

Dealing with Daily Challenges in Dementia (Deal-id Study)

Citation for published version (APA):

van Knippenberg, R. J. M., de Vugt, M. E., Ponds, R. W., Myin-Germeys, I., & Verhey, F. R. J. (2017). Dealing with Daily Challenges in Dementia (Deal-id Study): An Experience Sampling Study to Assess Caregivers' Sense of Competence and Experienced Positive Affect in Daily Life. *American Journal of Geriatric Psychiatry*, 25(8), 852-859. <https://doi.org/10.1016/j.jagp.2016.10.015>

Document status and date:

Published: 01/08/2017

DOI:

[10.1016/j.jagp.2016.10.015](https://doi.org/10.1016/j.jagp.2016.10.015)

Document Version:

Publisher's PDF, also known as Version of record

Document license:

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Dealing with Daily Challenges in Dementia (Deal-id Study): An Experience Sampling Study to Assess Caregivers' Sense of Competence and Experienced Positive Affect in Daily Life

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Objective: *Positive emotions and feelings of competence seem to play an important role in the well-being of caregivers of people with dementia. Both are likely to fluctuate constantly throughout the caretaking process. Unlike standard retrospective methods, momentary assessments in daily life can provide insight into these moment-to-moment fluctuations. Therefore, in this study both retrospective and momentary assessments were used to examine the relationship between caregivers' sense of competence and their experienced positive affect (PA) in daily life. Methods:* Thirty Dutch caregivers provided momentary data on PA and daily sense of competence ratings for 6 consecutive days using the experience sampling methodology. Additionally, they reported retrospectively on their sense of competence with a traditional questionnaire. **Results:** *A positive association was found between retrospective and daily measured sense of competence. Caregivers reported corresponding levels of sense of competence on both measures. Both daily and retrospective sense of competence were positively associated with the experienced levels of PA. However, daily sense of competence appeared to be the strongest predictor. Regarding the variability in PA, only daily sense of competence showed a significant association, with a higher daily sense of competence predicting a more stable PA pattern. Conclusion:* This study provides support for redirecting caregiver support interventions toward enhancement of positive rather than negative experiences and focusing more on caregivers' momentary emotional experiences. Momentary assessments are a valuable addition to standard retrospective measures and provide a more comprehensive and dynamic view of caregiver functioning. (Am J Geriatr Psychiatry 2017; 25:852–859)

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<http://dx.doi.org/10.1016/j.jagp.2016.10.015>

Key Words: Dementia, caregiver, momentary assessment, experience sampling methodology, sense of competence, positive affect

INTRODUCTION

The number of people living with dementia worldwide is expected to increase substantially in the near future.¹ Because of the rising costs of formal care, people with dementia are being urged to live at home for longer periods of time; consequently, informal caregivers are increasingly engaged in the caretaking process. However, providing years of extensive care for a person with dementia (PwD) might cause chronic stress and can increase the risk of developing physical and psychological symptoms, such as depression and anxiety.² Although caregiving is often associated with negative consequences, it can also elicit positive experiences.^{3,4} Caring itself can be rewarding and may provide a sense of self-efficacy and feelings of accomplishment.⁵

There is a growing trend toward a more positive view of dementia and of health in general. Huber et al.⁶ commented on the World Health Organization definition of health and argued for a more positive view of well-being. Huber et al.⁶ proposed defining health as the capacity to adapt and self-manage social, physical, and emotional challenges instead of merely “a state of complete physical, mental and social well-being”.⁷ When applying this new perspective to the definition of caregiver well-being, our focus should be directed more toward caregivers’ capacities to cope with their loved ones’ chronic diseases. Acceptance of the situation can lead to a better adaptation to the disease and a shift in focus toward possibilities rather than losses. Focusing on positive experiences facilitates a more positive interaction between the caregiver and PwD and increases positive emotions and well-being in both parties.⁸ Additionally, positive emotions enhance one’s ability to cope with stressful situations and help regulate negative emotions.⁹ According to the “broaden-and-build theory”, positive emotions broaden the scope of attention and cognition and enable more flexible and creative thinking. Consequently, a wider range of potential coping strategies emerges during times of stress and negative emotional experiences.¹⁰ Positive emotions thus seem to be important facilitators of adaptive coping^{9,11} and might

also reduce long-term negative impacts, such as stress or burden.¹²

A focus on positive emotions can also help caregivers feel more competent in providing care.² Caregiver’s sense of competence is an important concept in the field of dementia care and denotes the feeling of being capable of effectively meeting caregiving challenges.¹³ Feelings of competence may help caregivers adapt to continually changing demands and maintain their mental stability.¹⁴ However, caregivers’ feelings of competence and experience of positive emotions are likely to fluctuate over time and between situations throughout the caregiving process. Standard retrospective methods are unable to capture daily life fluctuations in subjective experiences and are highly susceptible to emotional and cognitive biases.^{15,16} In-the-moment daily life assessments could provide more detailed and ecologically valid information on caregivers’ subjective experiences of positive emotions and feelings of competence in the flow of daily life.

Therefore, in the current study, both retrospective and in-the-moment daily life assessments were used to examine the relationship between caregivers’ sense of competence and experienced positive affect (PA) in daily life. Overall, we hypothesized that a higher sense of competence would be related to higher levels of PA and less variability in PA. Furthermore, we explored whether retrospectively or daily measured sense of competence exhibited stronger relationships with intensity of PA and variability in PA in daily life.

METHODS

Subjects

Between February 2013 and February 2014, 31 informal caregivers participated in the study. Caregivers were recruited from the Memory Clinic of the Maastricht University Medical Center Plus, the Zuyderland Medical Center, and mental healthcare institutions in the southern Netherlands. Inclusion criteria were being a spousal caregiver of a person with a diagnosis of dementia and sharing a household with the PwD. Ex-

clusion criteria were having insufficient cognitive abilities to complete the daily life assessments and severe health problems that limited study participation (both based on clinical judgment).

The Medical Ethical Committee of the Maastricht University Medical Center Plus (#12-3-049) approved this study. The study is registered in the Dutch Trial Register (NTR3574).

Retrospective Assessments

Retrospective Sense of Competence

The Short Sense of Competence Questionnaire (SSCQ) was used to retrospectively assess caregivers' sense of competence during the previous week. The SSCQ is a shortened form of the 27-item Sense of Competence Questionnaire and assesses caregivers' feelings of being capable of caring for a PwD.¹⁷ The SSCQ consists of seven items rated on a five-point scale from 1 ("agree very strongly") to 5 ("disagree very strongly"). A total SSCQ sum score (range: 7–35) was calculated, with higher scores indicating higher levels of sense of competence (Cronbach's $\alpha = 0.89$).

Disease Severity

The Clinical Dementia Rating scale was used to assess the PwD's severity of dementia.¹⁸ The researcher applied the Clinical Dementia Rating scale score using a five-point scale (0 = "normal", 0.5 = "very mild dementia", 1 = "mild dementia", 2 = "moderate dementia", and 3 = "severe dementia") during a semi-structured interview with the caregiver.

Daily Life Assessments

The experience sampling methodology (ESM) was used to assess caregivers' momentary experiences.^{15,19} Participants were given a PsyMate (Maastricht UMC+, Maastricht, The Netherlands; <http://www.psymate.eu>), an electronic touchscreen device specifically developed for momentary assessments in clinical practice.²⁰ Recent results of our feasibility study, which was conducted in the same sample as the current study, showed that caregivers considered the PsyMate a user-friendly device in which they could accurately describe their feelings and experiences.²¹

The PsyMate was preprogrammed to generate 10 beeps (sound and vibration) daily at unpredictable times in a semi-random design between 7:30 A.M. and 10:30 P.M. After each beep, short ESM reports of current context (e.g., location, activity, social company) and mood (i.e., PA and negative affect) were collected. ESM reports had to be completed within 10 minutes after the beep. Additionally, participants were asked to complete an evening ESM questionnaire at the end of each day. This questionnaire consisted of items concerning the caregivers' overall feelings during the day and their daily sense of competence.

Levels of Momentary PA

PA was defined as the mean score of the following four items: "I feel cheerful", "I feel relaxed", "I feel enthusiastic", and "I feel satisfied" (Cronbach's $\alpha = 0.91$ for the mean-centered scores). The items were rated on seven-point Likert-scales, ranging from 1 ("not at all") to 7 ("very"). A mean PA score was calculated for each completed beep during the day, with higher scores reflecting higher levels of PA.

Variability in Momentary PA

Variability in momentary PA was defined as the absolute difference in PA between two succeeding beeps within 1 day (i.e., the mean PA score at one moment minus the mean PA score at the preceding moment). If a beep was missed, the mean PA score from a maximum of two beeps before was used. The variability score ranges from 0 to 6, with higher scores reflecting more variability in PA.

Daily Sense of Competence

Daily sense of competence was measured at the end of each day with an ESM evening questionnaire. This questionnaire contained three sense of competence items derived from the traditional SSCQ:¹⁷ "Today I felt stressed due to my care responsibilities", "Today I felt that the situation with my partner did not allow me as much privacy as I would have liked", and "Today I felt strained in the interactions with my partner" (Cronbach's $\alpha = 0.57$ for the mean-centered scores). During the ESM questionnaire development, these three items were considered most suitable for momentary

ratings according to the guidelines from ESM experts.²² Items were rated on seven-point Likert-scales, ranging from 1 (“not at all”) to 7 (“very”). Daily sense of competence was defined as the sum score of the three items. Scores were reversed to comply with the traditional SSCQ scoring system, in which higher scores represent more sense of competence.

Procedure

After informed consent was obtained, the study protocol for each participant included the following three sessions. The first was an introductory session in which a demographic interview was conducted to assess caregiver and care recipient characteristics (i.e., age, sex, level of education, type of dementia, disease severity, and dementia daycare attendance). Subsequently, a 30-minute training session was provided on operating the PsyMate, the meaning of all questions and response options, and procedures for carrying the device. A demonstration of the ESM questionnaire was completed to familiarize participants with the PsyMate. Participants were instructed to contact the researcher for any (technical) problems. The second session was a daily life assessment period in which participants were provided with a PsyMate for 6 consecutive days. The momentary data collection began the day after the introductory session. All participants were contacted once by telephone on the second day of sampling to resolve any problems. The third was a debriefing session. The day after the daily life assessment, participants were asked to complete the retrospective SSCQ concerning their sense of competence in the past week. Additionally, a debriefing questionnaire regarding their general experiences with the PsyMate and study procedure was administered. These feasibility results have been described in detail elsewhere.²¹

Statistical Analyses

ESM data have a hierarchical structure in which repeated ESM observations (beep level 1) are nested within days (day level 2) and days are nested within subjects (subject level 3). Because observations from the same subject are more similar than observations from different subjects, the residuals are not independent. Multilevel modeling techniques account for this lack of independence and are ideally suited for analyzing ESM data.²³ Data were analyzed with the XTMIXED

module in STATA 12.1 (StataCorp, College Station, TX) using a full maximum likelihood estimator. The best-fitting covariance structure was determined by performing likelihood ratio testing for each model. Based on previous ESM studies and guidelines from ESM experts, participants had to complete at least 33% of the ESM reports to be included in the analyses.^{22,24} Retrospective and daily sense of competence scores were standardized using means and standard deviations.

First, to examine the association between caregivers’ retrospective sense of competence (SSCQ) and daily sense of competence (ESM), a multilevel linear regression analysis was conducted with daily sense of competence (sum score 3 items) as the outcome variable and retrospective sense of competence (total SSCQ sum score) as the fixed factor. A random intercept model provided the best fit. Intercepts of the continuous daily sense of competence outcome were allowed to vary randomly across subjects and days. A separate sensitivity analysis was performed with the sum score of only the three items on the retrospective SSCQ as the fixed factor instead of the total SSCQ sum score. Furthermore, a paired t-test with aggregated data per subject was performed to examine potential differences in daily and retrospective levels of sense of competence.

Second, a series of multilevel linear regression analyses were performed to assess the extent to which the two different measures of sense of competence (retrospective and daily) were uniquely associated with the two PA measures (levels of PA and variability in PA). For models with levels of PA as the outcome variable, a random intercept and random slope model provided the best fit. Random effects were specified with an unstructured covariance matrix. Additionally, likelihood ratio testing suggested that additional specifications of the first-order autoregressive working correlation matrix (correlated residuals) best fit the model. Intercepts and slopes for the continuous PA outcome were allowed to vary randomly across subjects, days, and beeps. Additionally, a random intercept and slope for daily SSCQ score were added at the day level. For models with variability in PA as the outcome, a random intercept model provided the best fit. Intercepts for this continuous outcome were allowed to vary randomly across subjects and days. Within-person means of PA were added to the model to account for a subject’s typical level of PA. All models were adjusted

for caregiver's age, gender, and education level and availability of additional caring support (i.e., dementia daycare attendance of the PwD).

RESULTS

Subjects and Descriptive Statistics

Of the 31 caregivers in the study, 1 was excluded from the analyses for completing fewer than 20 valid reports (<33% of the total 60 ESM reports). The average number of completed ESM reports in the remaining 30 participants was 49.3 ± 5.2 of 60, indicating a completion rate of 80.4%. The completion rate of the ESM evening questionnaire was 86.7% (156/180). One participant forgot to complete all ESM evening questionnaires and was excluded from further analyses on daily sense of competence. Two participants did not complete the retrospective SSCQ and were excluded from the analyses on retrospective sense of competence. Table 1 presents the characteristics of the 30 participating caregivers and their care recipients.

Association between Retrospective and Daily Sense of Competence

Ratings of the independent and dependent variables are presented in Table 2. Caregivers who reported higher retrospective SSCQ scores also reported higher scores on daily sense of competence assessments ($\beta = 0.39$; 95% confidence interval [CI]: 0.16–0.62; standard error [SE]: 0.12; $z = 3.28$, $p = 0.001$). A sensitivity analysis, including only the three SSCQ items instead of all SSCQ items, yielded comparable results ($\beta = 0.45$; 95% CI: 0.25–0.65; SE: 0.10; $z = 4.37$, $p < 0.001$). There were no differences between the experienced levels of sense of competence when measured at the end of each day (mean: 2.06) and when measured retrospectively with the SSCQ (mean: 1.81) ($t(26) = -1.83$, $p = 0.078$).

Associations of Retrospective and Daily Sense of Competence with Experienced Levels of PA

The results showed that retrospective sense of competence was associated with levels of PA ($\beta = 0.36$; 95% CI: 0.01–0.71; SE: 0.18; $z = 2.00$, $p = 0.046$). Thus, a one-standard deviation increase in SSCQ score was related to an increase of 0.36 in PA in each ESM report. The

TABLE 1. Characteristics of Caregivers and Care Recipients

Variable	Caregivers (N = 30)	Care Recipients (N = 30)
Mean age \pm SD, yr (range)	69.9 \pm 5.8 (57–80)	73.7 \pm 6.2 (61–87)
Gender		
Male	12 (40.0)	18 (60.0)
Female	18 (60.0)	12 (40.0)
Level of education		
Low	13 (43.3)	16 (53.3)
Middle	8 (26.7)	6 (20.0)
High	9 (30.0)	8 (26.7)
Type of dementia		
Alzheimer's disease		22 (73.3)
Vascular dementia		3 (10.0)
Frontotemporal dementia		2 (6.7)
Dementia with Lewy bodies		1 (3.3)
Mixed dementia		2 (6.7)
Clinical Dementia Rating scale		
0.5: very mild		11 (36.7)
1: mild		11 (36.7)
2: moderate		7 (23.3)
3: severe		1 (3.3)
Dementia day care		
Yes		11 (36.7)
No		19 (63.3)
Mean dementia daycare hours/wk \pm SD		15.4 \pm 6.8

Note: Values are total number of cases with percents in parentheses, unless otherwise noted.

sensitivity analysis, including only the three corresponding SSCQ items, showed comparable results ($\beta = 0.55$; 95% CI: 0.25–0.86; SE: 0.16; $z = 3.52$, $p < 0.001$).

Daily sense of competence was also positively associated with levels of PA ($\beta = 0.75$; 95% CI: 0.40–1.10; SE: 0.18; $z = 4.17$, $p < 0.001$). A one-standard deviation increase in daily sense of competence was related to an increase of 0.75 in PA in each ESM report.

To further investigate whether daily or retrospectively measured sense of competence was a stronger predictor of the experienced levels of PA, an additional analysis was performed with both variables included as fixed factors. Data were checked for multicollinearity, yielding variance inflation factors of less than 10. The results showed that only the association between daily sense of competence and experienced PA remained significant, with $\beta = 0.83$; 95% CI: 0.43–1.24; SE: 0.21; $z = 4.02$, $p < 0.001$ for daily sense of competence and $\beta = 0.13$; 95% CI: -0.18 to 0.43; SE: 0.16; $z = 0.80$, $p = 0.425$ for retrospective sense of competence. The sensitivity analysis

TABLE 2. Mean, SD, and Range for All Variables Used in the Analyses

Variable	No. of valid ESM reports	N	M (SD)	Range
Positive affect ^a	1,448	30	5.07 (0.89)	2.97–6.46
Variability in positive affect ^b	1,229	30	0.53 (0.22)	0.25–0.98
Daily sense of competence (3 selected items) ^c	156	29	2.06 (0.55)	1.22–2.91
Retrospective SSCQ (3 selected items) ^c		28	1.81 (0.78)	0.25–3.00
Retrospective SSCQ (all 7 items) ^d		28	25.68 (6.60)	8.00–35.00

Notes: ^aFor each subject, a mean was calculated over all beeps. The mean per subject was aggregated over the group to attain a group mean (standard deviation [SD]).

^bVariability is defined as the absolute difference in positive affect between two succeeding ESM beeps. For each subject, a mean difference score was calculated over all beeps. The mean difference per subject was aggregated over the group to attain a group mean (SD).

^cThe three selected raw item scores were changed into an adjusted score ranging from 0 to 1 to correct for the difference in scoring range between the daily and retrospective SSCQ (1–7 versus 1–5) and to compare both scores. The sum score of the three adjusted items ranged from 0 to 3.

^dThe retrospective SSCQ total score is not adjusted to the difference in scoring range between the daily and retrospective SSCQ. The sum score of the SSCQ total score ranged from 7 to 35.

with only the three corresponding SSCQ items showed comparable results, with $\beta = 0.74$; 95% CI: 0.31–1.17; SE: 0.22; $z = 3.38$, $p = 0.001$ for daily sense of competence and $\beta = 0.23$; 95% CI: –0.09 to 0.56; SE: 0.17; $z = 1.41$, $p = 0.159$ for retrospective sense of competence.

Associations of Retrospective and Daily Sense of Competence with Variability in Experienced PA

Retrospective sense of competence was non-significantly associated with variability in PA ($\beta = -0.04$; 95% CI: –0.13 to 0.05; SE: 0.05; $z = -0.91$, $p = 0.365$). The sensitivity analysis with the three corresponding SSCQ items also showed non-significant results ($\beta = 0.01$; 95% CI: –0.09 to 0.10; SE: 0.05; $z = 0.15$, $p = 0.883$).

Daily sense of competence was significantly associated with variability in PA ($\beta = -0.17$; 95% CI: –0.29 to –0.06; SE: 0.06; $z = -2.89$, $p < 0.001$). Higher levels of daily sense of competence were related to less variability in PA during the day.

DISCUSSION

This study examined the relationship between caregivers' sense of competence and experienced levels of PA in daily life. Two types of measurements were used to assess sense of competence: retrospective and daily life assessments. The results showed a positive association between retrospective and daily sense of competence; thus, caregivers who report a higher sense of competence on traditional retrospective

questionnaires also experience more sense of competence in their natural daily environment. Furthermore, caregivers reported corresponding levels of sense of competence when measured daily at the end of each day and when measured retrospectively after 6 days with a traditional questionnaire. This finding indicates that caregivers' retrospective ratings of sense of competence are consistent with their experiences in real life and that researchers and clinicians can rely on standard retrospective questionnaires to examine levels of caregiver sense of competence and to develop potential support plans. Interestingly, several studies have documented discrepancies between momentary and retrospective self-reports of mood, symptoms, traits, and behaviors in both clinical and non-clinical populations, highlighting the risks associated with reliance on retrospective reports alone.^{25,26} One explanation for the contrasting finding in our study might be that we used assessments at the end of each day to assess daily sense of competence, which still requires the caregiver to reflect and integrate information from memory, increasing the risk of recall bias.²⁷ Furthermore, previous studies have demonstrated greater agreement between momentary and retrospective ratings when the experiences are relatively stable over time.^{28,29} Caregivers in our sample reported relatively high and stable levels of PA, which might explain our results. More ESM studies are needed to examine the correlations between momentary and retrospective self-report in caregivers of PwDs.

Consistent with our initial hypotheses, a higher sense of competence was related to more positive emotions

in the caregiver. It is plausible to assume that a reciprocal relationship exists between sense of competence and PA. Feeling competent in caring generates more positive emotions, and, vice versa, positive emotions can also buffer against the negative consequences of care.¹² Positive emotions are important facilitators of adaptive coping in stressful situations and might therefore prevent high levels of stress and caregiver burden.^{9,12} From a therapeutic perspective, this finding highlights the importance of increasing the awareness of positive rather than negative experiences throughout the caretaking process.

We additionally examined whether retrospective or daily sense of competence exhibited a stronger relationship with experienced PA. Based on the β coefficients, daily sense of competence appeared to show the greatest correlation to experienced levels of PA. Moreover, retrospective sense of competence did not significantly contribute to the prediction of experienced PA when both retrospective and daily sense of competence were added as predictors to the model. Therefore, we presume that daily sense of competence is a stronger predictor of caregivers' experienced PA in daily life. Hence, ESM should be considered for clinical purposes more frequently and can be considered as a valuable complement to standard retrospective questionnaires.³⁰

Regarding the association between caregivers' sense of competence and variability in PA, we found that higher levels of daily sense of competence were associated with less variability in PA. This indicates that caregivers of PwDs who report more feelings of competence in daily life also show a more stable pattern of experienced positive emotions. Retrospectively measured sense of competence was not significantly associated with variability in PA. Caregivers' feelings of competence are likely to fluctuate over time and between different situations because of the continuously changing care demands. Standard retrospective measures do not account for these fluctuations and reduce sense of competence to a stable characteristic. Momentary assessments capture the daily fluctuations in sense of competence and might therefore be predictive of the variability in experienced PA and be more strongly related to the intensity of experienced PA in daily life. These findings indicate that caregiver interventions should target caregivers' momentary feelings of competence and emotions more often when setting goals for treatment. Relying solely on general retrospective self-reports might bias the

estimation of caregiver strain and consequently affect treatment outcomes.³⁰

Certain limitations should be considered when interpreting the presented results. First, we included a selective sample of relatively young caregivers of people with mild dementia. It is unknown how our results might generalize to a more heterogeneous caregiver population. Nevertheless, our study sample was highly representative of a university memory clinic population, which more often includes young caregivers, who are more proactive in seeking support.³¹ Second, the cross-sectional nature makes it impossible to demonstrate causal relationships. Therefore, it is questionable whether caregivers' sense of competence influenced PA in daily life or whether PA influenced caregivers' feelings of competence; regardless, either explanation has clinical relevance. Finally, the potential problem of reactivity should be considered when interpreting the results of ESM studies. The repetitive nature of the assessments may lead people to pay unusually close attention to their internal states, which might influence their retrospective recall of emotions.³² In this study, the risk of reactivity was minimized by including a rigorous time sampling protocol and a randomized time schedule to desensitize participants to the ESM procedure.²²

Despite these limitations, the results have important implications for both research and clinical settings. Overall, they indicate that traditional retrospective questionnaires, which are currently most often used in scientific and clinical practice, adequately provide global information about daily caregiver functioning in terms of experienced levels of PA. However, concepts such as caregivers' sense of competence and positive emotions are considered to vary constantly over time and between different situations. Momentary assessment (i.e., ESM) enables a considerably more detailed and dynamic view of caregiver functioning and provides a "film" rather than a "snapshot" of daily life.³³ Although traditional retrospective questionnaires remain useful and important in assessing caregivers' perceptions of their own functioning, momentary assessments offer clinicians a more comprehensive view that can be useful in developing effective caregiver support interventions. Caregiver interventions can draw on the positive association between caregivers' sense of competence and positive emotions by focusing on positive rather than negative experiences. Our next step is to develop an

ESM-based intervention in which caregivers collect momentary data and receive personalized feedback on their daily patterns of PA and the context in which PA is experienced. The aim of such an intervention would be to enhance caregivers' self-awareness and refocus their behavior on situations that elicit positive emotions. Positive emotions and feelings of competence might reinforce each other and help caregivers of PwDs endure their care responsibilities.

The authors thank Inge Klinkenberg for her assistance with the data collection.

This study was supported by a grant from the Dutch Alzheimer Society (grant no. WE03-2011-06).

All authors contributed to the design of this study. RJMvK collected the data, performed the data analyses, and wrote the manuscript. IM-G assisted in the data analyses. MEdV, RWP, IM-G, and FRJV provided valuable feedback during the process of writing this manuscript.

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