01$). The relative risk on depression in the presence of problem solving coping behavior is 0.6. There's a higher prevalence of burden with problem solving coping behavior (RR 2.5).

2. Emotional coping behavior

For the study group we found higher scores for emotional coping behavior then for both control groups (T-test $p > 0.05$). Comparison between both control groups reveals more of this kind of coping in group MD then in group NMD although the difference is not significant. Male caregivers show less of this coping behavior then their female colleagues (ratio male/female 8/7, T-test $p = 0.5$). The relative risk of depression in the presence of emotional coping is 3.3. For this type of coping behavior we found a higher prevalence of burden (RR 4.1).

3. Supporting coping behavior

There is no significant difference in the mean scores of supporting coping behavior between all three groups. Neither there's a difference between male and female caregivers showing this type of coping (T-test =1). The prevalence of depression associated with supporting coping behavior is slightly lower than without this type of coping (RR 0.9).

In the presence of supporting coping behavior there's a higher risk on burden (RR 3.9).

Depression and quality of relation

There's no significant difference in quality of relation between all three groups. The relative risk of a depression in the presence of a poor quality of relation between the caregiver and the patient is 0.4 (95% CI 0.05-3.9). A high burden is not associated with a poor quality of relation (RR 0.6).

Background characteristics of the demented in relation to depression in the caregiver

Care need according to the Katz instrument

The overall relative risk of depression in caregivers of high care demanding elderly is 0.48 (n=93, 95%CI 0.12-1.8). In the group no mental disease the care need of the patient is not associated with a higher prevalence of depression in the caregiver (RR 0.7, 95% CI 0.07-6.6). A similar result was found for the study group (RR 0.2, 95% CI 0.02-1.7). In the group mental disease we found a relation between high care need and depression but the result is compromised by the low number of study subjects.

The relative risk of a high burden experienced by caregivers confronted with high care needing patients is 1.7 (95% CI 0.5-5.7). In the group no mental disease the care need of the patient is associated with the experience of burden in the caregiver (χ^2 4.4, $p=0.04$). Caregivers of demented patients do not experience a higher burden in association with high care need of their patient (RR 0.6, 95% CI 0.1-3.1). For the group with mental disease we can not draw a significant conclusion because of the low number of subjects.

Behavioral disturbances

The mean score on the scale of behavioral disturbances is higher for non depressed caregivers (F value 0.6, $p=0.5$). In contrast, behavioral

disturbances put a high burden on the caregivers in all three groups (F value 8, p 0.008).

It was not possible to discriminate between the three study groups because of the low number of completed questionnaires.

Clinical stage of dementia according to the CDR

The clinical stage of dementia is not responsible for depression in caregivers (F value 0.5, p 0.5). A higher burden was reported by caregivers caring for a relative with a higher score on this scale (F value 1.04, p 0.3).

It was not possible to discriminate between the three study groups because of the low number of completed questionnaires.

Frailty of the elderly

The mean score on the frailty-instrument appeared to be significantly higher in the study group than in both control groups (T-test p <0.05).

The relative risk of depression in caregivers caring for a frail elderly compared to less vulnerable patients is 1.3 (95% CI 0.4-4). In the group no mental disease depression in the caregivers is not associated with the frailty of the elderly (RR0.4, 95% CI 0.1-2.2). In the group demented patients there were only frail elderly. Little more than 40% of their caregivers were depressed. Caregivers of patients with a mental disease tend to be more often depressed although the result is influenced by the low number of subjects in this group.

The overall relative risk on a high burden experienced by caregivers caring for the same patient population is 1.6 (95% CI 0.5-4.5). In the group no mental disease high burden in caregivers is more frequently present when a high frailty is reported (RR 1.8, 95% CI 0.5-6.4). 70% of caregivers of demented elderly report a high burden in the presence of a high frailty. In the group mental disease frailty seems not to be linked to a high burden although the result might be influenced by the low number of subjects.

Continence according to the Katz-instrument

We considered the elderly as incontinent when we noted a score of 2 or more on this item on the Katz-instrument. The overall relative risk of depression in the presence of incontinence in the patient is 0.8. In the

group no mental disease the presence of incontinence seems not to be responsible for depression in the caregiver (RR 0.7, 95% CI 0.1-4). A similar result was found for the demented patients and their caregivers (RR 0.4, 95% CI 0.1-1.6). No conclusions can be drawn for the group mental disease because of the low number of subjects.

The overall relative risk of a high burden experienced by caregivers in the presence of incontinence is 1.7. Caregivers of patients without a mental disease or with dementia report more often high burden in the presence of incontinence (resp. RR 2.2, 95% CI 0.5-9.3; RR 2, 95% CI 0.4-8). For caregivers of patients with a mental disease we found the inverse result although the low number of subjects in this group should be considered.

Discussion

The results in this study are in accordance with other international publications. (1;17-23). They confirm that taking care of a community dwelling demented elderly reveals strong feelings of depression and burden on the family caregiver.

The overall prevalence of depression (30%) as well as the sex distribution (more women than men) are in accordance with the results found in similar populations. The mean depression scores for caregivers in the mental disease group are higher than in both other groups. Female caregivers show more depressive features than their male colleagues. The higher prevalence of depression in the study group versus the no mental disease group and in the mental disease group versus the demented group was described in other publications. Taking care of an elderly person with dementia, depression or signs of delirium means considerable stress for the caregiver.

The mean and even the lowest noted scores on the burden-scale are far above the cut off point for high burden. Caregivers of demented elderly experience most frequently a high burden. We can expect that the progressive and unpredictable character of dementia as well as the never ending need of supervision puts a high burden on the responsible caregiver.

The coping behavior determines the way the caregiver copes with stressful situations. Female caregivers use less of the problem solving copings strategies than their male colleagues. In the presence of this type of coping behavior, caregivers show less frequently signs of depression but more often feelings of high burden.

In female caregivers there are more features of this type of coping than in their male colleagues. Emotional coping strategies lead more often to depression and feelings of burden in caregivers. When using supporting coping strategies, caregivers are less frequently submitted to depressive moods but experience more often high burden. A poor quality of relation between the caregiver and his or her ill relative is not responsible for the presence of depression or feelings of high burden.

The care need, according to Katz, of a demented relative or relative without mental disease appeared not to be responsible for depression in the caregiver. Feelings of burden are not more frequent in caregivers of demented elderly. A higher care need in patients without mental disease reveal more often feelings of high burden in their caregivers.

Behavioral disturbances of the patient are strongly responsible for high burden in the caregivers but not for depression. A similar result was noted for the stage of dementia.

Demented patients appeared to show a higher frailty profile than patients in the control groups. The prevalence of depression and high burden is higher when caregivers are taking care of a frail relative.

Caregivers of demented relatives and of relatives without mental disease do not experience more often feelings of depression in the presence of continence problems. In contrast, feelings of burden are more often reported by caregivers of demented or not mentally ill relatives in the presence of incontinency.

Unfortunately, the results of this phase of the field study are negatively influenced by the unexpected small number of participating caregivers (response ratio 50 %, $n = 90/180$). The response ratios are strongly dependent upon the degree of difficulty and the burden associated with the instruments. In that perspective, we decided during the ongoing of the study to drop the household notebook for a random sample of the participating caregivers because of the considerable time investment. As a result, important identification data were lost for analysis. Above this, the identification and sociodemographic parameters appeared to be very poorly completed in the remaining files.

Some of our results may therefore be conflicting with other published material. For the variable "quality of relation" there's found unexpectedly no association with depression and burden. This may be due to a low response ratio on this instrument. Another explanation could be that the

quality of relation was still too good to be a predictive factor for negative feelings. Another conflicting result was that behavioral disturbances and stage of dementia seemed not to be responsible for depression in the caregiver. There could be accepted that in community dwelling elderly the degree of these disturbances is still limited. Remarkable was the finding that the physical care need, including incontinence, of a demented elderly was not a source of depression or burden in the caregiver. Frailty seemed to be a more confident parameter in predicting caregiver stress. This might be explained by the fact that providing physical support to a patient is the most accessible way of taking care of someone.

Conclusion

Our results are similar to what was published before. The prevalence of depression and the experienced burden in the caregiver of demented elderly appear to be high. Problem solving and supporting coping strategies seem to protect against feelings of depression. A high care need of the patient, behavioral disturbances, frailty, incontinence and more severe signs of dementia put a high burden on the caregiver but do not make him or her depressive.

For further research it might be important to lesser the burden of the interviews and to focus on both the experience of care giving and the social context of the home care situation. As we know that caregivers strongly appreciate any kind of outside support, even without efficiently contributing to improvement of the situation, it could be relevant to take in account all kinds of intervention.

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