The effect on caregiver burden of a problem-based home visiting programme for frail older people

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Abstract

Objective: caregiver effects of geriatric care models focusing primarily at the patient have not been consistently studied. We studied caregiver effects of a nurse-led comprehensive geriatric evaluation and management (GEM) programme for community-dwelling frail older people that showed—in a randomised comparison with usual care—health-related quality of life benefits for the care receivers.

Methods: this randomised trial included 110 caregiver/patient dyads who were followed up for 6 months. Primary analyses were intention-to-treat analyses of caregiver burden assessed with Zarit Burden Interview (ZBI; 0–88; higher means more burden). Preplanned subgroup analyses were conducted for cognition, living arrangement and patient/caregiver co-residence.

Results: overall, perceived caregiver burden showed no significant differences between study groups in changes over time. However, perceived burden was at baseline more than eight points higher in caregivers sharing a household with patients (n = 23) compared to caregivers living separately (n = 87). The intervention performed better in caregivers living together with the patient than in caregivers living separately (P for interaction = 0.04). Co-resident caregivers experienced six-Zarit point improvement compared with four-point deterioration in the non-co-resident caregivers.

Conclusions: GEM at home benefited patients, but maybe not caregivers. Caregiver effects are related to whether caregivers live with the patient or not.

Keywords: elderly, primary health care, frail elderly, health services for the aged, clinical trial, caregivers

Introduction

Increasingly, community-based alternatives for institutional geriatric care are disseminated throughout health care [1, 2]. There are very legitimate reasons for the uprise of primary care geriatric evaluation and management (GEM) models. More frail older people rely on primary health care as a result of population ageing and an increasing focus on patient autonomy [3, 4]. However, despite the promises this type of health care holds for vulnerable older people, these models will evidently affect the people who care for them. This influence is not necessarily only positive. Caregivers are in a special position, because on the one hand they are supporting the patient and on the other they are in need of support themselves [5]. Although some of these models provide a specific follow-up for the caregivers and their burden, successful intervention in patients often relies on the caregivers’ participation as well. ‘By recruiting even more of the caregivers’ assistance’ this may increase the burden of caring [6].

Many studies have evaluated the effect of interventions primarily aimed at caregivers [7–10]. These studies suggest that interventions aimed at the caregiver improve outcomes such as caregiver burden, depression or subjective well-being. The benefits of combined intervention programmes focusing on both patients and informal caregivers have also been shown, especially in persons with dementia [11]. The
The Dutch EASYcare study caregiver effects

Dutch Geriatric Intervention Programme (DGIP) is a comprehensive geriatric assessment model, consisting of nurse home visits for frail older patients, that has shown to effectively improve functional abilities and well-being of frail older patients at a reasonable cost [16, 17]. Based on the limited findings available [6, 13–15], we hypothesised that the intervention would also have a beneficial effect on caregiver burden. The objective of this paper is to describe the effects of this model of home visits on caregiver burden.

Methods

Design

We conducted an observer-blind randomised controlled trial of which the design was previously published [18]. The local ethical committee approved the study.

Study population

General practitioners referred independently living older patients to our model of nurse home visits. Patients lived in their own home or in a home for the aged and had to be 70 years of age or older. An informal caregiver was defined as a person who felt prime responsibility for the well-being of and care for the patient and who was closely involved in the care for the patient as non-professional.

We restricted patient inclusion to those patients with one or more limitations in cognition, (instrumental) activities of daily life, or mental well-being. We excluded persons already receiving forms of intermediate care or health care from a social worker or community-based geriatrician, persons on the waiting list for a nursing home and those who had a life expectancy of <6 months because of terminal illness.

Randomisation

Patients/caregiver dyads were randomised over two treatments arms: home visits and usual care. The control group received unrestricted care as usual: mainly focusing on single complaints with little attention for integral case management and health promotion. We used a two-step pseudo cluster randomisation procedure, because individual randomisation risked contamination because the general practitioner might learn from or use elements of DGIP and cluster randomisation risked selection bias due to expected treatment arm preferences of recruiting general practitioners [19–21]. Pseudo cluster randomisation divided the general practitioners in two groups; group H (high fraction of participants randomised to intervention arm) and group L (low fraction of participants randomised to intervention arm) [19–21]. The general practitioners were not informed which group they were in. The participants recruited through general practitioners of group H were then randomised in an 80/20 ratio to, respectively, DGIP and usual care; in group L this ratio was reversed: 20% DGIP and 80% usual care.

Intervention

The intervention (DGIP) used a problem-based selection procedure performed by the general practitioner. The problems targeted concerned cognition, nutrition, behaviour, mood or mobility, and required nursing assessment, coordination of care, therapeutic monitoring or case management. Up to six visits for GEM were planned within the next 3 months. The interventions focused on the care receiver in the first place. The nurse conducted the main part of the intervention. The general practitioners continued their usual medical care. Moreover, they made referrals, medication changes and other interventions as agreed upon during consultations with the nurse and geriatrician on individual cases. The general practitioner kept prime responsibility for the care of the patient and made the final decisions. As part of the home visits, the nurse also performed a caregiver burden assessment [22, 23]. The results were implemented in the care plan; for instance, the nurse gave extra attention to educate the caregiver about the disorders their relative suffered from, organised extra (adult day) care or taught the caregiver how to handle behavioural disturbances in dementia.

Data collection and outcome measures

A researcher interviewed patients at home to obtain written informed consent and to collect baseline demographic characteristics. If the patient was not capable to give informed consent, we asked a proxy to do so. We collected data on demographics of the caregiver, their relationship with the patient, type and amount of care provided, time spent on caring and caregiver burden. Also data were collected on competing time-demanding activities such as work, caring for a family or leisure time activities.

These measurements were repeated 3 and 6 months after inclusion. The primary outcome measure for the caregivers was caregiver burden measured with the Zarit Burden Interview (ZBI; range 0–88, with burden increasing with the score). The secondary outcome was time spent on care.

Statistical analysis

We performed intention-to-treat analyses on the difference in the change from baseline over time. A mixed linear model was used to account for clustering at the level of the general practitioner.

Subgroup analyses were performed for living independently versus living in a home for the aged, higher versus lower levels of cognitive function and patient and caregiver living together or not.

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of the caregivers, 11% indicated they could rely on no one else in the care for the patient. This was highest among spouse caregivers (6 of 20). Sixty-two per cent of the caregivers spent less time on other activities because of the care for the patient. At baseline, caregivers scored a mean ZBI score of 29.9. The age of the patient was higher in the usual care group (Table 1).

The nurse visited intervention patients 3.8 times (SD 1.3). These visits lasted 1.3 h on average. Problem analysis was an important component of these visits. The interventions focused mainly on advices and coordination of care. In 28 cases, the nurses taught the caregiver how to handle a specific behaviour, and in 15 cases they provided education and information to the caregiver about the disorders their relative suffered from. Further details on the contents of the DGIP intervention can be found in Melis et al [16]. A detailed comparison of the interventions received in both study arms (DGIP and usual care) is provided in the paper describing the cost-effectiveness results of the Dutch EASYcare study: comparison of the interventions received in both study arms (DGIP and usual care) is provided in the paper describing the cost-effectiveness results of the Dutch EASYcare study.

Table 1. Demographic characteristics and outcome measures of the study population at enrolment

<table>
<thead>
<tr>
<th></th>
<th>Usual care (n = 49)</th>
<th>Home visits (n = 61)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age patient (mean ± SD)</td>
<td>83.5 ± 6.1</td>
<td>81.1 ± 5.7</td>
<td>0.03</td>
</tr>
<tr>
<td>Female sex patient, n (%)</td>
<td>35 (71.4)</td>
<td>44 (72.1)</td>
<td>0.98</td>
</tr>
<tr>
<td>Patient living in a home for the aged, n (%)</td>
<td>9 (18.8)</td>
<td>6 (9.8)</td>
<td>0.24</td>
</tr>
<tr>
<td>Mini-Mental State Examination patienta</td>
<td>21.1 ± 5.6</td>
<td>21.9 ± 5.8</td>
<td>0.51</td>
</tr>
<tr>
<td>Caregiver</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age caregiver (mean ± SD)</td>
<td>56.3 ± 13.0</td>
<td>55.5 ± 12.6</td>
<td>0.52</td>
</tr>
<tr>
<td>Female sex caregiver, n (%)</td>
<td>33 (68.8)</td>
<td>46 (75.4)</td>
<td>0.39</td>
</tr>
<tr>
<td>Living together with the patient, n (%)</td>
<td>7 (14.3)</td>
<td>16 (26.2)</td>
<td>0.17</td>
</tr>
<tr>
<td>Travel distance (km), if living separately, median (interquartile range)</td>
<td>4.7 (2.1–13.0)b</td>
<td>5.1 (2.4–9.3)b</td>
<td>0.21c,d</td>
</tr>
<tr>
<td>Travel time by cars (min), if living separately, median (interquartile range)</td>
<td>10.0 (5.0–21.0)b</td>
<td>11.0 (6.5–18.0)b</td>
<td>0.15c,d</td>
</tr>
<tr>
<td>Relationship with patient, n (%)</td>
<td>5 (10.2)</td>
<td>15 (25.4)</td>
<td>0.08</td>
</tr>
<tr>
<td>Time spent… (h/week), median (interquartile range)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Together</td>
<td>5.5 (3.5–10.0)</td>
<td>6.0 (3.5–168.0)</td>
<td>0.06c</td>
</tr>
<tr>
<td>On personal care</td>
<td>0.4 (0–2.0)b</td>
<td>0.5 (0–3.0)b</td>
<td>0.83c</td>
</tr>
<tr>
<td>On assistive activities: housekeeping, administration, etc.</td>
<td>2.0 (1.0–4.0)b</td>
<td>3.0 (1.0–7.0)b</td>
<td>0.15c</td>
</tr>
<tr>
<td>Had no help from others in caring, n (%)</td>
<td>6 (12.2)</td>
<td>9 (14.8)</td>
<td>0.76</td>
</tr>
<tr>
<td>Had less time for other activities because of care for patient, n (%)</td>
<td>26 (53.1)</td>
<td>33 (54.1)</td>
<td>0.96</td>
</tr>
<tr>
<td>Zarit Burden Interview (mean ± SD)c</td>
<td>30.4 ± 14.5</td>
<td>27.9 ± 12.4</td>
<td>0.33</td>
</tr>
</tbody>
</table>

*aMMSE (Mini-Mental State Examination) ranges from 0 to 30, with 30 indicating best score.

bFor skewed variables, median and quartiles are presented.

cFor skewed variables, P-values were calculated using the square root transformed score.

dAlthough the medians are presented only for the caregivers who lived separately from their relative, the P-value was derived from a model testing the difference between the complete intervention and control group.

eZarit Burden Interview ranges from 0 to 88, with zero indicating best score.

Results

In and around Nijmegen, the Netherlands, 55 general practitioners participated. During an inclusion period of 21 months that started at 1 April 2003, 155 patients eligible for the study were included as patients (please see the figure Appendix 1 in the supplementary data available at Age and Ageing online). Of these, 110 patients with a caregiver were included in follow-up and analysis for the objectives described in this paper: 61 were allocated to the intervention arm and 49 to the control arm. The caregivers who participated in this trial had a mean age of 56.3 years and 73% of them were females (Table 1). They cared for very frail patients, who were mostly females (72%) with a mean age of 82.2 years and much comorbidity. Fifty-eight per cent of the caregivers were daughters or sons of the patient. Caregivers who did not share their household with the patient lived median only 5 km away.

Patients experienced episodes of anxiety, wandering or confused, restless or panicking behaviours, according to 96% of the caregivers. More than half the caregivers (52%) felt that they always had to be watchful. Caregivers and patients spent a median 6 h/week together. During this time, the caregivers spent half an hour on personal care and 2 h on assistive activities such as administration, organising care, domestics etc. These data were skewed; some caregivers spent more than a working week caring for their relative.

Of the caregivers, 11% indicated they could rely on no one else in the care for the patient. This was highest among spouse caregivers (6 of 20). Sixty-two per cent of the caregivers spent less time on other activities because of the care for the patient. At baseline, caregivers scored a mean ZBI score of 29.9. The age of the patient was higher in the usual care group (Table 1).

The nurse visited intervention patients 3.8 times (SD 1.3). These visits lasted 1.3 h on average. Problem analysis was an important component of these visits. The interventions focused mainly on advices and coordination of care. In 28 cases, the nurses taught the caregiver how to handle a specific behaviour, and in 15 cases they provided education and information to the caregiver about the disorders their relative suffered from. Further details on the contents of the DGIP intervention can be found in Melis et al [16]. A detailed comparison of the interventions received in both study arms (DGIP and usual care) is provided in the paper describing the cost-effectiveness results of the Dutch EASYcare study: less units of hospitalisation and institutionalisation were used, whereas more home care, adult day care and meals-on-wheels were used in the DGIP arm [17].

After 3 months of follow-up, the burden of caregivers in the intervention groups showed a non-significant decrease of −0.7 points [95% confidence interval −4.0–2.7] compared to the change in burden over this period in the control caregivers. After 6 months, the burden of caregivers in the
The subgroup analyses showed that at 6 months, the home visits programme improved burden by 6.2 points in caregivers in the intervention group sharing no household compared to the control caregivers (P-value for this interaction = 0.04) (Table 3). No other significant interactions were found.

### Discussion

Caregiver burden was high in the caregivers that participated in this study compared to reference populations [24, 25]. The nurse-led intervention model for frail older people that was tested in this randomised controlled trial had no overall positive effect on caregiver burden and the time the caregiver spent on caring. However, caregivers sharing a household with the patient may have benefited, whereas the intervention may have had negative effects on caregiver burden in those caregivers living separately.

Based on a review of the available literature, our initial hypothesis was that the intervention would have a beneficial effect on caregiver burden. Overall, the intervention did not show such an improvement of caregiver burden. Although the increase of the burden at 6 months with 2.3 points (−1.6–6.2) compared with the change over this time period in control caregivers (Table 2).

The intervention increased the time spent on assistive activities such as administration and housekeeping with 1.9 h/week (−2.2–6.0) at 6 months follow-up, but this increase was non-significant. No effect on the amount of time spent on personal care was found. Caregivers sharing a household with their relative (n = 23) were older (mean age 73 vs. 52 years for caregivers living separately), more frequently men (11 of 23 vs. 16 of 75), almost always spouse (20 of 23 vs. 0 of 85) and had higher ZBI scores at baseline [mean score 33.9 (SD 15.0) vs. 27.9 (12.8)] than caregivers living separately. Also, caregivers sharing a household spent more time on personal care (median 7.0 vs. 0.25 h/week) and more time on other assistive activities (median 10.5 vs. 2.0 h/week) at baseline.

The subgroup analyses showed that at 6 months, the home visits programme improved burden by 6.2 points in caregivers living together with the patient, while burden worsened by 4.0 points on ZBI in caregivers in the intervention group sharing no household compared to the control caregivers (P-value for this interaction = 0.04) (Table 3). No other significant interactions were found.

### Table 2. The effect of the intervention on caregiver burden and time spent on caring for the patient at 3 and 6 months follow-up\(^a\)

<table>
<thead>
<tr>
<th>Outcome measure</th>
<th>Baseline (T(_0))</th>
<th>3 months’ follow-up (T(_1))</th>
<th>6 months’ follow-up (T(_2))</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Home visits</td>
<td>Usual care</td>
<td>D CI N</td>
</tr>
<tr>
<td>Zarit Burden Interview(^b)</td>
<td>27.9 ± 12.4</td>
<td>30.4 ± 14.5</td>
<td>0.7 −4.0−2.7 (92) 28.7 ± 13.6 30.7 ±12.5 2.3 −1.6–6.2</td>
</tr>
<tr>
<td>Time spent on personal care (h/week)</td>
<td>0.5 (0−3.0)c</td>
<td>0.4 (0−2.0)c</td>
<td>0.5 (0−6.5)c</td>
</tr>
<tr>
<td>Time spent on other assistive activities (h/week)</td>
<td>3.0 (1.0–7.0)c</td>
<td>2.0 (1.0–4.0)c</td>
<td>2.0 (1.0–7.0)c</td>
</tr>
</tbody>
</table>

\(^a\)Intervention effect: difference (D) and its 95% confidence interval (CI) in changes over time from baseline to 3 and 6 months between intervention and control group for each of the strata of the possible effect modifiers and the P-value for the interaction (P interaction).

\(^b\)Primary outcome caregiver.

\(^c\)For skewed variables, median and quartiles are presented.

### Table 3. Subgroup analyses of the effect of the intervention on caregiver burden (ZBI) in association with possible effect modifiers\(^a\)

<table>
<thead>
<tr>
<th>Effect modifier</th>
<th>3 months’ follow-up (T(_1))</th>
<th>6 months’ follow-up (T(_2))</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>D CI N</td>
<td>D CI N</td>
</tr>
<tr>
<td>Patient Mini-Mental State Examination &lt;21 (n = 42)</td>
<td>0.0 0.75</td>
<td>1.7 0.75</td>
</tr>
<tr>
<td>Patient Mini-Mental State Examination ≥21 (n = 68)</td>
<td>−1.1</td>
<td>3.0</td>
</tr>
<tr>
<td>Patient independent (n = 94)</td>
<td>−0.6 0.42</td>
<td>2.3 0.19</td>
</tr>
<tr>
<td>Patient in home for the aged (n = 15)</td>
<td>−5.2</td>
<td>−9.5</td>
</tr>
<tr>
<td>Patient and caregiver live together (n = 23)</td>
<td>−2.7 0.53</td>
<td>−6.2 0.04</td>
</tr>
<tr>
<td>Patient and caregiver live separately (n = 85)</td>
<td>0.0</td>
<td>4.0</td>
</tr>
</tbody>
</table>

\(^a\)Intervention effect: difference (D) in change over time from baseline to 3 and 6 months between intervention and control group for each of the strata of the possible effect modifiers and the P-value for the interaction (P interaction).
caregivers probably did not satisfactorily describe the effect of the intervention on caregiver burden (Table 3). The intervention performed convincingly better in caregivers living together with the patient than in caregivers living separately. This observation certainly made sense, because the involvement of the caregivers also depended on their living arrangement: burden at baseline was almost eight points higher in caregivers living together, and they spent more time on caring. Because their needs were higher, caregivers sharing a household probably were more sensitive to intervention. In caregivers not sharing their household with the patient, the feeling that the intervention only implied extra tasks may have prevailed. The intervention may also have made them more conscious of the vulnerability and impairments of their relative.

Our finding of an interaction between living arrangement and treatment was in line with the results of a randomised study on caregiver support in dementia care that showed that beneficial effects were to be expected in caregivers sharing a household with the demented patient [27]. Other studies have also shown that caregiver burden and caregiver involvement may depend on living arrangement [28, 29].

How should we understand our overall non-beneficial and possibly negative effects of in-home GEM in comparison with the positive results found in other studies? We feel that the interaction between living arrangement and in-home GEM treatment offers the best explanation for these contradicting results; whereas our study included no >25% caregivers living together, other studies included numbers of ∼40–50% [6, 14, 15]. As stated, the intervention effect in our study was significantly better in precisely the group of caregivers sharing a household with the patients. Given that this was a randomised study that we were able to conduct—as stated below—without important methodological limitations, it was not very likely that our observations resulted from bias. Subgroup analyses can be a difficult issue to handle. Still, they show a plausible effect and were preplanned because heterogeneity of the study groups might condition the results; therefore, the potential impact of respondent groups should be considered. However, future studies are needed and will have to confirm the observed interaction between living arrangement and in-home GEM in order to prove its definitive relevance.

There were some methodological issues that deserve attention. Our study arms were different in size. Numerical imbalance between study arms harms statistical efficiency, but this only occurs when the imbalance is larger than a factor 2 [30]. Patient randomisation minimised the possibility of selection bias. The comparison of patients’ baseline characteristics (Table 1) and the results of sensitivity analyses confirmed this statement [20]. Patients in the usual care group were only slightly older. Therefore, we did perform a sensitivity analysis adjusting for age of patient, which showed approximately the same results as the uncorrected analysis (data not shown). A total of 10–20% of the included caregivers were not included in the primary analysis of burden, because of missing values. A sensitivity analysis of the primary outcome assigning the mean of the other group to the missing values gave about the same results.

Our trial results showed that the effect of GEM in the community on caregiver burden was probably dependent on the living arrangement of caregiver and patient; the intervention performed convincingly better in caregivers living together with the patient—who suffer the highest burden—than in caregivers living separately. This difference may be caused by different levels of involvement of the caregivers. This result deserves further attention in future research. With increasing popularity of primary care alternatives for vulnerable older people, attention for the caregiver is a necessity, both in developing health care interventions, as in their evaluation and implementation.

Key points

- Caregiver effects of in-home GEM models aiming at the care receiver in the first place have not been consistently studied.
- In the Dutch EASYcare study, caregivers not sharing a household with the care receiver may have experienced an increase in caregiver burden from the GEM intervention, whereas burden may improve in co-resident caregivers.
- With increasing popularity of primary care alternatives for vulnerable older people, attention for the caregiver is a necessity, both as part of the intervention, as in their evaluation.

Supplementary data

Supplementary data are available at Age and Ageing online.

Conflicts of interest

None declared.

References

Dutch EASYcare study caregiver effects


