

Care time and costs of care for elderly persons with dementia

by

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Abstract

Aim: List care activities of formal and informal carers and calculate costs of care for elderly people with dementia. Comparison with those not suffering from dementia (control group) at home and in residential settings.

Methods: The combined methodology of a retrospective questionnaire and a prospective diary was used to collect individual data on the use of health care (professional and informal care).

Results and conclusions: For home care, we found that professional care and costs of materials does not differ in any significant way between the dementia group and the control group. Professional care was on average 5,3 hours/week. However, we did observe a clear difference with regard to the informal care. The recorded time of informal carers was significantly higher for elderly persons with dementia (on average 38 hours/week) than for elderly persons not suffering from dementia (on average 16 hours/week).

In residential care facilities, the care time for dementia patients with intensive need of care (Katz score C or Cd) was almost twice that dedicated to dementia patients with slight to moderate need for care (score

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O, A or B on the Katz scale). However, this latter group did not differ much from the control group (predominantly score O). Therefore we conclude that the care categories indexed by the Katz scale provide, as such, an explanation for the care costs charged in the facilities.

The residential setting has a great impact on care provision. The recorded time spent by nurses and carers in home care is more than twice that spent in residential facilities, despite the fact that more intensive care situations are more likely to occur in residential care. This can mainly be attributed to the presence of informal carers who provide a great deal of nursing and care tasks.

Keywords: Dementia, Costs and Cost analysis

Introduction

In this section of the Qualidem study we investigated the need for care of elderly persons with dementia both in terms of care time and in financial terms. To this end, we compared the take-up of care by elderly persons with and without dementia. This was considered in the home situation as well as in residential settings. We set out from the broadly defined needs of persons requiring care, both in terms of professional care and of informal care.

Research method

We adopted a 'bottom up' approach, whereby our point of departure was the patient. Starting with a random sample of the target group we outlined the socio-economic situation and the care systems that exist for persons with dementia. Our mapping out of these care systems focused on the allocation of carers' use of time and, in connection with that, on the cost price. To this end we applied the survey instrument developed by the HIVA for the analysis of formal and informal costs of care and adapted it to the target group of persons with dementia (1).

1. Registration of care

Registration of professional care involved the use of diaries. In these diaries all professional carers noted their daily care tasks performed with the elderly, stating the duration of the visit, the time spent travelling, the therapeutic aids and appliances used and the price to be paid by the patient. These diaries covered a period of four weeks. We used the same instrument for home care and care in institutions. Medical and

paramedical carers falling within the scope of the INAMI/RIZIV (National Health and Disability Insurance Scheme) regulation (general practitioners, nursing staff, physiotherapists,...) and non-medical carers (social workers, home helpers and cleaners) filled in the diaries.

For home care we also used diaries to map out the use of time of informal carers over a period of one week. Furthermore, we collected extra information in home care via an interview with the informal carers. This interview included questions concerning (a) socio-demographic and economic details about the elderly person, the partner and the main carer, (b) the need for care of the elderly person and (c) the use of medication, medical appliances and durable aids. We then asked questions about (d) the use of inpatient and outpatient services and (e) informal support from persons living with the elderly and by volunteers over the past 12 months. Finally we also collected information concerning (f) the extra living costs and (g) the additional daily costs in the household resulting from the need for care.

2. Determining the cost of care

The total cost of care for the research group can be calculated on the basis of the data recorded in the diaries and the interviews. We calculated both the costs that families have to bear and the costs for society, either via the health insurance or via social compensations. The information obtained can be aggregated in a later stage to facilitate an estimation of the organizational and budgetary implications as regards services and provisions, carers and funding organisations and at macro level.

We used two different methods to calculate the cost of professional carers.

For nursing staff, carers and cleaners we used the labour costs as a proxy for the total cost. In order to avoid inordinately complex calculations, we worked with an average cost per time unit per carer category (2). The time spent was multiplied by the cost price per time unit. The following costs were applied: for nursing staff, 27 euros/hour; for home helpers, 23 euros/hour; for cleaners, 19 euros/hour. These are only estimates of the hourly rates (without overhead costs) and the costs based thereon are therefore to be taken as an indication only.

We calculated the costs for the other professional care-givers with reference to the fees recorded in the diaries and during the interview with the voluntary aid workers.

Informal time in home care is more difficult to evaluate. A first possibility is to calculate the opportunity cost of wages and profits lost resulting from care-giving. We did not use this approach because the majority of informal carers are pensioned. Another possibility is to consider the wages that are paid to professional care-givers as a shadow price for informal care. This is the method we adopted. We did not take account of the overhead costs required for formal care. We used shadow prices of 23 euros/hour, which corresponds to the cost price of a home helper. The informal care was divided into nursing and practical assistance (the hard core of care tasks) on the one hand and attendance and companionship on the other.

In home care we further recorded the material costs during the interview with the family carers. Firstly, these consist of extra expenditure for medical aids such as drugs, nursing material (in particular incontinence material) and durable appliances (walking aids, hospital beds, commodes,...). They also consist of extra living costs, such as additional spending for diets or special food, meals delivered at home, laundry, heating costs, electricity, etc. as a consequence of the need for care of the elderly person. The prices noted in the interview are used as a proxy for the material costs.

Random sample survey

The sample survey comprises two groups: a group of subjects with dementia and a control group of subjects not suffering from dementia. The dementia subjects in the *study group* suffer from dementia according to the Camdex scale (positive Camdex score) and have a score of ≤ 23 on the MMSE.

We used a control group to compare the information recorded for elderly persons with dementia with a reference group of people of the same age and gender not suffering from dementia. In this way we were able to discover the 'additional' cost of dementia. Two groups from the total Qualidem sample were combined to form the *control group*:

- A first group was made up of elderly persons with negative scores on the Camdex scale but with positive scores on the MMSE in an earlier phase.
- A second group consisted of elderly persons who scored negatively on the MMSE.

In home care a group of 76 elderly persons was finally selected from the Lier and Verviers regions (Belgium). This group included 28 persons

with dementia (study group) and 48 persons not suffering from dementia (control group). The average age of the dementia group and of the control group was 81.8 and 79.5 years. In both groups 80% were women. Of the dementia group 14% had KATZ-score A, 14% KATZ-score B and 7% KATZ-score C whereas only 4% of the control group belonged to those groups.

The sample in the institutions totalled 121 persons, 99 of which with dementia and 22 without dementia. The average age was 84 years for the dementia group and 82 years for the non-dementia group. Both the dementia group and the non-dementia group mainly consisted of women (86% and 81% respectively). The need for care of the dementia group in the institutions was much higher than that of the control group (see Table 1). Furthermore, the need for care of the dementia group in residential care was much higher than in home care, which is logical considering the fact that the step towards admission to a residential facility is not readily taken.

TABLE 1
Score on the Katz scale (2002)

Katz	Home care		Institutions	
	Control group	Dementia group	Control group	Dementia group
	(n=48)	(n=28)	(n=22)	(n=99)
O	96%	64%	45%	12%
A	2%	14%	14%	10%
B	2%	14%	32%	24%
C	0%	7%	5%	4%
Cd			5%	50%

Results

1. Results for home care

Description of the patients and their carers

The interview with the voluntary carers yielded a detailed picture of the clients receiving home care. 48% of the control group and 43% of the dementia group live alone. The dementia group is consequently typified by a somewhat higher presence of other members of the family or of the partner: 42% compared with 21% in the control group, or children living at home: 25% as against 13% in the control group, or both. These persons are at the same time the main family carers. Regarding the income position we find that practically everyone has a pension.

The rest of the income consists of earnings from property, allowance for help for the elderly, subsistence level income, unemployment benefit from CPAS/OCMW (Public Welfare Centre) or a home care bonus. The total net monthly income for both groups is situated at between 750 and 1,000 euros. Finally, approximately 60% of the elderly persons with dementia require attendance both day and night. Approximately one third of this latter group requires care frequently or constantly during the night.

Recording of care time

The total time dedicated by informal carers to caring for the elderly over a week is significantly higher than that spent by professional care-givers. The informal care time amounts to about 38 hours for the dementia group, which is equivalent to a full-time job, and 16 hours for the control group. The average total time professional care-givers in home care dedicate to the care of an elderly person with dementia amounts to 6.5 hours per week, compared with 4.5 hours per week for the control group. The results obtained are summarised in the figure 1.

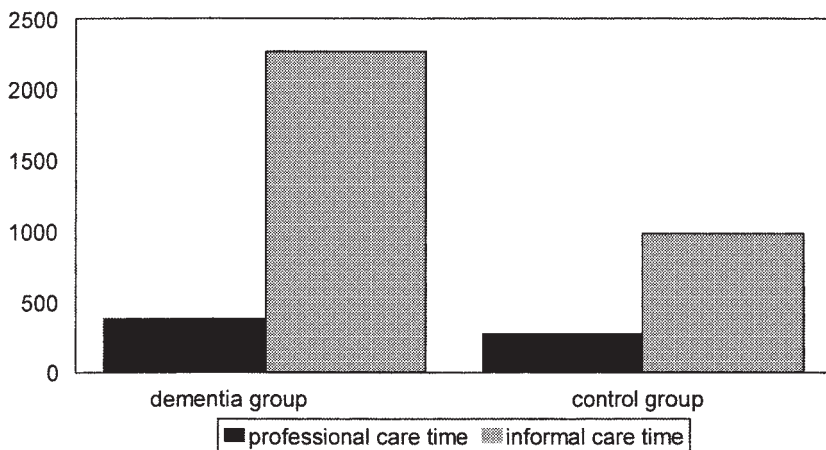


Fig. 1: Average professional and informal care time spent on elderly persons with dementia in home care, in minutes per week (2002)

Further detailing of the professional care time reveals that home helpers and cleaners spend the most time on elderly persons with dementia (on average 3 to 4 hours per week) (see Table 2). Since the

TABLE 2
Average professional and informal care time spent on elderly persons in home care,
in minutes per week (2002)

	Control group (n=48)	Dementia group (n=28)	Sign. lev. F value*	Pilot study in 1998 ¹ (n=31)
Professional care time:				
Home help and cleaning	192	222	n.s.	307
Nurse	58	128	0.05	221
Social work	12	0	n.s.	2
Physiotherapist	9	24	n.s.	75
General practitioner	7	11	n.s.	14
Other	-	-		32
Total professional care time	278	385	n.s.	651
Informal care time:				
Personal care	36	198	0.001	1 802
Practical assistance	174	696	0.001	1 650
Attendance and companionship	774	1374	n.s.	1 625
Total informal care time	984	2268	0.05	5 077

¹

* n.s.: difference is not significant

difference between home helpers and cleaners was found not to be always clear when analysing the data, we bundled the two categories together. Also the home nurse often calls at the house, especially for the group with dementia (average 2 hours per week). In terms of time use, physiotherapists, general practitioners and social workers are, on average, less involved in the assistance given to and care of the elderly.

A large part of the informal care time is spent on attendance and companionship and less on the hard core of care tasks (nursing and domestic assistance). This is not surprising, as approximately 60% of the dementia group require supervision during the day or at night. A further consideration is that more than a quarter of the family carers are the partner of a person with dementia and another quarter are children living at home.

We can compare our results with the pilot study conducted under the EACH project for persons with Alzheimer's disease in home care (1). A number of research instruments used in this study were included in the Qualidem study (diaries and interviews with voluntary carers), with the earlier results providing a point of reference (Table 3).

TABLE 3
 Cost price of professional care time spent on elderly persons with dementia in home care, in euros per week (2002)

	Control group (n=48)	Dementia group (n=28)	Sign. lev. F value*	Pilot study in 1998 ¹ (n=31)
Professional carers				
Home help and cleaning	67.2	77.7	n.s.	100.1
Home nurse	26.1	57.6	0.05	88.7
General practitioner	6.3	6.6	n.s.	11.1
Physiotherapist	4.9	15.6	n.s.	25.7
Specialist doctor	1.5	2.1	n.s.	–
Social work	5.4	0.0	n.s.	0.0
Other	1.2	2.5	n.s.	4.3
Material aids				
Medication	33.9	39.0	n.s.	29.33
Nursing aids	4.2	7.0		7.02
Durable aids	3.0	2.6	n.s.	11.73
Extra living costs	7.0	16.7	0.01	
Total professional care costs	155.3	227.4	n.s.	279.9
Personal care				
Personal care	13.8	75.9	0.001	600.8
Practical assistance	66.7	266.8	0.001	550
Attendance and companionship	296.7	526.7	n.s.	541.6
Total informal care costs	377.2	869.4	0.10	1,692.4
Total cost price (informal + professional care costs)	532.5	1,096.8	0.10	1,972.3

¹

* n.s.: difference is not significant

The large differences between the two studies are therefore surprising but open to interpretation. Both professional and informal care time is much greater in the pilot study. The differences for professional care are marked for nursing staff, home helpers and physiotherapists. One possible explanation is that the need for care of our research group is lower than in the pilot study, which included only elderly persons requiring intensive nursing and care (home nursing care Katz score B or C) with a high degree of co-morbidity. When we also compare the informal care time, we find a great discrepancy between both research groups with regard to the use of time for practical help and personal care. The time for personal care amounts, on average, to 9 times as much in the pilot study than in our research. In contrast to the Qualidem study, where

43% of the persons with dementia were living alone, the pilot study included only 12% of persons living alone. This indicates a greater degree of self-reliance in the first group and a greater availability of voluntary care in the second group (1)

This comparison may indicate that the cost of care increases enormously as the dementia reaches a more advanced stage. The group with serious dementia in our research was too small to test this hypothesis further.

Cost of care

The total costs may be estimated at an average of 1,096.80 euros per week and per elderly person with dementia (Table 3). Roughly three quarters of that figure is accounted for informal care. Leaving the informal costs out of the calculation gives a total of 227.40 euros per week.

Due to the limited response to the question on costs for temporary admission to a hospital, rest home or day-care centre, no account was taken of this factor in the presentation of the results.

Comparison with the earlier pilot study reveals that the dementia group from the Qualidem study occupies an intermediate position between the control group and the group from the pilot study. This reflects the observed differences in the amounts of time spent by professional and informal carers.

2. Comparison with the cost of care for elderly persons with dementia in residential care

Comparison of care time

The data in the diaries also enabled us to calculate the direct care time spent in nursing or rest homes on elderly persons with dementia (Table 4).

In order to make possible a comparison with home care, for which indirect care such as cleaning and preparing meals was also included in the calculation, we made an estimate of the average care time spent by maintenance, kitchen and entertainment staff in residential care. In the 20 institutions in which patients were registered for this study the proportion of maintenance, kitchen and entertainment staff to total care staff is something in the order of 45%. We assume that the mainte-

TABLE 4
Average professional care time spent on persons with dementia in residential care, in minutes per week (2002)

	Control group (n=22)	Dementia group (n=99)	Sign. lev. F value*
Nursing staff & carers	409	568	0.10
Physiotherapist	41	39	n.s.
General practitioner	4	4	n.s.
Social work	1	0	n.s.
Total	455	611	n.s.
Estimated indirect time for maintenance and kitchen work	262	262	
Total professional time	717	873	

* n.s.: difference is not significant

nance and kitchen staff dedicate a more or less equal amount of time to all residents and that the use of time is therefore identical for the members of the dementia group and those of the control group. We therefore increase the direct care time by the 45% of maintenance and catering time. We assume that this time amounts to 262 minutes per week. This brings the total professional care time in a residential facility to 717 minutes for the control group and 873 minutes for the dementia group.

Besides there is also other managerial staff (administrative personnel) involved, but they are left out of the equation in home care, too.

There is a significant difference between home care and institutions. Even if we only consider the professional care time and the strict informal care time in home care, the time spent is still double that of the professional care time in residential care. This shows that there is an appreciable difference in available 'time for care' in favour of home care, despite the fact that more intensive care situations occur in a residential care context. This difference may indicate a residential-side care supply deficit, but it may equally well arise partially from economies of scale existing in the facilities.

Given the highly heterogeneous make-up of the dementia group as regards their need for care (see Table 1), we further subdivided this group into persons with a minor need for care (score O, A or B on the Katz scale) and those with an intensive need for care (score C and Cd on the Katz scale). Once again we calculated the average care time (Table 5).

TABLE 5
Average care time of nursing staff and carers in residential care, in minutes per week related to dementia and the degree of need of care (2002)

	Control group (n=22)	Dementia group Score O, A or B on the Katz scale (n=45)	Dementia group Score C or Cd on the Katz scale (n=54)
Nursing staff & carers	409	399	717

The results of this breakdown are interesting: the care time for elderly persons with dementia with a minor need for care does not differ significantly from that for the control group. However, the care time for patients with dementia having an intensive need for care is significantly higher.

Comparison of care costs

In a second step we converted the care time to care costs. In the 20 institutions included in the survey information was collected on staffing levels (in FTEs) and personnel costs. We converted this into total wage costs per hour, assuming that per FTE 1,500 hours are actually spent on work for the residents. This was added to their price per hour, which is normally calculated on the basis of approximately 1,750 hours per year. This calculation produces an initial cost estimate of 25.60 euros per hour for nursing and caring staff (on the basis of 1,500 hours of service) and 18.20 euros per hour for maintenance and kitchen staff. These prices are in keeping with the rates we applied for home care. For the purposes of further comparison we assumed that the other care professions apply the same cost price as for home care. In Table 6 the final conversion of professional care time is given in terms of money. The total professional care and maintenance costs amount to 282 euros per week for the control group and to 348 euros for the dementia group. In institutions, too, the costs of care for clients with dementia are thus on average higher than for persons without dementia. This is due to a higher need for care of the dementia group.

Comparing residential care with home care, we can state that professional care given in residential care comes at a much higher price than home care. However, in home care, the – very considerable – informal care is usually left out of the equation. If this care were included in the calculation, home care might well be more expensive/onerous for the people involved, but more care time is devoted to the elderly care recipients. This probably also explains why home care is so often preferred to institutional care.

TABLE 6
 Cost price of professional care time spent on elderly persons with dementia in residential care, in euros per week (2002)

	Control group (n=22)	Dementia group (n=99)
Nursing staff & carers	174.5	242.4
Physiotherapist	24.6	23.4
General practitioner	3.0	3.0
Social work	0.5	0.0
Total	202.6	268.8
Estimated indirect costs for maintenance and kitchen staff	79.5	79.5
Average professional cost price	282.0	348.2
Average total cost (accommodation, living and care costs) in nursing homes*	432.8	

We can also measure the results obtained against administrative data on the care cost of the A.C.C. (3) for the affiliated non-profit nursing homes (more than 25% of nursing beds). Based on an analysis of annual accounts, the ACC estimates the cost per elderly patient in nursing homes at an average of 433 euros per week. This cost price includes the accommodation, living and care costs per resident. The estimated cost price is significantly higher than the cost price based on the time recorded in institutions. The higher cost price which emerges from this study is largely attributable to a broader cost definition in the ACC analysis, i.e., inclusive of hotel and living costs. Furthermore, we recorded only the direct care time spent with the patient. Time for education and training, for meetings, for administrative tasks and the like was not taken into consideration.

Finally, we can further subdivide the costs of care for the dementia group according to need for care. The cost price for the control group (predominantly score O on the Katz scale) and the dementia group with slight to moderate need for care (score O, A or B) is appreciably lower than for the serious dementia cases (score C or Cd) (Table 7). We therefore conclude that the care categories, as indexed by the Katz scale, already offer an explanation for the care costs in the facilities. Moreover, the close connection between ADL needs and disorientation or dementia problems and co-morbidity means that additional categories or parameters are most probably redundant (4).

TABLE 7
Care cost of nursing staff and carers in residential care, in euros per week (2002), related to dementia and the need for care

	Control group predominantly score O on the Katz scale (n=22)	Dementia group score O, A or B on the Katz scale (n=45)	Dementia group score C or Cd on the Katz scale (n=54)
Nursing staff & carers	174.5	170.2	305.9

Conclusions

In this study we compared the care available to elderly persons with dementia and to those not suffering from dementia.

For home care, we found that professional care does not differ in any significant way between the control group and the dementia group as regards both recorded care time and care costs. This is rather surprising considering the fact that the dependency of the dementia group is higher than that of the control group. Only for home nursing is care time significantly higher for patients with dementia. We do observe a clear difference though as regards the informal care. The recorded time for personal care and nursing and for practical assistance is significantly higher for elderly persons with dementia than for elderly persons not suffering from dementia. This would suggest the conclusion that informal care has become central to the care now available to elderly persons with dementia. The very fact of its existence means that admission of elderly dementia patients to a nursing home or a rest home may often be avoided, or at least delayed. This is why it is so important that that group should receive all the necessary support, be it financial or organizational.

We also compared the direct care time for elderly persons with dementia and for elderly persons not suffering from dementia in residential care facilities. The only observed disparity was that the care time for nursing staff and carers was significantly higher for the dementia group than for the non-dementia group. Given the highly heterogeneous make-up of the dementia group as regards need for care, we further subdivided the nurses and carers with reference to (i) slight to moderate need for care (score O, A or B on the Katz scale) and (ii) intensive need for care (Katz score C or Cd). The results were quite remarkable: the care time for dementia patients scoring C or Cd was almost twice that dedicated to dementia patients scoring O, A or B. However, this latter group did not differ much from the control group (predominantly score

O). From this it follows that the care cost for the control group and for dementia group members scoring O, A or B is appreciably lower than that for dementia group members scoring C or Cd. We therefore concluded that the care categories indexed by the Katz scale provide, in themselves, an explanation for the care costs charged in the facilities. Moreover, the close connection between ADL requirements and disorientation or dementia problems means that additional categories or parameters are most probably redundant.

We also observed that the residential setting has a great impact on care provision. The recorded time spent by nurses and carers in home care is more than twice that spent in residential facilities, despite the fact that more intensive care situations are more likely to occur in residential care. This is mainly to be attributed to the presence of informal carers who provide a great deal of nursing and care tasks. The residential setting also has an effect on the care costs. We can state that the professional care provided in an institution is much more expensive than that given in the comfort of one's own home. However, the not inconsiderable informal care provided in home care is usually not included in the calculation. Home care may well prove to be more expensive/onerous for the persons involved if calculated at shadow prices.

Acknowledgment

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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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Keywords: dementia, caregiver, stress, depression, workload

Introduction

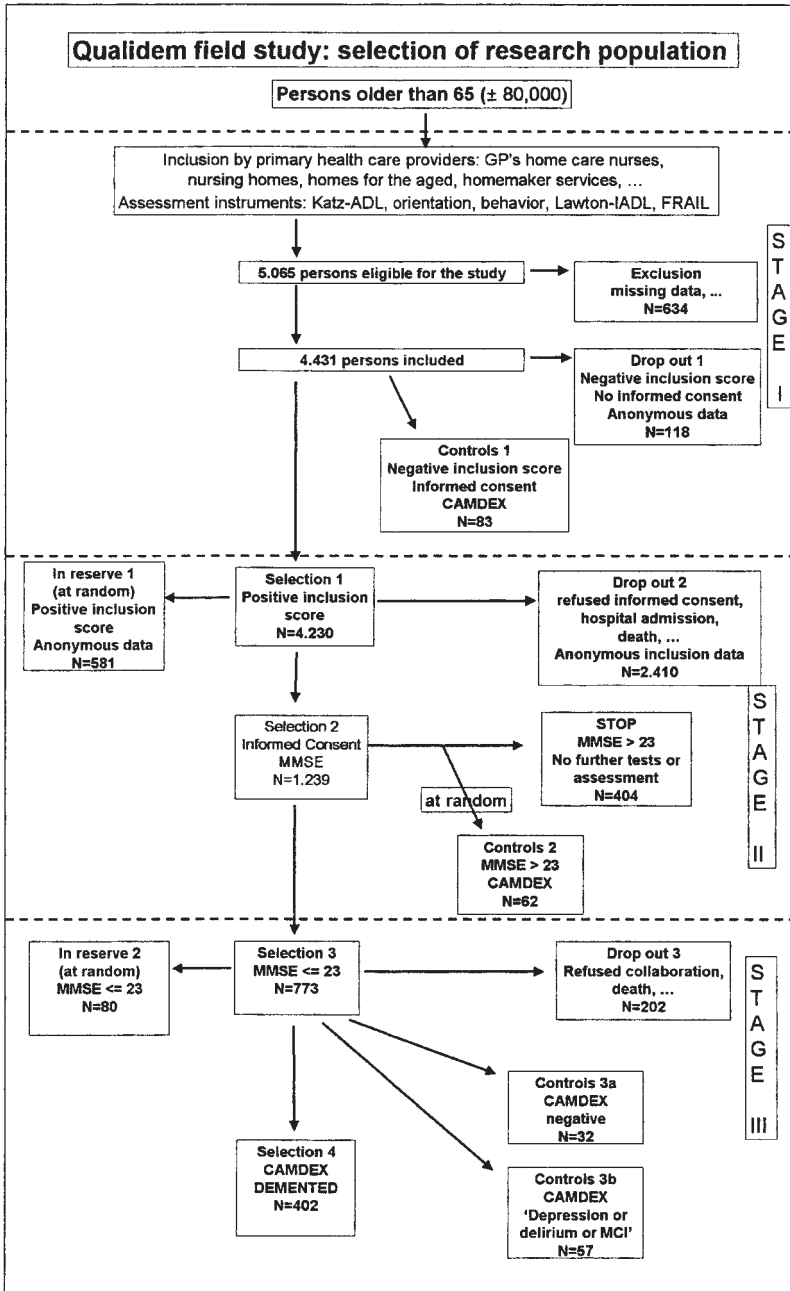
Taking care of a community dwelling demented family member implicates a significant burden on both physical and psychological wellbeing of all persons involved (1-4). Family caregivers of a demented elderly have a higher incidence of depression, feelings of stress en burnout all related to a higher use 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 de 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 (chi² 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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