The neuropsychiatry of dementia: psychometrics, clinical implications and outcome
Kat, M.G.

Citation for published version (APA):
Kat, M. G. (2009). The neuropsychiatry of dementia: psychometrics, clinical implications and outcome

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The emotional impact of psychiatric symptoms in dementia on partner carers. Do carer, patient and situation characteristics make a difference?

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Martin G. Kat
Willem van Tilburg
Cees Jonker
Rose-Marie Dröes

ABSTRACT

This study aims to investigate the emotional impact of psychiatric symptoms of patients with dementia on their caregiving partners, and to explore if carer, patient and situation factors predict this emotional impact on carers.

A cross-sectional design was used. Partners of patients with slight to moderately severe dementia who live in the community (n=85) were interviewed. In a subgroup (n=58) potential predictors of emotional impact of psychiatric symptoms on carers were studied. Agitation, irritability, apathy and disinhibition produced the highest mean emotional impact scores in carers. Besides by the neuropsychiatric symptoms themselves, the emotional impact of these symptoms on carers was predicted by sense of competence, degree of care needed by the patient and financial expenditure due to the caregiving situation.

The emotional impact of psychiatric symptoms on carers is predicted by several patient, carer and situation factors. Interventions aimed at decreasing the experienced burden of carers should therefore not only focus on the psychiatric symptoms of the patient, but also on the sense of competence of the carer and the financial burden due to the caregiving situation.

Keywords: burden, carer, dementia, emotional stress, predictors
INTRODUCTION

Dementia is the most disabling psychiatric disorder in the elderly. In the Netherlands, two-thirds of the elderly people with dementia live at home and they are often cared for by spouses, children, other close relatives or acquaintances. Despite the fact that many studies have reported on the negative physical, psychological and social consequences of caring for a person with dementia, policy makers aim at keeping persons with dementia in the community as long as possible, and this is also often the wish of the patients and carers themselves. Since experiences of burden and depression in carers are major predictors of nursing home admission, it would be interesting to know what specific factors determine carer burden. Insight into these determinants or predictors could be helpful in designing interventions aimed at diminishing the experienced burden by carers and could in that way perhaps lead to delayed nursing home admission. In the literature several models for carer burden are described. In studying the factors that determine carer burden, several perspectives have been used in the literature. Some studies focus mainly on patient characteristics, others focus on carer characteristics as well, and some also take into account factors related to the caregiving situation.9, 10, 11

In this study we used the emotional impact of psychiatric symptoms of patients with dementia as a proxy marker for carer burden. The aim of this explorative study was to investigate the emotional impact of psychiatric symptoms of patients with dementia who live in the community on their caregiving partners, and to explore whether carer, patient and situation factors can predict this emotional impact on carers. As the theoretical basis of this study we used the ‘Model of determinants of subjective burden of carers of persons with dementia’ by Dröes et al. (see Figure 1). This model combines several aspects of determinant models with the general stress-appraisal-coping theory of Lazarus and Folkman and the crisis model of Moos and Tsu. Dröes et al. assume that both the person with dementia and their carer have to deal with general adaptive tasks as a consequence of the disease. Adaptive tasks for the carer are e.g.: Coping with the disabilities and psychiatric symptoms of the person with dementia, maintaining a positive self-image, an emotional balance, and social relationships. Whether these tasks lead to (over)burden, negative physical, psychological or social consequences depends mainly on the way individual carers cope with them (see also 5, 25-27) and the sense of competence they experience as a result of this (see also 11). The model also describes how factors such as personal characteristics, health, and material and social circumstances (including the need of the person with dementia for care, and psychiatric symptoms) (see also 5, 10, 11), as well as received objective and experienced support
(see also 11, 21), might influence the ways the carer copes with the adaptive tasks. In this manner individual differences in the emotional impact of dementia on carers are explained.

Figure 1. Model of determinants of subjective burden of carers of persons with dementia by Dröes et al.14
METHODS

Design
In this study we used a cross-sectional design. Between May 2000 and February 2002, partners of patients with dementia who participated in the Meeting Centres Support Programme (MCSP) were interviewed at the start of the study or at the start of their participation in the programme. The interviews focused on the emotional impact they experienced from psychiatric symptoms of the person with dementia and on factors that might determine individual differences in this emotional impact on carers. In addition to carer characteristics (gender, age, education, work, coping, sense of competence), we also inventoried patient characteristics (gender, age, education, diagnosis, degree of needing care/assistance, and psychiatric symptoms) and situation characteristics (additional financial expenditure due to the caregiving situation, duration of caregiving, objective and experienced support).

Subjects
The study population was drawn from a large multicenter study on conditions for successful implementation of Meeting Centres for persons with dementia and their carers in the Netherlands (IMO-project). This study was conducted in ten meeting centres. In all recently started meeting centres (n=8) all clients that were admitted in the MCSP (patients with dementia and their carers) were asked to participate. In the two already existing meeting centres in Amsterdam new as well as current clients were asked. The reason for this was to increase the size of the study sample.

For the present study part of this study population was included, i.e. partners of persons with dementia and the persons with dementia they cared for. Of the 98 couples that were eligible, 13 (13%) were excluded (see Figure 2), while 85 (87%) participated in the study, after informed consent was obtained. In the new participating couples (n=58) all information was gathered as described above (see design). In the couples (n=27) that already participated in the MCSP only background features were collected and not the other potential determinants of burden (sense of competence, coping, objective and experienced support).
Figure 2. Flow chart of the study population (carers and the persons with dementia they care for).

Setting
All participants in the study (carers and patients) attended the MCSP. This is a comprehensive, combined programme for patients with dementia and their carers, that is organized in general community centres and centres for the elderly. It offers information and emotional, social and practical support to people with dementia and their informal carers by means of a social club for the person with dementia on three days a week, and eight to ten informative meetings and a bi-weekly long-term discussion group for the carers. Besides the support mentioned, both patient and carer can utilize the weekly consulting hour and participate in social festivities and excursions. Support and case-management are supplied by a small professional staff (f.i. a psychologist, an activity therapist and a nursing assistant) that cooperates according to a collaboration protocol with the local professional care and welfare services that are involved with persons with
dementia, f.i. the general practitioners, community work, home care, and the Regional Community Mental Health Care Organization.

The content of the programme, the applied support strategies and the research into the effectiveness of the support offered are described elsewhere in more detail.\textsuperscript{28-31} Theoretically the program is based on the so-called Adaptation-coping model\textsuperscript{32-34} (see also \textsuperscript{23,24}) and the Model of determinants of subjective burden of carers of persons with dementia.\textsuperscript{14} Both the patient with dementia and his carer are supported in coping with the adaptive tasks they encounter as a consequence of the dementia. Examples are: coping with disabilities, maintaining an emotional balance, preserving a positive self image, developing an adequate care relationship with professional carers, maintaining social relationships and preparing for an uncertain future.

**Instruments and procedures**

**Carer measures**
The emotional impact of psychiatric symptoms of the person with dementia on the carer was measured with the Dutch version of the NeuroPsychiatric Inventory Distress Scale or NPI-D\textsuperscript{35} that is part of the NeuroPsychiatric Inventory or NPI.\textsuperscript{36} In an interview the carers were asked to rate on a scale from 0 (not at all distressing) to 5 (extremely distressing), how distressing they consider each of the 12 psychiatric symptoms that are described in the NPI. The emotional impact of psychiatric symptoms is considered low when NPI-D score=0-1, medium when NPI-D score=2-3 and high when NPI-D score=4-5.\textsuperscript{35} In this study all interviews were conducted by independent, trained graduate students. During the interviews also sociodemographic and situational variables (age, gender, education, duration of caregiving, etc.) were registered.

In a subgroup of carers (n=58) the interviews consisted of more elaborate measurements. As (potential) determinants of feelings of burden the following aspects were measured: sense of competence, coping strategies, and objective and experienced support. These were assessed by means of the modified version of the Sense of Competence Scale\textsuperscript{37} ($\alpha=0.79$), the Jalowiec Coping Scale\textsuperscript{38,39} ($\alpha$ varies from 0.64 to 0.97), the Adapted Use of Services Checklist\textsuperscript{40,41} and the Social Support List\textsuperscript{42} ($\alpha=0.87$) respectively.

As it is not inconceivable that a particular order in tests and questionnaires may cause a systematic (group) effect, all tests and questionnaires were carried out on the basis of a so-called balanced incomplete block design.\textsuperscript{43}

**Patient measures**
Sociodemographic variables (age, gender, education) were registered during an interview with the carer. Information regarding the diagnosis and type of dementia was provided
according to the DSM-IV criteria\textsuperscript{44} and the Standard of the Dutch Society of General Practitioners,\textsuperscript{45} by the general practitioner or attending physician (f.i. a neurologist at the memory clinic). The severity of dementia was assessed with the Dutch version of Reisberg’s Global Deterioration Scale\textsuperscript{46, 47} ($\alpha$=0.90). The ‘degree of needing care/ assistance’ was assessed with subscale 1 of the Assessment Scale for Elderly Patients\textsuperscript{48} ($\alpha$=0.94) by the supervisor of the meeting centre. Neuropsychiatric symptoms were measured with the Dutch version of the NeuroPsychiatric Inventory\textsuperscript{36, 49, 50} ($\alpha$=0.88) during the interview with the carer. The presence of 12 neuropsychiatric symptoms was assessed, and if present, the frequency (range 1 to 4) and severity (range 1 to 3) of the symptom was measured. For each symptom a NPI score was calculated by multiplying the frequency and severity scores (range 1 to 12). The total NPI score was calculated by adding the 12 symptom scores (range 0-144).

\section*{Data analysis}
For the analysis of the data we used the SPSS-Windows 10.1 programme. To determine whether the ten meeting centres could be treated as one homogeneous group in the analysis, we first tested with the Kruskal Wallis test if they differed significantly on variables that, according to the literature, were likely to interfere with the relationship between psychiatric symptoms of the person with dementia and the emotional impact on the carer, i.e. severity of dementia and sense of competence of the carer.

The Cronbach’s alpha coefficient was determined to assess the internal consistency of the NPI.

To inventory the prevalence of psychiatric symptoms in persons with dementia and their emotional impact on carers, mean scores and standard deviations were calculated (n=85) for each symptom.

Subsequently, the relationship between psychiatric symptoms (frequency, severity, frequency times severity) and their emotional impact on carers was tested with Pearson’s correlation.

Hierarchical multiple linear regression analyses (with a stepwise selection strategy, using the F-statistic with $p=0.05$ as the criterion for selection) were performed to identify which carer, patient and situation factors besides psychiatric symptoms, predict the emotional impact of the psychiatric symptoms on carers (n=58). Residual analyses were performed to search for violations of necessary assumptions. All tests were two-tailed and we used a 5% significance level.
RESULTS

There were no significant differences between the different meeting centres with respect to severity of dementia ($\chi^2=8.47$, df=9, p=0.48) and sense of competence ($\chi^2=6.05$, df=7, p=0.53). We therefore treated the respondents as one homogeneous group.

Table 1 presents characteristics of the total group of carers and patients (n=85), and the subgroup who participated in the extensive measurement (n=58). These groups were comparable on most characteristics. As expected, the median of duration of caregiving was shorter in the extensive measurement group (which consisted of new clients). According to the general practitioner or attending physician, the diagnosis of dementia met the criteria of the DSM-IV or the Standard of the Dutch Society of General Practitioners in 82.4% of all patients, in 8.2% these criteria were not met (some of these patients had severe memory complaints but not a dementia syndrome, others had an amnestic syndrome or other diagnosis (f.i. depression)), and in 9.4% this information was missing. For the persons with other diagnosis than dementia at baseline, the diagnosis of dementia was confirmed during the experimental phase.

All but two patients showed psychiatric symptoms. Table 2 gives an overview of these symptoms that were observed by the carers in the patients (n=83) and their mean emotional impact on carers. Cronbach’s $\alpha$ was calculated on data from all respondents and was 0.62 for NPI total score, 0.64 for NPI frequency, 0.64 for NPI severity, and 0.71 for NPI emotional impact.

Apathy and depression were the most common symptoms, being present in 63 and 52 patients respectively, and these symptoms have a high mean emotional impact on carers compared to other symptoms in our study as do agitation, irritability, and disinhibition.

The emotional impact of psychiatric symptoms on carers is significantly related to the NPI total score ($r=0.83$, p < 0.01), frequency of symptoms ($r=0.83$, p < 0.01), and severity of symptoms ($r=0.89$, p < 0.01).
### Table 1. Carer and patient characteristics at baseline

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Total group (n=85)</th>
<th>Extensive measurement group (n=58)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Carer</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>male</td>
<td>25 (29.4%)</td>
<td>17 (29.3%)</td>
</tr>
<tr>
<td>female</td>
<td>60 (70.6%)</td>
<td>41 (70.7%)</td>
</tr>
<tr>
<td>Age</td>
<td>71.1 (sd 8.8)</td>
<td>72.0 (sd 8.1)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>lower (vocational) education</td>
<td>39 (45.9%)</td>
<td>29 (50.0%)</td>
</tr>
<tr>
<td>secondary education</td>
<td>34 (40.0%)</td>
<td>23 (39.7%)</td>
</tr>
<tr>
<td>higher (vocational) education</td>
<td>12 (14.1%)</td>
<td>6 (10.3%)</td>
</tr>
<tr>
<td>Work</td>
<td></td>
<td></td>
</tr>
<tr>
<td>paid work</td>
<td>5 (5.9%)</td>
<td>3 (5.2%)</td>
</tr>
<tr>
<td>other</td>
<td>80 (94.1%)</td>
<td>55 (94.8%)</td>
</tr>
<tr>
<td>Duration caregiving (in months)</td>
<td>36 (median)</td>
<td>24 (median)</td>
</tr>
<tr>
<td>range</td>
<td>5-156</td>
<td>5-120</td>
</tr>
<tr>
<td>Additional financial expenditures</td>
<td></td>
<td></td>
</tr>
<tr>
<td>yes</td>
<td>48 (56.5%)</td>
<td>31 (53.4%)</td>
</tr>
<tr>
<td>no</td>
<td>37 (43.5%)</td>
<td>27 (46.6%)</td>
</tr>
<tr>
<td>Limited in activities by this:</td>
<td>5 (5.9%)</td>
<td>3 (5.2%)</td>
</tr>
<tr>
<td><strong>Patient</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>male</td>
<td>62 (72.9%)</td>
<td>42 (72.4%)</td>
</tr>
<tr>
<td>female</td>
<td>23 (27.1%)</td>
<td>16 (27.6%)</td>
</tr>
<tr>
<td>Age</td>
<td>73.9 (sd 7.6)</td>
<td>75.0 (sd 6.3)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>lower (vocational) education</td>
<td>30 (35.3%)</td>
<td>24 (41.4%)</td>
</tr>
<tr>
<td>secondary education</td>
<td>40 (47.1%)</td>
<td>26 (44.8%)</td>
</tr>
<tr>
<td>higher (vocational) education</td>
<td>15 (17.6%)</td>
<td>8 (13.8%)</td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alzheimer’s disease/Vascular Dementia</td>
<td>60 (70.6%)</td>
<td>32 (55.2%)</td>
</tr>
<tr>
<td>Other types of dementia</td>
<td>14 (16.5%)</td>
<td>18 (31.0%)</td>
</tr>
<tr>
<td>Amnestic Syndrome*</td>
<td>1 (1.2%)</td>
<td>1 (1.7%)</td>
</tr>
<tr>
<td>Severe memory complaints*</td>
<td>2 (2.4%)</td>
<td>2 (3.5%)</td>
</tr>
<tr>
<td>Depression*</td>
<td>2 (2.4%)</td>
<td>1 (1.7%)</td>
</tr>
<tr>
<td>Unknown</td>
<td>6 (7.1%)</td>
<td>4 (6.9%)</td>
</tr>
<tr>
<td>Severity of dementia (GDS)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very mild cognitive decline</td>
<td>12 (14.1%)</td>
<td>9 (15.5%)</td>
</tr>
<tr>
<td>Mild cognitive decline</td>
<td>17 (20.0%)</td>
<td>15 (25.4%)</td>
</tr>
<tr>
<td>Moderate cognitive decline</td>
<td>25 (29.4%)</td>
<td>16 (27.6%)</td>
</tr>
<tr>
<td>Moderately severe decline</td>
<td>22 (25.9%)</td>
<td>15 (25.9%)</td>
</tr>
<tr>
<td>Severe cognitive decline</td>
<td>5 (5.9%)</td>
<td>3 (5.2%)</td>
</tr>
<tr>
<td>Unknown</td>
<td>4 (4.7%)</td>
<td>-</td>
</tr>
<tr>
<td>Degree of needing care/assistance (0-46)</td>
<td>NA</td>
<td>7.6 (sd 5.1)</td>
</tr>
</tbody>
</table>

* These persons were included despite different diagnoses at baseline because during the experimental phase the diagnosis of dementia was confirmed.

NA: not available  GDS = Global Deterioration Scale<sup>46</sup>
Table 2. Prevalence of psychiatric symptoms in persons with dementia (n=83) and their mean emotional impact on carers.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>n</th>
<th>Frequency Mean (SD)</th>
<th>Severity Mean (SD)</th>
<th>Severity x freq. Mean (SD)</th>
<th>Emotional impact Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Delusions</td>
<td>27</td>
<td>2.6 (1.2)</td>
<td>1.7 (0.8)</td>
<td>4.5 (3.2)</td>
<td>3.0 (1.4)</td>
</tr>
<tr>
<td>Hallucinations</td>
<td>11</td>
<td>2.7 (1.1)</td>
<td>1.6 (0.7)</td>
<td>4.7 (3.3)</td>
<td>2.4 (1.7)</td>
</tr>
<tr>
<td>Agitation/Aggression</td>
<td>41</td>
<td>2.5 (1.0)</td>
<td>1.9 (0.7)</td>
<td>4.9 (3.1)</td>
<td>3.3 (1.1)</td>
</tr>
<tr>
<td>Depression/Dysphoria</td>
<td>52</td>
<td>2.1 (1.1)</td>
<td>1.5 (0.7)</td>
<td>3.3 (2.6)</td>
<td>2.9 (1.3)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>42</td>
<td>2.3 (1.1)</td>
<td>1.6 (0.7)</td>
<td>3.7 (2.7)</td>
<td>2.6 (1.4)</td>
</tr>
<tr>
<td>Euphoria</td>
<td>19</td>
<td>1.9 (1.1)</td>
<td>1.3 (0.6)</td>
<td>2.7 (2.5)</td>
<td>1.8 (1.5)</td>
</tr>
<tr>
<td>Apathy</td>
<td>63</td>
<td>3.4 (0.9)</td>
<td>1.8 (0.7)</td>
<td>6.2 (3.3)</td>
<td>3.1 (0.9)</td>
</tr>
<tr>
<td>Disinhibition</td>
<td>34</td>
<td>2.1 (1.1)</td>
<td>1.6 (0.7)</td>
<td>3.6 (3.3)</td>
<td>3.1 (1.4)</td>
</tr>
<tr>
<td>Irritability</td>
<td>38</td>
<td>2.6 (1.1)</td>
<td>1.6 (0.7)</td>
<td>4.4 (3.4)</td>
<td>3.3 (1.2)</td>
</tr>
<tr>
<td>Aberrant motor behavior</td>
<td>42</td>
<td>3.3 (0.9)</td>
<td>1.8 (0.7)</td>
<td>6.2 (3.1)</td>
<td>2.5 (1.3)</td>
</tr>
<tr>
<td>Nighttime behavior disturbances</td>
<td>15</td>
<td>3.0 (0.9)</td>
<td>1.5 (0.6)</td>
<td>4.5 (2.8)</td>
<td>2.9 (1.1)</td>
</tr>
<tr>
<td>Appetite and eating abnormalities</td>
<td>50</td>
<td>3.2 (1.1)</td>
<td>1.6 (0.7)</td>
<td>5.2 (3.1)</td>
<td>1.8 (1.6)</td>
</tr>
<tr>
<td>NPI total scores</td>
<td>83</td>
<td>14.0 (7.3)</td>
<td>8.6 (4.6)</td>
<td>24.4 (15.2)</td>
<td>14.4 (8.9)</td>
</tr>
</tbody>
</table>

*NPI = NeuroPsychiatric Inventory*
Table 3 contains the data on potential determinants of burden c.q. emotional impact of psychiatric symptoms, i.e. sense of competence, coping strategies, and objective and experienced support (n=58).

Table 3. Other potential determinants of emotional impact of psychiatric symptoms on carers.

<table>
<thead>
<tr>
<th></th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sense of Competence (total) (28-108)</td>
<td>80.3 (11.0)</td>
</tr>
<tr>
<td>Coping (total) (0-180)</td>
<td>68.4 (16.9)</td>
</tr>
<tr>
<td>Objective support</td>
<td></td>
</tr>
<tr>
<td>Number of institutions providing emotional support (0-14)</td>
<td>0.4 (0.7)</td>
</tr>
<tr>
<td>Number of institutions providing practical support (0-14)</td>
<td>1.1 (0.9)</td>
</tr>
<tr>
<td>Experienced support</td>
<td></td>
</tr>
<tr>
<td>Satisfaction with support from institutions (0-2)</td>
<td>1.8 (0.4)</td>
</tr>
<tr>
<td>Social support (total) (4-48)</td>
<td>27.9 (5.6)</td>
</tr>
</tbody>
</table>

The results of the multiple regression analyses are presented in Table 4. Variables were entered in blocks following the model of determinants of carer burden of Dröes c.s.\textsuperscript{14}. 
Table 4. Results of hierarchical multiple regression analyses: predictors of emotional impact of psychiatric symptoms on carers.

<table>
<thead>
<tr>
<th>Block 1</th>
<th>Standardized Betas&lt;sup&gt;a&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Neuropsychiatric symptoms (NPI total)</td>
<td>0.73 **</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Block 2</th>
<th>Standardized Betas&lt;sup&gt;a&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Characteristics and circumstances</td>
<td>ns</td>
</tr>
<tr>
<td>gender carer</td>
<td>ns</td>
</tr>
<tr>
<td>age carer</td>
<td>ns</td>
</tr>
<tr>
<td>education carer (1=low)</td>
<td>ns</td>
</tr>
<tr>
<td>paid work</td>
<td>ns</td>
</tr>
<tr>
<td>duration caregiving</td>
<td>ns</td>
</tr>
<tr>
<td>additional financial expenditures (1=yes)</td>
<td>0.21 *</td>
</tr>
<tr>
<td>Alzheimer’s disease (1=yes)</td>
<td>ns</td>
</tr>
<tr>
<td>degree of needing care/assistance</td>
<td>-0.38 **</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Block 3</th>
<th>Standardized Betas&lt;sup&gt;a&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Competence and coping</td>
<td>ns</td>
</tr>
<tr>
<td>sense of competence</td>
<td>-0.29 *</td>
</tr>
<tr>
<td>coping total</td>
<td>ns</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Block 4</th>
<th>Standardized Betas&lt;sup&gt;a&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Objective and subjective support</td>
<td>ns</td>
</tr>
<tr>
<td>number of institutions providing emotional support</td>
<td>ns</td>
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<tr>
<td>number of institutions providing practical support</td>
<td>ns</td>
</tr>
<tr>
<td>satisfaction with support of institutes</td>
<td>ns</td>
</tr>
<tr>
<td>social support (SSL)</td>
<td>ns</td>
</tr>
<tr>
<td>Adjusted R&lt;sup&gt;2&lt;/sup&gt;</td>
<td>0.70</td>
</tr>
</tbody>
</table>

<sup>a</sup> Standardized betas in final model

* p ≤ 0.05; ** p ≤ 0.01

The psychiatric symptoms observed by the carers in the persons with dementia proved a major predictor of the experienced emotional impact. It explained 52% of the variance. Other predictors of emotional impact of psychiatric symptoms were sense of competence of the carer, the amount of care needed by the patient and financial expenditure due to the caregiving situation. The emotional impact of psychiatric symptoms was higher in carers that had a low sense of competence or had more
financial expenditure or of whom the persons with dementia needed less care. The final regression model explained 70% of the variance in emotional impact of psychiatric symptoms on carers.

**DISCUSSION**

The emotional impact of psychiatric symptoms of people with dementia on their carers was the main interest in this study. Our study population consisted of partners of persons with (mainly) slight to moderately severe dementia. The most common psychiatric symptoms in the persons with dementia were apathy and depression, and carers experienced these symptoms, together with agitation and irritability, as the most distressing. This confirms what has been found in other (population) studies.¹⁵, ³⁵, ⁵¹-⁵⁵

Furthermore, our study examined predictors of the emotional impact of psychiatric symptoms on carers. As expected, the emotional impact was mainly predicted by the frequency and severity of the psychiatric symptoms themselves. However, almost 50 percent of the variance in emotional impact could not be explained by the psychiatric symptoms as such. This is in line with the outcome of a recent review in which the percentage of variance in carer burden scores that could be explained by behavioural and psychological symptoms varied from 5.6% to 71%.⁵⁶ Behavioural and psychological symptoms were the strongest predictors of burden in only half of the studies on which these analyses were based. Other predictors found in this review were caregiver factors (age, gender, education), patient factors (gender, functional impairment and attachment-style) and situation factors (social support).

In our explorative study, other predictors of emotional impact were characteristics of the carer (sense of competence) and patient and situation characteristics (degree of care needed by patient and financial expenditure due to the caregiving situation respectively).

The lower the sense of competence, the higher the emotional impact on carers. This is in line with our expectations based on the Model of determinants of subjective burden of carers.¹⁴ The sense of competence reflects the perceived ability by the carer to cope with the task of caring for the person with dementia.

The degree of care needed by persons with dementia was inversely related to the emotional impact of psychiatric symptoms, which suggest that the emotional impact of behaviour changes is largest in the early phases of the disease (see also ⁵⁷). An earlier study found the same association.⁷ Behaviour problems have often been found to be related to carer burden or institutionalization.¹⁴, ¹⁶, ¹⁹, ²¹, ⁵⁸, ⁵⁹ Later stages of dementia may
also be associated with less emotional impact of psychiatric symptoms because carers may have learned to cope with the dementia over time.60

More financial expenditure due to caregiving, such as travelling costs and costs for the use of community-based services by the person with dementia, proved to be related to higher emotional impact on carers. More service use has been related to higher burden on carers in other studies as well.7, 57, 61

Though some of the determinants of carer burden in the model by Dröes et al14 proved to be related to higher emotional impact on carers, that is material and social circumstances and sense of competence, we did not find evidence in our study that other potential determinants such as coping strategies or experienced support influence the emotional impact of psychiatric symptoms on carers.

Some limitations should be noted in interpreting the results of this explorative study. The carers involved in our study were all partners of patients with dementia who participated in the Meeting Centres Support Programme.29 Although the patients they care for live in the community, this group is perhaps not representative of all partner carers in the community. This means that we should be cautious in generalizing the study outcome to all partner carers of persons with dementia living in the community.

Furthermore, because only partners of dementia patients were included this resulted in a reduction of the sample size. The reason to focus our study on partner carers was that several studies reported differences in (correlates with) burden and institutionalization between spouse carers and other carers.5, 16, 19, 62, 63 As spouse carers were the main group in the MCSP we opted for this group.

A final limitation is the cross-sectional study design, which hampers firm conclusions on the causality of relations. Because of these limitations it must be emphasized that our findings need to be viewed with caution. In future studies, longitudinal research is recommended and also a larger and preferably random sample. The latter would allow studying predictors of the emotional impact of separate psychiatric symptoms such as agitation/aggression, irritability and apathy, that proved very distressing for the partners in our study and that other studies found to be very distressing for carers in general as well.35, 64

The results of our study support the importance of combined interventions for persons with dementia and their carers in reducing the emotional impact of psychiatric symptoms on carers. These interventions should not only be aimed at the psychiatric symptoms themselves f.i. by psychosocial or pharmacological therapies for the persons with dementia, but also at increasing the sense of competence of the carers. For example by providing them with timely support to cope with the consequences of dementia (see also 65) and to use adapting management strategies (see 66). The MCSP
has been proven successful in this respect.\textsuperscript{28, 30, 31}

Also, situational factors such as financial burden due to the caregiving situation should not be forgotten in supporting carers and patients in the community, because they can increase the emotional burden of carers.

**Acknowledgements**

The authors thank all participants and personnel of the meeting centres that participated in this study for their cooperation. We thank Novartis Pharma BV, The Netherlands, for sponsoring this study.
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