Cognitive functioning in spousal caregivers of dementia patients: findings from the prospective MAASBED study

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Abstract

Background: Spousal caregivers are usually of the same age as the dementia patient and therefore at risk of age-related cognitive decline. Suboptimal cognitive functioning in caregivers may have profound implications.

Methods: Fifty-four spousal caregivers of dementia patients from the Memory Clinic of the Academic Hospital Maastricht and the Regional Institute for Community Mental Health Care in the Netherlands were compared with 108 non-caregiving controls. Data were collected on patient and caregiver characteristics and caregiver cognitive functioning. Repeated measures statistical analyses were carried out to investigate the relationship between caregiver cognitive functioning at baseline and patient behavioural problems and caregiver competence during 1 year of follow-up.

Results: Caregivers performed significantly worse on several cognitive domains compared with control subjects. Low performance on a verbal memory task was related to a decrease in caregiver subjective competence and an increase in patient hyperactivity.

Conclusion: The results indicate that screening for cognitive impairment of spousal caregivers may be helpful, because suboptimal cognitive functioning may affect the ability to provide adequate care.

Keywords: dementia, caregiver, cognition, behavioural problems, elderly

Introduction

A vast majority of dementia patients are cared for at home by their spouse. These spousal caregivers often provide years of extensive care for their partner and must be able to adapt to a continuously changing and demanding situation. The quality of life of both patient and caregiver and the ability to provide care at home are greatly dependent upon the ability of the caregiver to adequately adapt and respond to the problems and needs of the patient. This ability to care for a demented partner may be compromised by cognitive impairments in spousal caregivers themselves. However, cognitive status in spousal caregivers of dementia patients has hardly been assessed in studies on caregiver functioning.

Spousal caregivers are usually of the same age as the patients and therefore at risk of some age-related cognitive decline. For example, information processing usually becomes slower and less efficient with age [1]. In addition, caregivers are likely to experience prolonged elevated levels of stress, which make them particularly vulnerable to cognitive deterioration such as memory problems [2]. As a consequence, the elderly caregiver may not be able to respond
accurately to the novel and complex problems they are confronted with in the caregiving process. In such highly stressful and demanding situations, suboptimal cognitive functioning in the caregiver may be related to decreased competence to provide adequate care. Furthermore, it may also affect patient functioning, as especially behavioural problems, in contrast to cognitive impairment, seem to be sensitive to patient–caregiver interaction. For example, caregiver management strategies have been found to affect behavioural problems in the patient, in particular hyperactivity symptoms [3]. However, the impact of cognitive problems in spousal caregivers on patient behaviour has not been studied yet. Cognitive functioning in elderly caregivers has hardly been documented. Only two studies were found that addressed this issue. Boucher and colleagues [4] found that patients with spousal caregivers who scored below the cut-off of a cognitive screening test used fewer community resources and experienced difficulties with medication compliance. This study did not include caregiver educational level as a possible confounder in the relationship between cognitive status and caregiver skills. In a study of Caswell and colleagues [5], it was found that spousal caregivers have lower levels of complex attention and speed of information processing than non-caregivers, because of chronic stress. However, these studies did not focus on the consequences of compromised cognitive functioning on patient and caregiver functioning. The aim of the present study was to examine the cognitive functioning of spousal caregivers of dementia patients and to explore the consequences for patient and caregiver functioning. A prospective design was used to investigate the hypothesis that impaired caregiver cognitive functioning is related to lower levels of caregiver competence and higher levels of patient behavioural problems.

Methods

Subjects

Subjects were spousal caregivers of ambulatory patients with dementia according to DSM-IV [6]. The present study is part of the MAastricht Study of BEhavior in Dementia (MAASBED) [7]. Of the 119 informal caregivers participating in MAASBED, 64 were spouses, of whom 54 agreed to undergo a neuropsychological examination at baseline (84.4%). Caregivers who participated were significantly younger than non-participants ($t = 2.2, P = 0.030$). There were no differences between the groups in caregiver sex, education, length of care, depressive symptoms, dementia severity or patient behavioural problems.

Caregivers were matched with 108 control subjects for age, sex and level of education. Control subjects were selected from a large pool of healthy controls, which was collected for use in the MAastricht Aging Study (MAAS) [8], a longitudinal investigation on the determinants and consequences of pathological and successful ageing with respect to cognitive functioning. The participants enrolled in MAAS were selected from a register of 15 general practitioners in the south of the Netherlands. Subjects were excluded if there were any active or inactive medical conditions that might interfere with normal cognitive function or psychosocial contraindications (e.g. actual major life events). More details on the MAAS population can be found elsewhere [8].

The present study refers to the 1 year of follow-up. Missing values in the follow-up were due to refusal ($n = 11$) or death of the patient ($n = 5$). Caregivers lost to follow-up did not differ from those who were not, in terms of age, sex, education, contact hours, length of care, disease duration, depressive symptoms, feelings of competence and patient cognitive or behavioural problems.

Measures

Patient functioning

Patient behavioural problems were measured with the Neuropsychiatric Inventory (NPI) [9]. In a previous study, principal component analysis of the NPI identified three behavioural subsyndromes: a hyperactivity factor, a mood/apathy factor and a psychosis factor [7]. These three factors were used in this study.

The severity of dementia was rated with the Global Deterioration Scale [10]. Patient’s level of interference with regard to daily activities was measured with the Interview for Deterioration in Daily living activities in Dementia [11]. The Mini-Mental Status Examination (MMSE) [12] was used to measure patient’s cognitive functioning.

Neuropsychological assessment

Cognitive functioning of caregivers and controls was assessed by means of tasks measuring verbal memory, speed of information processing and cognitive flexibility. Global cognitive functioning was assessed with the MMSE [12]. The delayed recall score of the Auditory Verbal Learning Test (AVLT) [13] was used to measure memory retrieval. The speed of information processing was assessed with the Letter Digit Coding Test (LDCT), which is a modified version of the Symbol Digit Modalities Test [14]. Cognitive flexibility was assessed with the Stroop Colour-Word Test [15, 16]. The dependent variable is the time needed to read Stroop card III minus the mean time needed to read cards I and II. A shortened form of the Groninger Intelligence Test [17] was used to obtain a measure of general intelligence.

Additional measures

The Symptom-Checklist 90 [18] depression subscale and anxiety subscale were used to assess psychological complaints in caregivers and controls.

For each of the 12 behavioural symptoms on the NPI, caregivers rated the level of distress they experienced. Caregiver’s subjective competence was measured with the Short Sense of Competence Questionnaire [19]. Cronbach’s alpha in this study is 0.77.

Physical health complaints were measured with the physical functioning subscale of the RAND-36 questionnaire [20].
Statistical analysis

Univariate comparisons were performed with Student’s t-test, chi-square test and Mann–Whitney U-test. Caregiver cognitive performance was converted to standard z-scores using the data from the control group as the reference. In order to explore group differences in cognitive functioning and the mediating effect of psychological functioning, we performed three forced entry regression analyses to predict cognitive functioning (memory, information processing speed and cognitive flexibility) by age, education, sex (entered at step 1), group (controls versus caregivers; entered at step 2), depression and anxiety (entered at step 3).

Next, caregiver cognitive performance was examined as predictor of patient behaviour with repeated measures analysis of covariance (MANCOVA). Therefore, caregivers were assigned to ‘low-performance’ and ‘high-performance’ groups, according to a median split on the memory delayed recall score, Stroop interference score and LDCT score. Differences in patient behaviour between high- and low-performance groups for the three cognitive domains were analysed using MANCOVA with ‘group’ (high versus low performance) and sex as between-subject factor and ‘time’ (timing of patient behaviour measurement: baseline, 6 months’ and 12 months’ follow-up) as within-subject factor; age, education and dementia severity were co-variates. This analysis was repeated to examine caregiver cognitive performance as predictor of caregiver competence. Significance was tested with two-tailed tests, with α = 0.05.

Results

Sample description

The mean caregiver age was 68.4 (SD = 8.5), and the median educational level was 2 [on a 3-point scale ranging from 1 (i.e. low) to 3 (i.e. high) educational level]. There were 22 men (40.7%) and 32 women (59.3%). At baseline, the median of duration of care was 24 months (ranging from 3 to 120 months), and the mean contact hours per month was 153.6 (SD = 14.1). There were 33 (61.1%) male patients and 21 (38.9%) female patients with a mean MMSE score of 18.4 (SD = 5.3). Forty-one patients had Alzheimer’s disease (AD), seven vascular dementia, two fronto-temporal dementia, two Parkinson’s disease, one primary progressive aphasia and one mixed dementia (AD/vascular), according to regular criteria.

Table 1. Demographic and psychological characteristics and cognitive performance in caregivers and controls

<table>
<thead>
<tr>
<th></th>
<th>Caregivers (n = 54)</th>
<th>Controls (n = 108)</th>
<th>Test value</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex [n (%)]</strong></td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>Male</td>
<td>22 (40.7%)</td>
<td>44 (40.7%)</td>
<td>χ² = 0.0</td>
<td>1.000</td>
</tr>
<tr>
<td>Female</td>
<td>32 (59.3%)</td>
<td>64 (59.3%)</td>
<td></td>
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</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td>t = 0.1</td>
<td>0.927</td>
</tr>
<tr>
<td>68.4 (8.5)</td>
<td>68.3 (8.4)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Level of education (range)</strong></td>
<td>1.78 (1–3)</td>
<td>1.76 (1–3)</td>
<td>t = 0.1</td>
<td>0.888</td>
</tr>
<tr>
<td>15.3 (5.2)</td>
<td>15.2 (7.3)</td>
<td></td>
<td>Z = -0.2</td>
<td>0.219</td>
</tr>
<tr>
<td><strong>SCL anxiety</strong></td>
<td></td>
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<tr>
<td>27.7 (9.7)</td>
<td>26.0 (11.9)</td>
<td></td>
<td>Z = -1.5</td>
<td>0.134</td>
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<tr>
<td><strong>SCL depression</strong></td>
<td></td>
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<tr>
<td>114.1 (13.7)</td>
<td>115.1 (11.6)</td>
<td></td>
<td>t = -0.5</td>
<td>0.638</td>
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<tr>
<td><strong>IQ score</strong></td>
<td></td>
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<tr>
<td>27.9 (1.6)</td>
<td>28.6 (1.7)</td>
<td></td>
<td>Z = -3.1</td>
<td>0.002</td>
</tr>
<tr>
<td><strong>MMSE</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8.6 (3.3)</td>
<td>10.1 (2.9)</td>
<td></td>
<td>t = -2.7</td>
<td>0.006</td>
</tr>
<tr>
<td><strong>AVLT (delayed recall)</strong></td>
<td>117.3 (49.4)</td>
<td>104.0 (35.5)</td>
<td>t = 1.9</td>
<td>0.053</td>
</tr>
<tr>
<td><strong>Stroop interference (seconds)</strong></td>
<td>36.6 (12.6)</td>
<td>44.5 (8.8)</td>
<td>t = -4.1</td>
<td>0.001</td>
</tr>
</tbody>
</table>

AVLT, Auditory Verbal Learning Test; LDCT, Letter Digit Coding Test; MMSE, Mini-Mental State Examination; SCL, Symptom-Checklist.

*Differences in patient behaviour between high- and low-performance groups were dichotomised by a median split in a high and low caregiver performance group. Differences between caregiver cognitive performance groups were tested with univariate analysis of covariance (MANCOVA). Therefore, caregivers were assigned to ‘low-performance’ and ‘high-performance’ groups, according to a median split on the memory delayed recall score, Stroop interference score and LDCT score.

Cognitive functioning in caregivers and controls

Caregivers and control subjects did not differ in psychological complaints or IQ score (Table 1). Univariate analysis of group differences in cognitive functioning indicated that caregivers performed significantly worse than the control subjects on all cognitive domains, except for cognitive flexibility (Table 1).

Psychological complaints were examined as possible mediators of the relationship between group and cognitive performance. In the caregiver group, 15 (28%) subjects scored high on anxiety and 24 (44%) scored high on depression compared with norm scores. Forced entry regression analyses were performed to predict cognitive functioning by age, education, sex (entered at step 1), group (entered at step 2), depression and anxiety (entered at step 3). Control subjects performed better than caregivers on tasks measuring global cognitive functioning (t = 2.5, P = 0.012), memory delayed recall (t = 2.9, P = 0.004) and information processing speed (t = 3.7, P ≤ 0.001) but not for cognitive flexibility (t = -1.8, P = 0.083). In addition, complaints of depression and anxiety were only predictive for memory performance (t = 2.5, P = 0.014 and t = -2.9, P = 0.004, respectively), accounting for 6% of variance in memory performance with the total model explaining 22% (F = 6.1, P ≤ 0.001).

Differences between caregiver cognitive performance groups

Cognitive measures (AVLT, Stroop interference and LDCT) were dichotomised by a median split in a high and low caregiver performance group. Table 2 summarises descriptive data of the low and high cognitive performance groups for each cognitive domain. The high cognitive performance group was significantly younger than the low-performance group on all cognitive domains (all P-values lower than 0.010). Furthermore, caregivers in the low cognitive speed
group were significantly lower educated ($t = -2.7, P = 0.009$) and had more physical health complaints ($Z = -2.8, P = 0.006$) than caregivers in the high cognitive speed group. Also, caregivers in the low cognitive flexibility group had more physical health complaints ($Z = -2.4, P = 0.015$). The low-performance group on information processing speed tended to use more medication (three caregivers used antidepressants and two used anxiolytics in the low-performance group; in the high-performance group only one used antidepressants) ($\chi^2 = 3.7, P = 0.054$). There were no differences in medication use between the high- and low-performance groups for memory ($\chi^2 = 0.1, P = 0.771$) and cognitive flexibility ($\chi^2 = 0.8, P = 0.386$).

### Caregiver cognitive functioning as predictor of patient behaviour

A MANOVA was performed to investigate differences in patient behaviour between the high and low cognitive performance groups, adjusted for age, sex, education and dementia severity. Results showed no significant overall difference in general levels of behavioural symptoms (total NPI) between the groups (intercept: $F_{1,32} = 0.1$, $P = 0.777$), cognitive flexibility ($F_{1,32} = 0.4, P = 0.539$) or cognitive speed ($F_{1,32} = 0.1, P = 0.777$). There was a near-significant time–memory performance interaction effect ($F_{2,64} = 2.9, P = 0.065$), with an increase in patient behavioural problems in the low memory performance group in the first 6 months’ follow-up (Figure 1). Therefore, an additional MANOVA was performed to test differences in change between both memory performance groups in the first 6 months’ follow-up. Indeed, this analysis showed a significant increase in the low-performance group in comparison with the high-performance group ($F_{1,32} = 5.1, P = 0.030$). Thus, lower caregiver memory performance was related to an increase in patient behavioural problems. Post hoc comparison at 12 months’ follow-up revealed no significant difference ($t = 0.8, P = 0.442$).

To examine differences in specific types of patient behaviours between the high and low memory performance group, MANOVA was repeated for the three behavioural subsyndromes (mood/apathy, hyperactivity and psychosis). Results showed no overall group differences for memory performance in patient hyperactivity ($F_{1,32} = 1.1, P = 0.302$), psychosis ($F_{1,32} = 0.4, P = 0.520$) or mood/apathy ($F_{1,32} = 3.7, P = 0.064$). However, there was a significant difference in change in hyperactivity over time ($F_{2,64} = 4.7, P = 0.021$). Again, there was an increase in patient hyperactivity in the low memory performance group of caregivers in the first 6 months’ follow-up. Post hoc comparison at 12 months’ follow-up revealed no significant difference ($t = 0.7, P = 0.489$).

To investigate whether the impact of caregiver memory performance on patient hyperactivity was mediated by caregiver distress, we performed an additional MANOVA.
significantly after adjusting for caregiver distress (F \_2,62 = 4.9, P = 0.018) remained significant after adjusting for caregiver distress (F \_2,31 = 27.4, P \leq 0.001).

**Caregiver cognitive functioning as predictor of caregiver competence**

In addition, we hypothesised that patients of caregivers with lower levels of cognitive functioning might feel less competent than patients of caregivers with higher levels of cognitive functioning. Therefore, MANOVA was performed to investigate differences in caregiver competence between the high and low cognitive performance groups, adjusted for age, sex, education and dementia severity. Results showed no significant overall difference in feelings of competence between the groups for memory (F \_1,29 = 1.5, P = 0.228), cognitive flexibility (F \_1,29 = 0.03, P = 0.863) or cognitive speed (F \_1,29 = 0.001, P = 0.974). There were also no significant interaction effects between cognitive performance and feelings of competence, although memory performance showed a decrease in feelings of competence between baseline and 6 months’ follow-up in the low memory performance group (Figure 2). To test this difference in change between both groups, an additional MANOVA was performed for baseline and 6 months’ follow-up. Indeed, this analysis showed that the low memory performance group had a significant decrease in feelings of competence when compared with the high memory performance group from baseline to 6 months’ follow-up (F \_1,39 = 6.3, P = 0.016). Post hoc comparison at 12 months’ follow-up revealed no significant difference (t = -1.4, P = 0.170).

**Discussion**

The results show that spousal caregivers of dementia patients have on average lower levels of cognitive functioning than age-, sex- and education-matched controls. Caregivers performed significantly worse on measures of general cognitive functioning, speed of information processing and verbal memory. In general, spousal caregivers were only subtly below the controls in their level of cognitive ability. Furthermore, low performance on verbal memory was related to a decrease in caregiver competence and an increase in patient behavioural symptoms, in particular hyperactivity symptoms.

Interestingly, Caswell and colleagues [5] recently obtained evidence that is compatible with our findings. They found lower levels of complex attention and speed of information processing in caregivers compared with controls, after adjustment of age differences. Cognitive suboptimal functioning in caregivers can probably be explained by chronic stress levels because of the caregiving situation. Behavioural problems lead to chronic stress which in turn can elevate levels of cortisol in caregivers of dementia patients [21]. High levels of cortisol have been widely associated with impaired cognitive functioning, particularly with reduced cognitive attention and memory [2, 22–24]. Data on psychological complaints were available in the control group and used as a proximate measure of chronic stress to investigate the mediating effect of psychological functioning in the association between group and cognitive performance. However, differences in cognitive functioning between the groups were not associated with psychological complaints and may be better explained by more specific measures of stress. Furthermore, group differences in cognitive functioning may be related to differences in physical health problems and related medication use. The control group consisted of healthy subjects without medical conditions or psychotropic drug use that could interfere with normal cognitive function. In contrast, caregivers of dementia patients are known to perceive their health to be worse than non-caregivers, to use more psychotropic medication and to visit their physician more often [25–27], which may reduce cognitive functioning [28]. Indeed, caregivers in the low-speed and cognitive flexibility performance groups reported more health complaints than caregivers in the high-performance groups. However, there were no differences in medication use, hence this could not explain group differences in cognitive performance. In addition, control subjects were not selected on marital status, which might affect the comparability of the two groups. However, control subjects were excluded if there was any kind of psychosocial stressor (such as taking care of a spouse with a chronic illness).

Potential effects of suboptimal caregiver cognitive functioning on patient outcomes were assessed longitudinally. Low performance on a measure of verbal memory was related to an increase in patient behavioural symptoms, in particular hyperactivity symptoms. This finding is in line with previous results from MAASBED [3] that caregivers who use less-effective care strategies increase the risk of hyperactive behaviour in the patient. Effective care strategies may greatly depend on the cognitive abilities of the caregiver, in order to meet the needs and shortcomings of the patient. Given the complex and changing demands in the caregiving situation, suboptimal cognitive functioning may affect daily caregiver functioning, even without a clear cognitive impairment [5]. Therefore, cognitively ‘impaired’ caregivers may be less able to develop adequate care strategies, resulting in increased hyperactive behaviour in the patient [3].
In addition, low memory performance in caregivers was associated with a decrease in feelings of competence in caregivers. Again, this can be explained by the possible influence of cognitive abilities on care strategies. Previous results from MAASBED [3] indicated that caregivers who use a non-adapting strategy feel less competent than caregivers who use other care strategies. Furthermore, poorer cognitive functioning may be disconcerting to caregivers and cause lower feelings of competence, as they may even worry about getting dementia themselves. This may also explain why only memory performance was associated with lower feelings of competence, as memory problems are the most salient characteristic of dementia and therefore may cause the most uneasiness in caregivers about their own mental health.

At 1 year of follow-up, group differences were no longer present. Several explanations might be possible, such as a successful treatment of patient symptoms that reduced levels of behavioural problems, adaptation of the caregiver to their caregiver role or an increase in professional support for caregiver and patient. In addition, at 1 year of follow-up, several patients were institutionalised, which reduced the interaction between patient and caregiver. However, when institutionalised patients were excluded from the analyses, there were still no significant differences at 12 months' follow-up.

There were several limitations to this study. First, lowered cognitive functioning in caregivers may have biased the reports of patient problems, because part of patient information was only obtained by caregiver judgement. However, the fact that reduced memory performance was specifically related to higher levels of patient hyperactivity and not to other problems makes it unlikely that a bias in caregiver reports can explain this finding.

Second, there probably exist a bidirectional relationship between caregiver competence, patient behaviour and caregiver cognitive functioning. High levels of patient problems will cause caregiver stress, which in turn is associated with impaired cognitive functioning. However, the finding that patient behavioural problems increased in the low memory performance group while no significant differences existed between the groups in patient behaviour at baseline supports the view that reduced cognitive functioning is also a predictor of patient behaviour and caregiver competence.

Our findings indicate that spousal caregivers of dementia patients show reduced levels of cognitive functioning compared with healthy matched controls. Furthermore, suboptimal cognitive functioning in caregivers has profound implications for patient as well as caregiver outcomes. Low memory performance was associated with a reduction in caregiver’s feelings of competence and an increase in patient behavioural symptoms, especially hyperactivity. These results imply that one should be alert to cognitive problems in older caregivers. Even minor memory problems in caregivers may affect their ability to provide adequate care and the quality of life of both patient and caregiver.

Cognitive functioning in spousal caregivers

Key points
- Spousal caregivers show suboptimal cognitive functioning compared with healthy controls.
- Suboptimal caregiver cognitive functioning is associated with a decrease in feelings of caregiver competence and an increase in levels of patient hyperactivity.

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References

Role of depressive and cognitive status in self-reported evaluation of quality of life in older people: comparing proxy and physician perspectives

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Abstract

Objective: to assess the quality of life (QOL) of older adults aged over 65 years, who were healthy or suffering from depressive syndrome (DS) and/or Alzheimer’s disease (AD); to analyse agreement between participants’ and proxies’ QOL ratings; to evaluate the association between participants’ depressive and cognitive symptoms and QOL rating; to correlate participants’ health ratings and the severity of physician assessment.

Methods: 138 non-institutionalised older people of both genders and their respective caregiver and treating doctor were consecutively recruited (response rate 74.6%). Forty suffered from AD, 36 from DS, 35 from both conditions and 27 had neither. All participants were evaluated by Mini Mental State Examination, Geriatric Depression Scale and World Health Organization Quality of Life (WHOQOL) questionnaire. The caregiver filled out QOL-Proxy and the physician filled out the ‘Health and Severity of Illness’ form.

Results: the four groups scored significantly differently in all areas of WHOQOL-100 (WHOQOL questionnaire with 100 items). Participants with DS perceived their QOL as poorer than did healthy and AD subjects. Participants with AD and DS obtained intermediate scores. Severity of depression correlated with worsening QOL. Subjects with DS—but not those with...