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# BMJ Open Interaction of caregiver-expressed emotions and neuropsychiatric symptoms in persons with dementia: a longitudinal cohort study

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#### **ABSTRACT**

Objectives Neuropsychiatric symptoms (NPS) have a major impact in persons with dementia (PwD). The interaction between the caregiver and the person with dementia may be related to the emergence of NPS. The concept of expressed emotion (EE) is used to capture this dyadic interaction. The aim of the present study is to examine longitudinally the association between EE in caregivers and NPS in PwD living at home.

Design A longitudinal cohort study with 2 years of follow-

Setting PwD and their informal caregivers living at home in the south of the Netherlands.

Participants 112 dyads of PwD and their caregivers from the MAAstricht Study of BEhavior in Dementia.

Main outcome measures EE was measured at baseline with the Five-Minute Speech Sample and was used to classify caregivers in a low-EE or high-EE group. Associations between EE and neuropsychiatric subsyndromes (hyperactivity, mood and psychosis) measured with the Neuropsychiatric Inventory (NPI) were analysed over time.

Results Seventy-six (67.9%) caregivers were classified in the low-EE group and 36 (32.1%) in the high-EE group. There was no difference between the EE groups in mean NPI scores over time. In the high-EE group, hyperactivity occurred more frequently than in the low-EE group at baseline (p=0.013) and at the other time points, but the mean difference was not always significant. There were no differences for the mood and psychosis subsyndromes. PwD with caregivers scoring high on the EE subcategory critical comments had an increased risk of institutionalisation (OR 6.07 (95% CI 1.14 to 32.14, p=0.034)) in comparison with caregivers scoring low on critical comments.

Conclusions High EE in informal caregivers is associated with hyperactivity symptoms in PwD. This association is likely to be bidirectional. Future studies investigating this association and possible interventions to reduce EE are needed.

#### INTRODUCTION

Neuropsychiatric symptoms (NPS), such as a depressive mood and agitation, are a major problem in persons with dementia

### Strengths and limitations of this study

- This is a longitudinal cohort study with a relatively large sample size with 2-year follow-up.
- The association between expressed emotion in caregivers and neuropsychiatric symptoms in persons with dementia living at home was examined taking into account multiple confounding factors.
- Factors associated with expressed emotion were explored as well as the association between expressed emotion and institutionalisation rate.
- We used the Five-Minute Speech Sample to measure expressed emotion; this is a feasible instrument, but not the gold standard for measuring the level of expressed emotion.
- The level of expressed emotion was only assessed at baseline: therefore, we were not able to study possible changes in expressed emotion over time.

(PwD). They may have several negative effects for the person with dementia and result in a loss of quality of life. 12 NPS may also have a great impact on the family caregiver of the person with dementia and lead to an increased burden and negative health effects.<sup>3</sup> NPS are also important determinants for nursing home placement. 4 NPS are associated with patient-related factors such as age, sex and comorbidity.<sup>5 6</sup> However, the psychosocial environment, such as interpersonal interactions between the caregiver and the person with dementia, may also influence the behaviour of the person with dementia. One of the concepts that has been developed to capture interpersonal interaction is expressed emotion (EE).

The construct of EE was developed by Brown et al and used in multiple studies to investigate the associations between relapses in patients with schizophrenia and the interactions between these patients and their relatives. A commonly used definition of EE is given in an overview of Hooley from 2007: 'expressed emotion is a measure of how much criticism, hostility, or emotional overinvolvement (EOI) the caregiver expresses when speaking about a person with psychopathology'.8 Caregivers expressing a more-than-usual amount of criticism, hostility or emotional overinvolvement (EOI) are generally classified as having high EE levels. The concept of EE has also been studied in PwD and their caregivers. Several studies have focused on caregiver well-being and found that a high EE was related to several negative effects in caregivers, such as depression and distress. 10 11 There are also several studies suggesting a link between high EE and negative effects for PwD. 12 The interaction mechanisms between PwD and their caregivers are complex.9 According to the ecological model of Lawton, <sup>13</sup> PwD are more vulnerable to the demands of their psychosocial environment because of their decreased competences, which may lead to behavioural problems if the demands of the environment exceed those of the person and their abilities. For example, due to the dementia (verbal) communication may become affected, unmet needs may arise and result in behavioural challenges if those around the person cannot meet those needs. This requires a great deal of flexibility from the caregiver. Caregivers who are less flexible and more self-critical are thought to project this to the PwD.<sup>9</sup> In line with this, a recent study in Hong Kong showed that the negative impact of NPS on outcomes in dementia caregivers was mediated by EE.<sup>14</sup> Another study found that daughters who believe that their parent's behaviour was within the control of that parent were more likely to exhibit high EE, 15 and they suggest that educating these daughters may help reduce

However, a systematic review did not find any consistent effects of relationship factors such as EE on outcomes such as institutionalisation and quality of life in PwD. They did find an association between relationship quality and global challenging behaviour, though the evidence was weak. The methodological quality of the included studies was assessed as poor (eg, risk of confounding, small sample sizes and no reporting of effect sizes).

From the existing literature the question arises whether EE is a state-like or trait-like characteristic. Overall, it is assumed that a 'dual-identities model' of both state and trait-like features is most likely: some caregivers will always show a higher EE compared with others, but the level of EE can change over time<sup>9</sup> and might, therefore, be modifiable. For example, a vulnerable caregiver might have a high EE even when there is not a significant amount of stress. On the other hand, a caregiver who is quite resilient will only show high EE behaviour with multiple serious stressors. It is important to know which factors can influence EE. A recent study in caregivers of patients with Alzheimer's disease found that depressive temperament traits might predict higher levels of EE. <sup>16</sup>

To identify possible targets for interventions to reduce NPS, it is important to have a better understanding of the association between EE and NPS. Furthermore, it is important to investigate whether this interaction is indeed modifiable and, thus, if it is related to stable and/ or influenceable characteristics of the caregiver. The aim of the present study is to examine the association between EE in informal caregivers and NPS in PwD living at home. Data from a longitudinal cohort study<sup>17</sup> were used to (1) examine a possible association between baseline EE in caregivers and NPS in PwD at baseline and over time, (2) explore factors associated with EE, (3) examine the association between EE and institutionalisation rate and (4) examine the impact of EE on caregiver functioning. It is hypothesised that high EE is related to higher levels of NPS in PwD, higher risk of institutionalisation and more negative effects in caregivers.

### METHODS Subjects

The present study uses data from the MAAstricht Study of BEhavior in Dementia (MAASBED). MAASBED is a 2-year follow-up study focussing on the course and risk factors of NPS in dementia.<sup>17</sup> Dyads of patients and their caregivers were recruited at the Memory Clinic of the Maastricht University Medical Center or at the geriatric division of the Community Mental Health Care (Regionale Instelling voor Ambulante Geestelijke Gezondheidszorg,(RIAGG)), Maastricht, the Netherlands. PwD were included if they met the Diagnostic and Statistical Manual of Mental Disorders-IV (DSM-IV) criteria for dementia, 18 were outpatients and had a reliable informant. Caregivers were included if they were the primary caregivers and had contact with the patient at least once a week. At baseline, all PwD were living at home. Written informed consent was obtained from all subjects. The study was approved by The Medical Ethics Committee of the University Hospital Maastricht.

#### **PwD** measures

General characteristics such as age, sex, dementia type, time of diagnosis and educational background were collected. Cognitive functioning was measured with the Mini–Mental State Examination (MMSE).<sup>19</sup> Patient dependency with regard to daily activities was measured with the Interview for Deterioration in Daily living activities in Dementia (IDDD).<sup>20</sup> Furthermore, the severity of dementia was measured with the Global Deterioration Scale (GDS).<sup>21</sup> Data about psychotropic medication use (antidepressants, antipsychotics and benzodiazepines) were collected summarily.

NPS were measured with the Neuropsychiatric Inventory (NPI).<sup>22</sup> The NPI is a structured interview with the caregiver who measures NPS in 12 domains: delusions, hallucinations, depression/dysphoria, aggression/agitation, fear, euphoria, apathy, disinhibited behaviour, liability, repetitive behaviour, sleeping problems and change of eating patterns. The scoring in each domain is obtained by multiplying the severity (1 'mild' to 3 'severe') by the frequency (1 'sometimes' to 4 'very



often'). A previous factor analysis of the NPI identified three behavioural subsyndromes: mood/apathy, psychosis and hyperactivity, with anxiety as a separate syndrome.<sup>23</sup> Total scores for each subsyndrome were computed as the sum of observed NPI item scores for each factor.

Measurements were carried out every 6 months. If a person with dementia was admitted to a nursing home during the 2-year follow-up, data were still collected for the next follow-up time after admission.

#### **Caregiver measures**

General characteristics such as sex, age, educational level, kinship type and number of contact hours with the person with dementia were collected. EE was assessed by the Five-Minute Speech Sample (FMSS).<sup>24</sup> The FMSS is a non-time-consuming method to assess EE: caregivers are asked to speak without interruption for 5 min, describing their relative and how they get along together. The speech samples are audiotaped and transcribed. The number of critical comments, the amount of EOI, the initial statement and the relationship between patient and caregiver are rated. In this study, two trained and qualified raters coded the transcripts using the guidelines described for coding EE. In order to assess the inter-rater reliability, 12 interviews were randomly selected and rated by two other highly experienced blind raters to assess reliability and consistency. The inter-rater reliability between these highly experienced raters and the two qualified raters was 100%. Caregivers were classified as 'high-EE' if they scored on the critical scale and/or on the EOI scale, and otherwise they were rated as 'low-EE', according to the method described by Magana et al.<sup>24</sup> In the low-EE group, caregivers were rated as 'borderline EOI' or 'borderline critical' if there were some indications for a high EE score but not enough to fulfil the high EE criteria.

For each of the 12 NPS on the NPI, caregivers rated the level of distress they experienced on a scale from 0 (none) to 5 (extreme). The NPI-Distress score is the sum of these 12 ratings (range 0–60).<sup>22</sup>

Caregiver subjective competence was measured with the Short Sense of Competence Questionnaire (SSCQ).<sup>25</sup> This questionnaire consists of seven items rated on a 5-point scale (1 'agree very strongly' to 5 'disagree very strongly'; range 7–35). These items reflect three domains of caregivers' feelings of being capable of caring for a person with dementia: (a) satisfaction with the person with dementia as a recipient of care, (b) satisfaction with one's own performance as a caregiver and (c) consequences of involvement in care for the personal life of the caregiver.

Depressive symptoms were measured with the Montgomery-Asberg Depression Rating Scale (MADRS) 22, a structured interview administered by the clinician. Ratings (from 0 to 6) on 10 items were summed (range 0–60).<sup>26</sup>

Personality traits were assessed with the NEO-Five Factor Inventory (NEO-FFI).<sup>27</sup> The NEO-FFI is a shortened version of the NEO Personality Inventory-Revised.<sup>27</sup>

#### Statistical analyses

Demographic and clinical characteristics of the patients and the caregivers were calculated as means with SD or as frequencies for categorical data. To examine baseline differences (in the characteristics of the patient and caregiver) between the low-EE and high-EE groups, the independent-sample t-test, linear regression and  $\chi^2$  test were used. Square root transformations were used to normalise distributions if necessary (for NPI scores) for statistical tests, the data itself are represented in their raw form (eg, means) for a better understanding of the data. Spearman's correlations were used to explore the pairwise relationships between the PwD variables and the caregiver variables, see online supplemental tables 1 and 9

Linear mixed models tested the association between EE and change in NPI scores over time. The models included a random intercept and random slope with an unstructured correlation matrix. An interaction term between EE and time was included, and analyses were adjusted for the age and sex of the PwD and MMSE score. Logistic regressions were used to investigate possible associations between EE group and binary outcome variables such as institutionalisation. Additionally, the high-EE group was subdivided into a critical and an EOI group, and comparisons were made of critical versus not critical and high in EOI versus not high in EOI. Independent sample t-test was used to explore differences between personality traits and EE groups.

All analyses were done in Stata/SE V.12.1 (StataCorp), and the level of statistical significance was p<0.05 in two-sided tests.

#### Patients and public involvement statement

No patients and/or public were involved.

#### **RESULTS**

#### **Baseline characteristics**

Of the 119 informal caregivers participating in MAASBED, 112 (94.1%) agreed to be interviewed at baseline. Therefore, a total of 112 dyads of PwD and their caregivers were included in the analysis. Caregivers who participated did not differ from those who did not participate in terms of age, sex, education or depressive symptoms, nor did the respective patients in terms of dementia severity or NPS. During the 2-year follow-up, 47 dyads were lost to follow-up because of refusal (n=21) or death (n=26), see online supplemental figure 1. Caregivers and PwD lost to follow-up did not differ from those who did not in terms of sex (caregiver and PwD), age of the PwD, total NPI scores or EE-group; but caregivers lost to follow-up were relatively older compared with caregivers not lost to follow-up (67.7 vs 61.4, p=0.003), and more PwD had a GDS score of 5 or 6 (p=0.032).

The PwD had a mean age of 78.7 (SD=8.3, range 56–99), and 66 (58.9%) were women. Eighty-four PwD (75.0%) had Alzheimer's disease, 19 (17.0%) vascular



Table 1 High-EE versus low-EE: caregiver characteristics

	Low-EE N=76	High-EE N=36	P value
Relationship			0.336
Spouse	43	15	
Son/daughter	28	18	
Other	5	3	
Gender female (%)	47 (61.8%)	27 (75%)	0.170
Age (SD)	64.7 (1.5)	60.9 (1.7)	0.129
Educational level			0.024
Low	40	27	
High	36	9	
Contact hours per week			0.083
<50 hour/week	27	19	
>50 hour/week	49	17	
MADRS (SD)	8.0 (6.1)	9.0 (6.8)	0.440
SSCQ (SD)	24.8 (5.7)	21.1 (6.1)	0.003

The bold values resemble the significant level (P <0.05). EE, expressed emotion; MADRS, Montgomery-Asberg Depression Rating Scale; SSCQ, Short Sense of Competence Questionnaire.

dementia, 2 (1.8%) frontotemporal dementia, 3 (2.7%) Parkinson's disease, 1 (0.9%) primary progressive aphasia and 3 (2.7%) mixed dementia. The mean duration of illness was 42.3 months (SD=30.4, range 6–120) and the mean MMSE score was 18.1 (SD=4.7). Concerning the GDS score, 17.9% having stage 3 cognitive functioning, 53.6% stage 4, 27.7% stage 5% and 0.9% stage 6.

The mean age of the caregivers was 63.5 years (SD=12.2, range 36–90), 74 (66.1%) were women, 58 (51.7%) were spouses, 46 (41.1%) were children and 8 (7.1%) had another relationship (eg, close friends). The mean duration of care was 27.9 months (SD=26.1, range 3–120), and the caregivers spent a mean of 92.8 contact hours per week (SD=70.8, range 2–168) with the PwD.

#### **EE** and baseline group differences

Seventy-six (67.9%) caregivers were classified in the low-EE group, and 36 (32.1%) caregivers were classified in the high-EE group. In the high-EE group, 19 caregivers scored on critical comments, 11 caregivers were emotionally overinvolved and 6 caregivers were both critically and emotionally overinvolved. In the low-EE group, 12 caregivers were borderline-critical, and 9 caregivers were borderline-emotionally overinvolved.

There were no differences between the high-EE and low-EE groups in caregiver age, sex or kind of relationship with the patient (table 1). The caregivers in the low-EE group had a higher educational level.

In addition, there were no differences between the high-EE and low-EE groups in patient age, sex, disease severity, cognitive status or disease duration (table 2).

Table 2 High-EE versus low-EE: patient characteristics							
	Low-EE N=76	High-EE N=36	P value				
Gender female (%)	44 (57.9%)	22 (61.1%)	0.747				
Age (SD)	78.6 (8.4)	78.7 (8.4)	0.977				
GDS			0.761				
Stage 3	15	5					
Stage 4	39	21					
Stage 5	21	10					
Stage 6	1	0					
MMSE (SD)	17.8 (4.7)	18.7 (4.5)	0.325				
Disease duration, months (SD)	39.8 (30.0)	47.5 (31.1)	0.214				
NPI score (SD)	20.1 (20.2)	26.1 (26.0)	0.241				
IDDD-initiative IDDD- performance	22.9 (9.7) 19.8 (10.9)	21.6 (9.9) 19.9 (10.6)	0.519 0.968				
Psychotropic medication							

Table 2 High-FF versus low-FF: nationt characteristic

EE, expressed emotion; GDS, Global Deterioration Scale; IDDD, Interview for Deterioration in Daily living activities in Dementia; MMSE, Mini-Mental State Examination; NPI, Neuropsychiatric Inventory.

%)

17 (22.4

8 (10.5%)

19 (25%)

13 (36.1 %)

3 (8.3%)

7 (19.4%)

0.125

0.716

0.515

#### EE as predictor of NPS at baseline

Antidepressants

**Antipsychotics** 

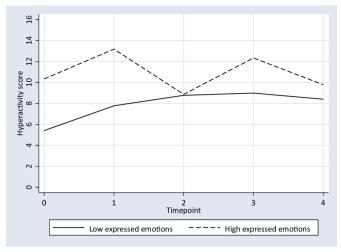
Benzodiazepines

There was a six-point difference between the EE groups in mean baseline NPI score, but this difference was not statistically significant (low EE: 20.1, high EE: 26.1, p=0.241). Analyses were repeated for the three behavioural subsyndromes to examine differences in mood/apathy, hyperactivity and psychosis. In the high-EE group, the mean hyperactivity scores were higher than those in the low-EE group (10.3 vs 5.4, p=0.021), but this was not the case for the mood or psychosis subsyndrome (9.2 vs 8.6, p=0.943 and 3.9 vs 4.1, p=0.748, respectively). Hyperactivity also showed a significant result when correcting for PwD age, sex and MMSE score (p=0.013).

#### **EE** as predictor of NPS over time

Performing regression analyses for the three behavioural subsyndromes per time point showed higher mean scores for the hyperactivity symptoms in the high-EE group compared with the low-EE group (figure 1). However, not all mean scores differed significantly at each time point when correcting for PwD age, sex and MMSE score: on baseline p=0.013, on T1 p=0.003, on T2 p=0.913, on T3 p=0.099 and on T4 p=0.838.

Analyses were also repeated for caregivers who scored high on critical comments compared with caregivers scoring low on critical comments, and the results showed higher mean scores for hyperactivity symptoms over time in the 'critical' group (figure 2). At all time points except



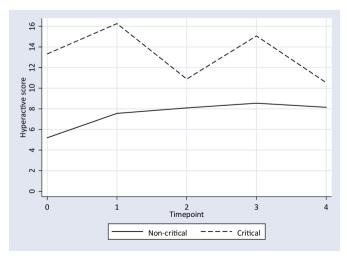
**Figure 1** Mean hyperactivity score on the NPI by EE-group. EE, expressed emotion; NPI Neuropsychiatric Inventory.

for T2 and T4, scores differed significantly when correcting for PwD age, sex and MMSE score: on baseline p=0002, on T1 p<0.001, on T2 p=0.217, on T3 p=0.007 and on T4 p=0.616. There was no significant difference between the high-EOI group and the low-EOI group.

Linear mixed models showed no associations between EE groups and the change in NPI scores over time, also not when repeating the analyses for the subsyndromes. There was also no significant time-by-group interaction effect.

#### **EE** and institutionalisation

PwD with caregivers in the high-EE group had a higher risk of admission to a nursing home (OR 3.74 (95% CI 1.01 to 13.87, p=0.048, corrected for PwD age, sex and MMSE score)). When comparing caregivers scoring high on critical comments versus caregivers scoring low on critical comments, the risk increased (OR 6.07 (95% CI 1.14 to 32.14, p=0.034, corrected for PwD age, sex and MMSE score)). Correcting for IDDD instead of MMSE score, as



**Figure 2** Mean hyperactivity score on the NPI by EE subgroups critical versus non-critical. EE, expressed emotion; NPI Neuropsychiatric Inventory.

well as also correcting for NPI score, did not have a major impact on the results.

## Exploring caregiver characteristics associated with low versus high EE

Associations between caregiver personality traits assessed with the NEO-FFI and EE were explored. Mean scores on neuroticism were higher in the critical EE group than in the non-critical EE group (34.1 (SD 7.8) vs 29.6 (SD 6.9), p=0.015), whereas other personality traits did not significantly differ. Also, caregiver subjective competence measured with the SSCQ differed between the two groups. Mean scores were higher in the low-EE group than in the high-EE group (24.8 (SD 5.7) vs 21.1 (SD 6.1), p=0.0026). The difference was bigger comparing the non-critical EE group with the critical EE group (24.2 (7.1) vs 19 (5.6), p=0.001).

There were no significant differences between EE groups in scores on MADRS. However, caregivers in the high-EE group reported significantly more distress on the NPI at baseline but not at the other follow-up moments. Caregivers scoring high on critical comments reported significantly more distress on the NPI at each time point (table 3), except on T4.

#### **DISCUSSION**

The aim of the current study was to examine the association between EE in caregivers and NPS in PwD living at home. Our results show that high levels of EE were present in 32.1% of the caregivers. High EE was related to more hyperactivity symptoms in PwD on the NPI. Scores were even higher in the high-critical-EE subgroup of caregivers. No associations were found between EE subgroups and mood/apathy or psychosis. PwD with caregivers who gave more critical comments were more likely to become institutionalised during the 2-year follow-up.

The present study confirms previous studies and adds to the evidence that there is an association between interpersonal interaction and behaviour in the person with dementia. 12 14 28 Hooley et al described that it seems most likely that this direction is at least bidirectional, it could be that our results fit this theory. Especially in dementia, where verbal communication may become affected, interactions may become more complex, and high EE may lead to negative interaction sequences. In this study, a higher number of critical comments was related to more hyperactivity symptoms. In the unmet-needs model of Cohen-Mansfield et al,<sup>29</sup> problem behaviour such as hyperactivity is thought to arise from difficulties communicating one's needs. Caring for a person with dementia can be very difficult, time-consuming and energy-consuming and frustrating, which may lead to a caregiver becoming exhausted and reacting frustratedly. High levels of criticism from the caregiver towards the person with dementia may result in an unsafe environment where the caregiver is not able to meet the needs of the person with dementia. As a result, the person with dementia may become irritated or



Table 3 Mean scores on NPI distress

	NPI distress (mean)					
EE group	Baseline	T1	T2	Т3	T4	
EE: low vs	9.6 vs 14.6	11.7 vs 16.1	11.8 vs 16.2	10.5 vs 17.4	11.1 vs 12.7	
high	p=0.015	p=0.084	p=0.079	p=0.071	p=0.71	
Critical comments: low vs high	9.6 vs 16.1	11.4 vs 18.6	11.5 vs 19.4	10.4 vs 22.2	10.3 vs 14.7	
	p=0.002	p=0.011	p=0.008	p=0.009	p=0.437	

Note: due to loss to follow-up and institutionalisation, numbers get smaller over time; T4 analyses are based on n=29 with n=6 in the high-EE group and n=3 in the high critical group.

EE, expressed emotion; NPI, Neuropsychiatric Inventory.

offended with no ability to cope with critical comments or to react in a non-agitated verbal way. The association between critical comments and symptoms of hyperactivity such as agitation may be part of a more complex web of interactions between the caregiver and the person with dementia. This complex web is also highlighted by the fact that caregivers in the high EE group had a higher distress score on the NPI and reported lower caregiver competence measured with the SSCQ on baseline.

In this study, high EE was associated with the hyperactivity subsyndromes on the NPI but not with the subsyndromes mood/apathy and psychosis. However, we know that symptoms other than hyperactivity also have an impact on caregiver functioning. For example, apathy is known to have a big impact on caregivers<sup>30</sup> and was found to be associated with deterioration of the relationship quality in a previous study using MAASBED,<sup>31</sup> but we did not find an association between apathy and high EE in the present study.

The present study indicates that EE is partly determined by the stable characteristics of the caregiver. First, caregivers in the low-EE group had a significantly higher educational level. Second, caregivers in the critical comment subgroup had higher scores on neuroticism. This is in line with an earlier study using MAASBED that found caregivers with a non-adapting strategy reported more patient hyperactivity than did caregivers who used a supporting strategy.<sup>32</sup> Stable caregiver characteristics were thought to be important determinants of the caregiver management strategy. We also found caregiver distress related to NPS, measured with the NPI, to be higher in caregivers in the critical comments group. This might be a possible target for intervention. The prevalence of NPS in PwD might be reduced when caregivers receive interventions designed to improve positive interactions with the PwD. Promoting an early and positive adaptation in the caregiver role and more leisure time for the caregiver might be important.<sup>33 34</sup> Additionally, psychoeducation and teaching of effective coping strategies, such as seeking distraction, seeking social support and fostering reassuring thoughts, might be effective in reducing negative responses to stressful events in daily life. 35 Reducing stigma, for example, by large-scale awareness campaigns, might reduce EE, since the caregiver's experience of stigma is found to be associated with high

EE.<sup>36</sup> In the end, reducing EE might even delay patient institutionalisation.

The strengths of the present study are the relatively large sample size, the 2-year follow-up and the fact that confounding factors were taken into account. However, the study has some limitations. First, the FMSS is not the gold standard for measuring the level of EE. The FMSS has a tendency to underidentify high-EE relatives, 37 which could have masked the association between NPS and caregiver EE. However, in the context of this large study, it was not feasible to use a more extensive and time-consuming measure, such as the Camberwell Family Interview, which takes approximately 5 hours per person (interviewing and scoring). 37 Additionally, the level of EE was only assessed at baseline, so we could not study possible changes in EE over time. Therefore, we could only analyse the association with baseline EE and NPS over time, and we were not able to analyse whether EE changed during follow-up and the association of this possible change with NPS. It could be that EE changed significantly during follow-up and that this influenced NPS during follow-up. Future studies should include a follow-up of EE to further investigate whether EE is a stable characteristic. Another limitation might be that caregiver reports were used to assess NPS. Caregivers in the high-EE group might rate NPS more frequently and more severely. However, the finding that high EE was only associated with symptoms of hyperactivity and not with other NPS contradicts this argument. Also, we did not have enough data of any psychosocial interventions during the study period, relationship quality of the dyad, caregiver strain and of the presence of other informal caregivers or community services. Future studies could include this to investigate whether these factors influence the interactions in the dyad or not. Also, it is important that future studies analyse the caregiver characteristics associated with low versus high EEs more extensively. Finally, it was notable that mean hyperactivity scores in the high EE group dropped on T2. Inspection of the data showed that this was due to measurements in three patients who went from a high hyperactivity score on T0 and T1 to a score of 0 on T2 for unknown reasons. Leaving these measurements out of the analysis resulted in a mean difference in hyperactivity scores of 4.06 (p=0.043).



#### **CONCLUSION**

In conclusion, high EE in caregivers is associated with more hyperactivity symptoms in PwD. In dementia care, it seems crucial to pay attention to interpersonal interactions between caregivers and PwD. Interactions between PwD and caregivers may be complex, but reducing caregiver EE may attenuate hyperactivity symptoms in PwD. Future intervention studies that focus on the empowerment of dyads or the support of caregivers in the context of dementia should consider including measures of EE to study if EE can be reduced and if this affects outcomes in the PwD, such as hyperactivity symptoms. Eventually, this could improve the quality of life of PwD and their caregivers and possibly also delay institutionalisation.

**Contributors** ET: researched and analysed the data, wrote the manuscript. MV: reviewed/edited the manuscript, contributed to the discussion. KD: researched and analysed the data, reviewed/edited the manuscript. JMAGS: reviewed/edited the manuscript, contributed to the discussion. FRV: reviewed/edited the manuscript, contributed to the discussion.

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Competing interests None declared.

Patient consent for publication Not required.

**Ethics approval** The study was approved by The Medical Ethics Committee of the University Hospital Maastricht (METC 99-127).

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