

Dealing with daily challenges in dementia (deal-id study)

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Dealing with daily challenges in dementia (deal-id study): an experience sampling study to assess caregiver functioning in the flow of daily life

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Objective: Accurate assessment of caregiver functioning is of great importance to gain better insight into daily caregiver functioning and to prevent high levels of burden. The experience sampling methodology (ESM) is an innovative approach to assess subjective experiences and behavior within daily life. In this study, the feasibility of the ESM in spousal caregivers of people with dementia was examined, and the usability of ESM data for clinical and scientific practice was demonstrated.

Methods: Thirty-one caregivers collected ESM data for six consecutive days using an electronic ESM device that generated ten random alerts per day. After each alert, short reports of the caregiver's current mood state and context were collected. Feasibility was assessed by examining compliance and subjective experiences with the ESM. Usability was described using group and individual ESM data.

Results: Participants on average completed 78.8% of the reports. One participant completed less than 33% of the reports and was excluded from data analyses. Participants considered the ESM device to be a user-friendly device in which they could accurately describe their feelings and experiences. The ESM was not experienced as too burdensome. Zooming in on the ESM data, personalized patterns of mood and contextual factors were revealed.

Conclusions: The ESM is a feasible method to assess caregiver functioning. In addition to standard retrospective measurements, it offers new opportunities to gain more insight into the daily lives of people with dementia and their caregivers. It also provides new possibilities to tailor caregiver support interventions to the specific needs of the caregiver. Copyright © 2016 John Wiley & Sons, Ltd.

Key words: dementia; caregiver functioning; experience sampling methodology; feasibility

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Introduction

Caring for a person with dementia (PwD) has a considerable impact on caregivers' psychological and physical well-being (Pinquart and Sörensen, 2003; Schulz *et al.*, 1995). Caregivers have a high risk of developing depression and are vulnerable to becoming overburdened (Joling *et al.*, 2010). Levels of caregiver distress and burden also play an important role in the behavior of the PwD. Caregiver distress has been found to predict feeding difficulties (Rivière *et al.*,

2002) and delusions in the PwD (Riello *et al.*, 2002). Moreover, non-adapting caregiver strategies can result in negative interaction patterns that influence the emergence of behavioral problems in the PwD (de Vugt *et al.*, 2004). Therefore, accurate assessment of caregiver functioning is of great importance to improve quality of life of both the caregiver and the PwD.

Traditional retrospective measures, such as clinical interviews and retrospective questionnaires, are highly susceptible to recall biases (Stone *et al.*, 2003). Many studies have shown that people are generally not able

to accurately describe real-life experiences retrospectively and tend to overestimate or underestimate the frequency of symptoms (Kahneman *et al.*, 2004; Bradburn *et al.*, 1987). Moreover, retrospective assessments do not provide information regarding fluctuations in mood or symptoms that emerge over time or across different situations. Assessing individual patterns in the flow of daily life rather than in retrospective reports could offer personalized and relevant information for clinical practice.

In recent years, innovative methods have emerged to assess phenomena in real time within daily life and are referred to as the experience sampling methodology (ESM) (Delespaul, 1995; Hektner *et al.*, 2007). The ESM is a structured diary method for assessing subjective experiences and events in the moment they occur, in their natural setting. By collecting real-time data, ecological validity is maximized, and retrospective recall biases can be avoided (Shiffman, 2000). Moreover, the ESM enables the exploration of temporal relationships between variables and reveals detailed information regarding daily fluctuations in subjective experiences (Myin-Germeys *et al.*, 2009). The ESM data may improve both the caregiver's and the clinician's insight into daily patterns of emotions and behavior, thus creating an opportunity to tailor support interventions to the specific needs of the caregiver. By using devices, such as personal digital assistants, real-time data can be recorded electronically and are immediately available to both caregivers and professionals. This creates the opportunity to provide explicit, visualized feedback on daily patterns of emotions and behavior. The feedback may help to redirect caregivers toward situations that increase their positive affect (PA). PA has been found to play an important role in resilience against stress and might increase caregivers' emotional strength (Fredrickson, 2004).

The ESM has been applied with success in the study of various patient groups (Myin-Germeys *et al.*, 2009; Stone *et al.*, 2003; Nyholm *et al.*, 2004). However, to the best of our knowledge, only two studies have employed this methodology in dementia research (Fonareva *et al.*, 2012; Poulin *et al.*, 2010). Using the ESM, Fonareva *et al.* (2012) compared stress ratings obtained in research settings with stress ratings collected in natural settings. Data were collected over a single 24-h period and included only five questions. Compliance with the ESM procedure was high, suggesting that short-term ESM is feasible in this population. To gain more insight into fluctuations of caregivers' subjective experiences over time, a period of ESM data collection longer than 24 h is recommended

(Myin-Germeys and van Os, 2007). In the study by Poulin *et al.* (2010), spousal caregivers of people with chronic illness, including dementia, were asked to collect ESM data for seven days to measure helping behavior and positive and negative affect (NA). Poulin *et al.* (2010) reported no dropouts; however, they did not explore compliance and caregivers' experiences with the ESM procedure.

Although study results from Poulin *et al.* (2010) and Fonareva *et al.* (2012) indicate the ESM to be highly promising as a clinical or research tool for caregivers of PwD, more studies are needed to assess feasibility in this specific population. Compliance and subjective experiences of caregivers regarding the ESM should be properly examined because we are dealing with a vulnerable and often elderly population who is already pressured by many external demands because of their complex care situation.

The present study was conducted using the ESM with spousal caregivers of PwD (i) to test the feasibility of performing the ESM over a six-day period and (ii) to demonstrate the usability of ESM data on a group and individual level.

Methods

Participants

A total of 31 caregivers participated in the study. Participants were recruited in the Memory Clinic of the Maastricht University Medical Center Plus, the Zuyderland Medical Center, and in mental health care institutions in the southern Netherlands. Study inclusion criteria were as follows: (i) being a spousal caregiver of a person diagnosed with dementia and (ii) sharing a household with the PwD. Exclusion criteria were as follows: (i) having insufficient cognitive abilities to engage in the ESM and (ii) being overburdened or having severe health problems, both based on clinical judgment.

Instruments

Experience sampling methodology device. The ESM was implemented using the PsyMate, an electronic device that is specifically developed for momentary assessment in clinical practice (www.psymate.eu). The PsyMate is a small, lightweight touchscreen device with a user-friendly interface that is easily accessible for participants with limited familiarity with technological devices (Myin Germeys *et al.*, 2011). The PsyMate was preprogrammed to generate ten alerts

(sound and vibration) per day for six consecutive days. Alerts were generated at unpredictable moments in a semi-random design between 7:30 AM and 10:30 PM. Upon noticing an alert, participants were asked to respond to a 43-item questionnaire presented on the screen of the PsyMate. Decisions regarding the time sampling protocol (number of days and number of alerts per day) and the development of the ESM questionnaire were made according to information available from previous ESM studies (Oorschot *et al.*, 2012; Myin-Germeys *et al.*, 2002), guidelines from ESM experts (Palmier-Claus *et al.*, 2011) and knowledge about the range of experiences that caregivers of PwD could be expected to encounter in daily life. Moreover, an initial version of the ESM questionnaire was piloted with three health care professionals and three caregivers of PwD to ensure that no relevant domains were missing. Modifications were made based on their comments.

An exploratory factor analysis with oblique rotation was performed with the final items of the ESM questionnaire and resulted in four components of caregiver functioning: PA (four items; $\alpha = .91$); NA (eight items; $\alpha = .81$); self-esteem (four items; $\alpha = .24$); and physical well-being (four items; $\alpha = .57$). Only PA and NA were used for further data analyses, because self-esteem and physical well-being appeared to be less-reliable concepts. The remaining items concerned the caregivers' current activity, social company, location, and important events that occurred since the previous alert. At the end of each questionnaire, participants were asked to rate whether the alert disturbed them. Responses were collected using 7-point Likert scales (from 1 "not at all" to 7 "very much"), bipolar scales (from -3 "very unpleasant/very unimportant" to +3 "very pleasant/very important"), and box-checking formats. Completed responses could not be corrected afterwards. Appendix A provides an overview of the ESM items, response choices and corresponding concepts. Participants were required to complete at least 33% of the ESM reports to be included in the data analyses (Delespaul, 1995).

Assessment of general experiences with the experience sampling methodology. Caregivers' subjective experiences regarding the ESM were assessed in a debriefing questionnaire concerning user-friendliness of the PsyMate, difficulty, time burden, and overall acceptability of the methodology. Items were scored using a 7-point Likert scale ranging from 1 "not at all" to 7 "very much."

Disease severity. The Clinical Dementia Rating (CDR) scale was used to assess the severity of

dementia (Hughes *et al.*, 1982). The researcher rated the CDR score on a 5-point scale (0="normal"; 0.5="very mild dementia"; 1="mild dementia"; 2="moderate dementia"; and 3="severe dementia") according to information obtained during a semi-structured interview with the caregiver.

Procedure

Participants were screened to ensure that they fulfilled all of the inclusion criteria. After informed consent was obtained, the study protocol for each participant included the following:

(1) *Introductory session:* During the introductory session, the researcher conducted a demographic interview to assess the caregiver's and care recipient's characteristics (including age, sex, level of education, type of dementia, disease severity, caregiver hours of contact with the PwD, caregiver hours of taking care of the PwD, and PwD hours spent in a dementia day care setting). Subsequently, a 30-min training session was provided on operating the PsyMate, the meaning of all questions and response choices, and procedures for carrying the device. Additionally, a demo questionnaire was completed to familiarize the participants with the PsyMate. A leaflet containing all of the information regarding the use of the PsyMate was distributed. Participants were instructed to contact the researcher in the event of (technical) problems.

(2) *ESM period:* Participants were provided with a PsyMate to carry with them for six consecutive days. The ESM period commenced the day after the introductory session. All participants were contacted once by telephone on the second day of sampling to resolve any problems. If necessary, a second phone call was arranged later in the week to provide support.

(3) *Debriefing session:* After the ESM period, participants completed a debriefing questionnaire regarding their general experiences with the ESM during a semi-structured interview conducted by the researcher.

Statistical analyses

Descriptive analyses were conducted to summarize response rates and overall experiences regarding the ESM and to generate pie charts and graphs including group and individual ESM data.

Results

Group characteristics

A total of 123 caregivers of PwD were approached to participate in the study. After screening for eligibility, 13 caregivers were excluded because of severe health problems, a deceased or institutionalized partner, or not sharing a household with the PwD. Of the remaining 110 caregivers, 79 refused to participate after hearing an explanation of the study procedure. Main reasons for refusal were being too busy with care responsibilities, no need for support, and not feeling comfortable with technical devices. Eventually, 31 caregivers (28%) agreed to participate in the study. Table 1 presents the characteristics of the 31 participating caregivers and their care recipients. Of the caregivers, 61% were women (19/31), and 71% took care for a spouse diagnosed with Alzheimer's disease (22/31). Of the care recipients, 71% showed a mild severity of dementia (CDR 0.5 or 1: 22/31).

Feasibility and acceptability

Each participant was alerted ten times per day over six days, giving a group total of 1860 alerts. On average, participants responded to 78.8% (1466/1860) of the

alerts ($M=49.1$, $SD=5.9$). One participant did not fully understand the instructions concerning the ESM data collection and completed no more than five reports. The exclusion of this person resulted in an overall response rate of 81.1% (1461/1800). The average time for completing a single ESM questionnaire was 2 min 44 s ($SD=45$ s, range = 1 min and 25 s to 8 min and 8 s). There were no dropouts during the study.

The results of the debriefing questionnaire regarding the subjective experiences with the ESM are presented in Table 2. Participants indicated few difficulties operating the PsyMate and reported satisfaction with the explanation of the procedure. Overall, participants reported that they were able to hear the alerts and read the text on the screen. Participants with hearing or visual impairment experienced difficulties, and environmental factors (e.g., noisy circumstances and bright sunlight) seemed to play a role in those difficulties. In total, six participants experienced technical problems with the PsyMate because of software problems or a defective touch screen. Although participants indicated that a few PsyMate items were difficult or unclear with respect to content or phrasing of items, they still felt that they were able to accurately describe their experiences. Participants reported that they made several mistakes while completing the questionnaire, which was primarily due to

Table 1 Characteristics of caregivers and care recipients

Variable	Caregivers ($N=31$)	Care recipients ($N=31$)
Age (M , SD , range)	70.3 ± 6.1 (57–82)	74.0 ± 6.5 (61–87)
Gender (n , %)		
Male	12 (38.7)	19 (61.3)
Female	19 (61.3)	12 (38.7)
Level of education (n , %)		
low	14 (45.2)	16 (51.6)
middle	8 (25.8)	7 (22.6)
high	9 (29.1)	8 (25.8)
Hours of contact with PwD per week (M , SD)	153.3 ± 12.4	
Hours of taking care for PwD per week (M , SD)	56.4 ± 59.5	
Type of dementia (n , %)		
Alzheimer's disease		22 (71.0)
Vascular dementia		4 (12.9)
Frontotemporal dementia		2 (6.5)
Dementia with Lewy bodies		1 (3.2)
Mixed dementia		2 (6.5)
Clinical dementia rating scale (n , %)		
0.5		11 (35.5)
1		11 (35.5)
2		8 (25.8)
3		1 (3.2)
Dementia day care (n , %)		
Yes		12 (38.7)
No		19 (61.3)
Dementia day care hours per week (M , SD)		15.6 (6.5)

PwD, person with dementia; SD , standard deviation.

Table 2 Mean scores on the positive and negative items of the debriefing questionnaire regarding participants' general experiences with the ESM

	<i>M</i>	<i>SD</i>
Positive items		
Could you read the text on the screen of the PsyMate clearly?	5.42	1.77
Could you hear the signal of the PsyMate clearly?	5.36	1.38
Was the verbal explanation concerning the use of the PsyMate clear?	6.61	0.62
Was the leaflet containing information about the use of the PsyMate clear?	6.45	0.77
Did you feel like you were able to accurately describe your experiences when responding to the questions that were asked?	5.37	1.25
Negative items		
Did you find it difficult to switch on the PsyMate?	1.07	0.25
Did you find it difficult to operate the PsyMate?	1.10	0.30
Did you find the PsyMate questions difficult or unclear?	2.68	1.87
Did you find the use of the PsyMate aggravating or stressful with respect to the number of alerts per day	2.07	1.48
the time it took to answer the questions for a single alert	1.77	1.28
the sound volume	1.71	1.42
Did any technical problems arise?	1.87	1.82
Did participation in the study affect your mood?	1.77	1.23
Did participation in the study affect your activities?	1.42	0.92
Did participation in the study affect your contact with other people?	1.32	0.79
Did participation in the study obstruct any of your daily activities?	1.52	0.96
Did you make many mistakes answering the questions in the PsyMate?	3.00	1.18

Ratings on a 7-point Likert scale from 1 "not at all" to 7 "very much." *M*: Mean, *SD*: standard deviation.

the change in positively and negatively formulated items and answering questions too rapidly. In general, participants reported that using the PsyMate was neither aggravating nor stressful. Participants' ratings on the ESM item 'this alert disturbed me' were on average 2.2 ($SD=1.0$), showing that the PsyMate did not substantially interfere with their daily functioning. During the semi-structured interview, participants often mentioned that six consecutive days of data collection was time-intensive, however, still feasible. Overall, participants indicated that adding an extra ESM day would be too burdensome.

Usability of the experience sampling methodology data for clinical and scientific practice

Experience sampling methodology patterns on a group level. Looking at the collected ESM data on a group level, the average ratings of PA and NA were 5.1 ($SD=0.9$) and 1.9 ($SD=0.8$), respectively. With regard to contextual patterns, caregivers reported spending a large amount of time at home (82%) (Figure 1(a)) and in the company of their partner (73%) (Figure 1(b)). Moreover, they reported frequently being involved in relaxation activities (25%), household activities (19%), or other activities (16%). At the time the PsyMate alerted them, they were caring for their partner in only 7% of the cases (Figure 1(c)).

Individual experience sampling methodology mood patterns. Standard retrospective measures provide a global view of caregiver functioning and might, therefore, mask individual differences between caregivers. The ESM offers the possibility to reveal individual differences in moment-to-moment and day-to-day mood fluctuations. To illustrate how these mood fluctuations can differ between persons, ESM data are shown for two caregivers.

Figure 2 shows the moment-to-moment fluctuation in PA and NA over a period of one week (six consecutive days). For caregiver 1, PA and NA seem to be relatively stable during the day and week (Figure 2(a)), whereas for caregiver 2, fluctuations seem to be present over time (Figure 2(b)).

Individual experience sampling methodology contextual patterns. The ESM data may also be useful to demonstrate individual contextual patterns. Figure 3 shows the time spent on various activities for one caregiver. This specific caregiver had few moments of relaxation and spent a large amount of time on caring for the PwD (Figure 3(a)). Subsequently, this contextual information can be linked to ESM data about the caregiver's mood state. Figure 3(b) shows experienced level of PA by the caregiver during different types of activities. Similar graphs can be drawn using other contextual variables, such as social company and location.

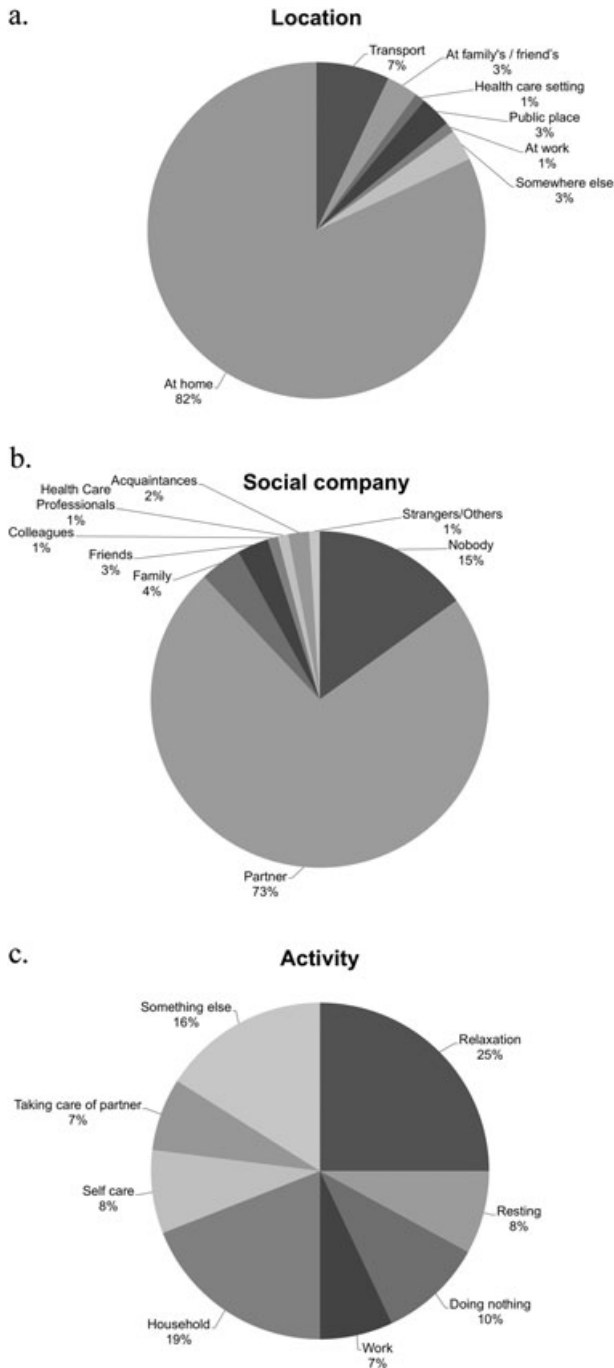


Figure 1 Group data illustrating the average time spent in different daily contexts: “location” (a), “social company” (b), and “activity” (c).

Discussion

This study was designed to determine the feasibility of the ESM in spousal caregivers of PwD and to demonstrate the usability of ESM data for clinical and scientific practice. Overall compliance with the ESM procedure was generally high, with a response rate of

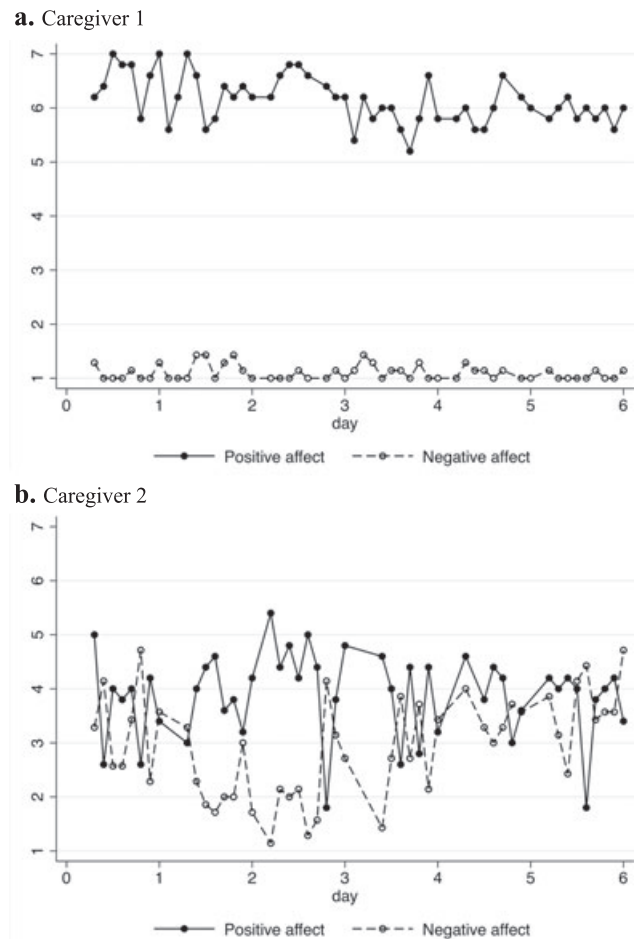


Figure 2 Moment-to-moment fluctuations in positive and negative affect over a one-week period for two caregivers.

78.8% to the alerts. Additionally, the results of the debriefing questionnaire regarding the general experiences with the ESM showed that the method was experienced positively by the sample as a whole. Participants considered the PsyMate to be a user-friendly device in which they could accurately describe their feelings and experiences. Additionally, participants did not feel that the use of the device was too burdensome, nor did they feel that it interfered with their daily functioning. These findings are largely consistent with the positive feasibility outcomes in previous ESM studies of caregivers of PwD (Fonareva et al., 2012; Poulin et al., 2010). Poulin et al. (2010) reported no dropouts during a seven-day ESM period, suggesting that participants did not find the ESM procedure too burdensome. Fonareva et al. (2012) reported a comparable compliance rate of 85%. Their ESM testing, however, included only three or four assessments consisting of five items over a one-day period. The current study showed a high response rate

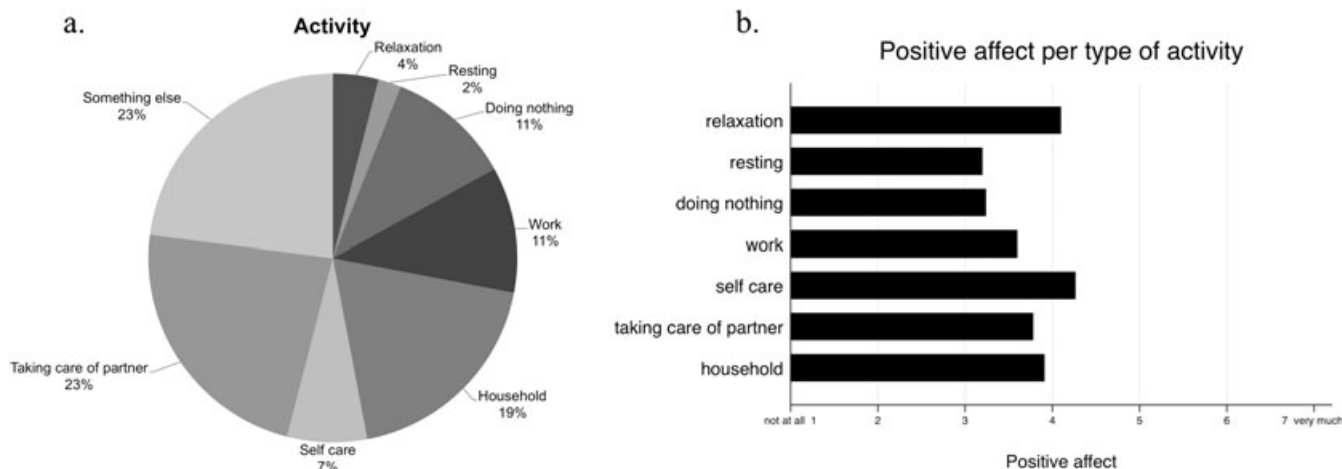


Figure 3 Individual data from one caregiver with regard to time spent on different activities in daily life (a) and experienced levels of positive affect during different daily activities (b).

and positive experiences with the ESM using a more elaborate and intensive ESM protocol.

It is, nonetheless, important to consider the time-consuming nature of the ESM. A study from Stone *et al.* (2003) found that the intensity of the sampling density, that is, the number of alerts per day, did not affect levels of compliance. However, perceived burden and interference with daily activities increased with more intensive ESM protocols. In our study, participants mentioned that six days of ESM data collection consisting of ten alerts per day was time intensive but still feasible. However, the majority of the participants considered that a longer ESM period would be overly burdensome. Additionally, the large number of caregivers that refused to participate because of a too busy time schedule should be taken into consideration. More ESM studies with caregivers of PwD are needed to evaluate different durations and intensities of time sampling.

The ESM data provide both the caregiver and the clinician with detailed information regarding daily mood and context patterns that could not have been captured using standard clinical interviews or traditional retrospective measurements. In this study, we presented both group and individual data to illustrate the usability of ESM data.

At a group level, caregivers reported spending a large proportion of their time at home and in the company of their partner. Previous studies have shown that caregivers often lack social contact and support and experience feelings of social isolation (Brodaty and Hadzi-Pavlovic, 1990). Social isolation and decreased social activity are risk factors for caregiver burden and need to be taken into consideration

when developing effective caregiver support interventions (Rodakowski *et al.*, 2012).

Furthermore, the group data showed that caregivers were involved in relaxation activities during 25% of the ESM reports and in care-related activities during only 7% of the reports. In studies with traditional retrospective questionnaires, caregivers often report the opposite; they feel as though they are taking care of their partner 24 h a day and barely have time to pursue other interests and needs in their lives (Lindgren *et al.*, 1990). The ESM might be a valuable complement to standard retrospective questionnaires, because it provides the opportunity to reveal potential differences between actual and subjectively experienced time spent on positive activities. In this way, the ESM may help to increase caregivers' awareness of their daily functioning and strengthen feelings of control over their lives that help to achieve better adaptation and understanding of the situation, acceptance of changes and more confidence regarding their own strength (Dias and Santos, 2015).

The analyses of group data alone mask dynamics that occur at the individual level. Therefore, we presented examples of individual data to reveal personalized daily patterns of emotions and contexts. The individual data show that caregivers seem to differ with respect to moment-to-moment and day-to-day fluctuations in mood and with respect to contextual patterns. This finding underscores the added value of the ESM for assessment of individual caregiver functioning and for adapting caregiver support interventions to their individual situation and needs.

The primary limitation of our study is its selective sample, primarily consisting of caregivers of people

with mild dementia. A large number of caregivers refused to participate, which might have caused a selection bias toward caregivers that are not yet facing extreme difficulties and stress levels in the caregiving process. In our study, caregivers reported relatively high levels of PA and low levels of NA, which might be specific to caregivers who are not yet exposed to extreme external demands of the caretaking process. This might also explain why caregivers in our sample reported spending only a small amount of time on caring for the PwD. It is unknown how our results might generalize to a more heterogeneous caregiver population. Another limitation of this study concerns the content of the ESM questionnaire. The effort to implement the ESM as a standard assessment tool is still in its infancy, and standardized sets of ESM items are not yet available. Therefore, the ESM item selection was based on previous ESM studies with psychiatric populations, guidelines from ESM experts, and clinical knowledge about caregiver experiences. Future studies are needed to validate the content of the ESM questionnaire used in this study. Finally, the potential problem of reactivity should be taken into consideration when interpreting the results of ESM studies. Repeated assessments may lead people to pay unusual attention to their internal states and own behavior (Scollon *et al.*, 2009). In our study, we included an intense time sampling protocol and a randomized time schedule to desensitize participants to the ESM procedure and to minimize the risk of reactivity and preparation for completing the ESM questionnaire (Palmier-Claus *et al.*, 2011).

Nevertheless, the results of our study have important implications for the assessment of caregiver functioning in both research and clinical settings. The ESM can be implemented in clinical practice by developing ESM interventions in which caregivers become more aware of implicit daily patterns of emotions and behavior by giving them explicit visualized feedback on their daily functioning. More insight into these daily patterns might help caregivers to redirect their behavior toward situations that elicit positive emotions and might strengthen them in enduring their care responsibilities. A recent study applied a six-week ESM intervention in persons with depression to gain more insight into personalized patterns of PA and the context in which PA is experienced (Kramer *et al.*, 2014). Its results showed that personalized feedback on PA increased self-awareness and resulted in a significant decline in depressive symptoms. Future studies are needed to examine the effectiveness of ESM interventions for caregivers of PwD.

The present study is an initial step toward developing a better understanding of the use of the ESM in caregivers of PwD. The positive compliance and acceptability findings suggest that the ESM is a highly feasible method in this specific population and might be a promising intervention tool for supporting caregivers of PwD in their daily lives.

Conflict of interest

None declared.

Key points

- Accurate assessment of caregiver functioning in dementia caregivers is of great importance to prevent high levels of burden in a later stage.
- The experience sampling methodology offers the possibility to assess caregiver functioning in the flow of daily life.
- The experience sampling methodology is a feasible method in spousal caregivers of people with dementia and reveals personalized patterns of caregiver functioning.

Ethics statement

The Medical Ethical Committee of the MUMC+ (#12-3-049) approved this study.

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Appendix A: Description of the experience sampling methodology concepts, items, and response choices

Concept	Item	Rating scale
Positive affect	1. I feel cheerful	7-point scale (1 "not at all" to 7 "very much")
	2. I feel relaxed	7-point scale (1 "not at all" to 7 "very much")
	3. I feel enthusiastic	7-point scale (1 "not at all" to 7 "very much")
	4. I feel satisfied	7-point scale (1 "not at all" to 7 "very much")
Negative affect	5. I feel insecure	7-point scale (1 "not at all" to 7 "very much")
	6. I feel lonely	7-point scale (1 "not at all" to 7 "very much")
	7. I feel anxious	7-point scale (1 "not at all" to 7 "very much")
	8. I feel irritated	7-point scale (1 "not at all" to 7 "very much")
	9. I feel down	7-point scale (1 "not at all" to 7 "very much")
	10. I feel desperate	7-point scale (1 "not at all" to 7 "very much")
	11. I feel confident	7-point scale (1 "not at all" to 7 "very much")
	12. I feel tensed	7-point scale (1 "not at all" to 7 "very much")
Self-esteem	13. I like myself	7-point scale (1 "not at all" to 7 "very much")
	14. I am ashamed of myself	7-point scale (1 "not at all" to 7 "very much")
	15. I doubt myself	7-point scale (1 "not at all" to 7 "very much")
	16. I am satisfied with myself	7-point scale (1 "not at all" to 7 "very much")
Physical	17. I am tired	7-point scale (1 "not at all" to 7 "very much") well-being
	18. I feel well	7-point scale (1 "not at all" to 7 "very much")
	19. I am in pain	7-point scale (1 "not at all" to 7 "very much")
	20. I have problems in walking	7-point scale (1 "not at all" to 7 "very much")
Activity	21. What am I doing? (just before the alert)	Doing nothing; resting; work; household; self care; taking care of partner; relaxation; something else
	22. And also?	Doing nothing; resting; work; household; self care; taking care of partner; relaxation; something else
	23. And...?	taking care of partner; relaxation; something else
	24. I like doing this	7-point scale (1 "not at all" to 7 "very much")
	25. I would rather be doing something else	7-point scale (1 "not at all" to 7 "very much")
	26. This is difficult for me	7-point scale (1 "not at all" to 7 "very much")
	27. I feel I am being active	7-point scale (1 "not at all" to 7 "very much")
	28. I can do this well	7-point scale (1 "not at all" to 7 "very much")
	29. I am doing this activity together with my partner	Yes; no
Location	30. Where am I?	At home; at family's/friend's place; at work; health care setting; public place; transport; somewhere else
Social company	31. Who am I with?	Partner; family; friends; colleagues; health care professional; acquaintances; strangers/others; nobody
	32. With whom else?	Partner; family; friends; colleagues; health care professional; acquaintances; strangers/others; nobody
	33. And...?	Partner; family; friends; colleagues; health care professional; acquaintances; strangers/others; nobody
	Branching questions in case of being in company	
	34. I would prefer to be alone	7-point scale (1 "not at all" to 7 "very much")
	35. I think my company is pleasant	7-point scale (1 "not at all" to 7 "very much")
	36. I feel at ease in this company	7-point scale (1 "not at all" to 7 "very much")
	Branching questions in case of being alone	
	34. I would prefer to be in company	7-point scale (1 "not at all" to 7 "very much") of others
	35. I enjoy being alone	7-point scale (1 "not at all" to 7 "very much")
	36. I feel at ease being alone	7-point scale (1 "not at all" to 7 "very much")
Events	37. Since the last alert the most important	(take an event in mind before you continue) thing that happened is...
	38. How pleasant was this event?	bipolar scale (-3 "very unpleasant" to +3 "very pleasant")
	39. I had this situation under control	7-point scale (1 "not at all" to 7 "very much")
	40. Was this situation unexpected?	7-point scale (1 "not at all" to 7 "very much")
	41. The event was important to me	bipolar scale (-3 "very unimportant" to +3 "very important")
	42. With whom was I?	Partner; nobody; someone else General
	43. This alert disturbed me	7-point scale (1 "not at all" to 7 "very much")