# Experience sampling in dementia care

# EXPERIENCE SAMPLING IN DEMENTIA CARE

**An innovative intervention to support caregivers in daily life**

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PROEFSCHRIFT

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# CONTENTS

# 1

## General introduction

## DEMENTIA AND INFORMAL CARE

The majority of people with dementia are living at home and are cared for by their relatives. Although caring for a person with dementia (PwD) is associated with an increased risk of developing psychological and physical symptoms[1], there are large individual differences among caregivers in how they adapt to the daily challenges of dementia[2]. Caregivers may encounter negative as well as positive experiences in the process of caring for their loved ones[3]. Positive experiences might be crucial to keep a caregiver going and may even help to reduce negative feelings, such as stress and burden[4,5]. "So, why not think about it more positively then?", as proposed by a caregiver in the following quote:

> *"In fact, I had always been an optimistic and cheerful person. But facing a husband with dementia, how could I be happy? His illness would not get better; not a thing was inspirational. Since taking care of my spouse, everything looked so dark…but… since his illness and my caregiving role are realities; nothing will change. Why not think about it more positively then?"*[6]

This positive view on dementia is in line with recent trends to perceive health from a more positive perspective, by focusing on one's capacity to adapt and self-manage social, physical, and emotional challenges rather than merely on the treatment of disease-related symptoms[7], and could be an interesting target in newly developed caregiver interventions.

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## CAREGIVER INTERVENTIONS THUS FAR

Numerous psychosocial interventions have been developed to support caregivers of people with dementia, including psycho-education, counseling, support groups, and cognitive-behavioral therapies[8]. A recent systematic review on the efficacy of these interventions showed promising results on caregiver outcomes[9], but effects are in general small and the methodological quality of most studies is limited[8]. Existing interventions mainly focus on dealing with the negative consequences of the caregiving process and do not take into account individual differences among caregivers[10]. Interventions that are tailored to the specific needs of the caregivers and aimed at enhancement of positive rather than negative caregiver experiences could foster the adaptation process and promote positive emotions and well-being in both the caregiver and the PwD[11]. Positive emotions have been found to be important facilitators of adaptive coping in stressful situations and might also increase caregivers' feelings of being capable to care for the PwD[4,12].

## ECOLOGICAL MOMENTARY INTERVENTIONS

Recent technological developments provide new opportunities to extend interventions beyond the clinical setting into caregivers' everyday lives. Mobile devices, such as personal digital assistants (PDAs) or smartphones, can be used to collect information and deliver support in daily life, while caregivers are engaging in their normal daily activities. These interventions are also referred to as ecological momentary interventions (EMIs) and reflect a high ecological validity, because they provide real time support in the real world[13,14]. EMIs have already proven to be effective in the treatment of various patient groups, including persons with diabetes, asthma, and severe mental illness[14,15], and could also be promising in the field of dementia care. Following the trend towards a more positive view on dementia, EMIs could be helpful to increase caregivers' ability to manage the daily challenges of dementia, by asking caregivers to self-monitor experiences in the flow of daily life and by providing them with personalized feedback on positive affect experience. This may increase awareness of adaptive and dysfunctional patterns of emotions and behavior, and may induce behavioral change accordingly[16]. For example, caregivers could learn to become more aware of and to engage more in behaviors that elicit positive emotions, such as relaxation and social activities. In addition, monitoring caregiver functioning in daily life may increase both caregiver's and clinician's insight into caregiver well-being and could help to provide care more efficiently, at times and in situations when it is most needed[13].

## THE EXPERIENCE SAMPLING METHOD

As part of this thesis, we developed and evaluated an EMI to support spousal caregivers of people with dementia in everyday life, by making use of the experience sampling method (ESM)[17], also known as ecological momentary assessment[18] or ambulatory assessment[19]. The ESM is a structured diary method, which has been developed over the past decades and can be used to self-monitor subjective experiences in daily life[20]. One of the main advantages of the ESM is that it assesses experiences in-the-moment, resulting in less memory biases compared to traditional retrospective measures, such as retrospective questionnaires and clinical interviews[21]. Moreover, the repeated nature of the ESM assessments allows for exploration of temporal relationships between variables and revelation of detailed information on daily fluctuations in subjective experiences. This is of particular importance in caregivers of PwD, as caregiver experiences are likely to fluctuate over time in response to constantly changing care demands. The ESM has been performed with success in a wide range of health-related areas[20]. However, its application in the field of dementia care is still novel and requires further exploration.

## AIM AND OUTLINE OF THE THESIS

The main aim of this thesis was to explore the use of the ESM within an intervention to support spousal caregivers of people with dementia in daily life. To examine how such an intervention should look like, an exploratory study was initially performed to answer to following three research questions:

1.  *Is the ESM a feasible method in spousal caregivers of PwD and how can it be used in clinical practice?*
    Compliance and subjective experiences with the ESM need to be examined properly, as we are dealing with a vulnerable and often elderly population who is already pressured by many external demands and might be unfamiliar with technological devices (Chapter 2).

2.  *What is the relationship between caregivers' sense of competence and their experienced positive affect in daily life?*
    As noted earlier, a focus on positive rather than negative experiences in caregiver interventions could promote caregiver well-being. Feelings of competence in managing caregiving challenges and positive emotions might reinforce one another and could, therefore, be an important target in our intervention (Chapter 3).

3.  *Which caregiver characteristics modify emotional reactivity to daily life stress?*
    Individual differences in vulnerabilities (e.g. age, gender, and education level) and resources (e.g. sense of competence, mastery, and coping) could affect caregivers' emotional response when facing stressful situations throughout the caregiving process. More insight into factors that influence caregivers' emotional stress reactivity could help to identify relevant elements to focus on in our intervention (Chapter 4).

Based on the results of the exploratory study, the experience sampling method intervention 'Partner in Sight' was developed and evaluated in a randomized controlled trial (RCT). The design of this RCT is described in Chapter 5. With respect to the evaluation of the intervention, the following research questions were addressed:

1.  *What are the process characteristics of the experience sampling method intervention 'Partner in Sight'?*
    A process evaluation can be used to determine the internal and external validity of the intervention and provides valuable information on the barriers and facilitators for future implementation in clinical practice (Chapter 6).

2.  *What are the effects of the experiences sampling method intervention 'Partner in Sight' on retrospective measures of caregiver sense of competence, mastery, and*

*psychological complaints (depression, anxiety, and stress) and on momentary measures of positive and negative affect?*
This is the first study that examines the effectiveness of an experience sampling method intervention to support spousal caregivers of PwDs in daily life. The results, therefore, provide a valuable contribution to our knowledge of delivering caregiver interventions, based on experience sampling techniques, in real life (Chapter 7).

The main findings and implications of the various chapters in this thesis are discussed in Chapter 8.

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# 2

# An experience sampling study to assess caregiver functioning in the flow of daily life

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## ABSTRACT

**Objectives:** 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.

## INTRODUCTION

Caring for a person with dementia (PwD) has a considerable impact on caregivers' psychological and physical well-being[1,2]. Caregivers have a high risk of developing depression and are vulnerable to becoming overburdened[3]. 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[4] and delusions in the PwD[5]. Moreover, non-adapting caregiver strategies can result in negative interaction patterns that influence the emergence of behavioral problems in the PwD[6]. 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[7]. Many studies have shown that people are generally not able to accurately describe real-life experiences retrospectively and tend to over- or underestimate the frequency of symptoms[8,9]. 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)[10,11]. 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[12]. Moreover, the ESM enables the exploration of temporal relationships between variables and reveals detailed information regarding daily fluctuations in subjective experiences[13]. 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 (PDAs), 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[14].

The ESM has been applied with success in the study of various patient groups[7,13,15]. However, to the best of our knowledge, only two studies have employed this methodology in dementia

research[16,17]. Using the ESM, Fonareva et al.[16] compared stress-ratings obtained in research settings with stress-ratings collected in natural settings. Data were collected over a single 24-hour 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 hours is recommended[18]. In the study by Poulin et al.[17], 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.[17] reported no dropouts; however, they did not explore compliance and caregivers' experiences with the ESM procedure.

Although study results from Poulin et al.[17] and Fonareva et al.[16] 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 due to their complex care situation.

The present study was conducted using the ESM with spousal caregivers of PwD (1) to test the feasibility of performing the ESM over a six-day period and (2) 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 (MUMC+), the Zuyderland Medical Center, and in mental health care institutions in the southern Netherlands. Study inclusion criteria were: (1) being a spousal caregiver of a person diagnosed with dementia; and (2) sharing a household with the PwD. Exclusion criteria were: (1) having insufficient cognitive abilities to engage in the ESM; and (2) being overburdened or having severe health problems, both based on clinical judgment.

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

**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[19]. The PsyMate was pre-programmed 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[20,21], guidelines from ESM experts[22], 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 (4 items; α = .91); NA (8 items; α = .81); self-esteem (4 items; α = .24); and physical well-being (4 items; α = .57). Only PA and NA were used for further data-analyses, since 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 1 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[10].

*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 scale (CDR) was used to assess the severity of dementia[23]. 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:

*(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-minute 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% was female (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 minutes 44 s (SD = 45 s, range = 1 minute 25 s - 8 minutes 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 due to software problems or a defective touchscreen. Although participants indicated 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 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.

**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 - very mild | | 11 (35.5) |
| 1 – mild | | 11 (35.5) |
| 2 – moderate | | 8 (25.8) |
| 3 – severe | | 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; M = mean; SD = standard deviation

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

|  | M | SD |
|---|---|---|
| **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 beeps per day | 2.07 | 1.48 |
| The time it took to answer the questions for a single beep | 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 het 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'

## 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 positive affect (PA) and negative affect (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 1a) and in the company of their partner (73%) (Figure 1b). 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 1c).
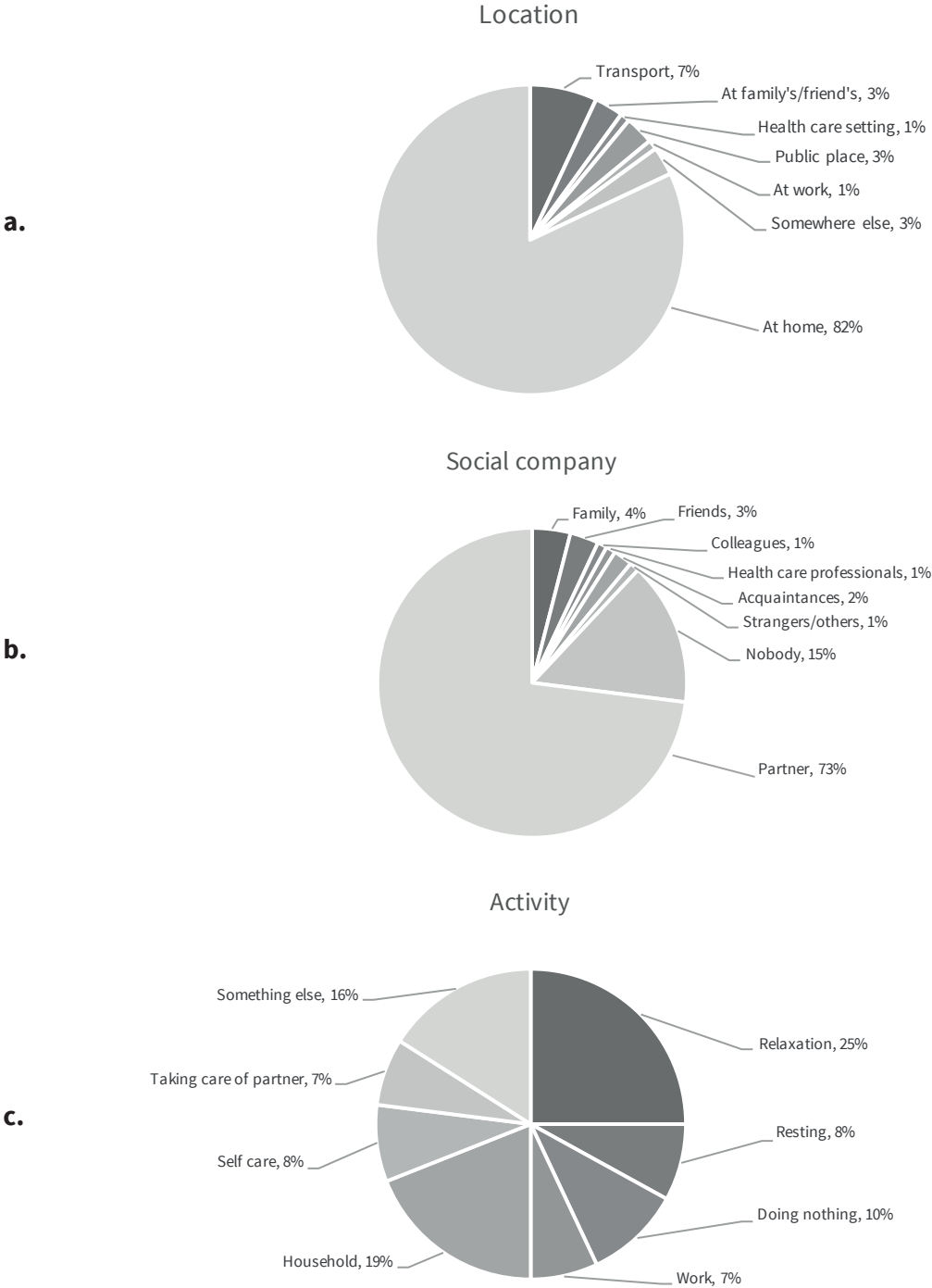
**Figure 1.** Group data illustrating the average time spent in different daily contexts: 'location' (1a), 'social company' (1b), and 'activity' (1c)

*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 2a), whereas for caregiver 2, fluctuations seem to be present over time (Figure 2b).

**a.** Caregiver 1
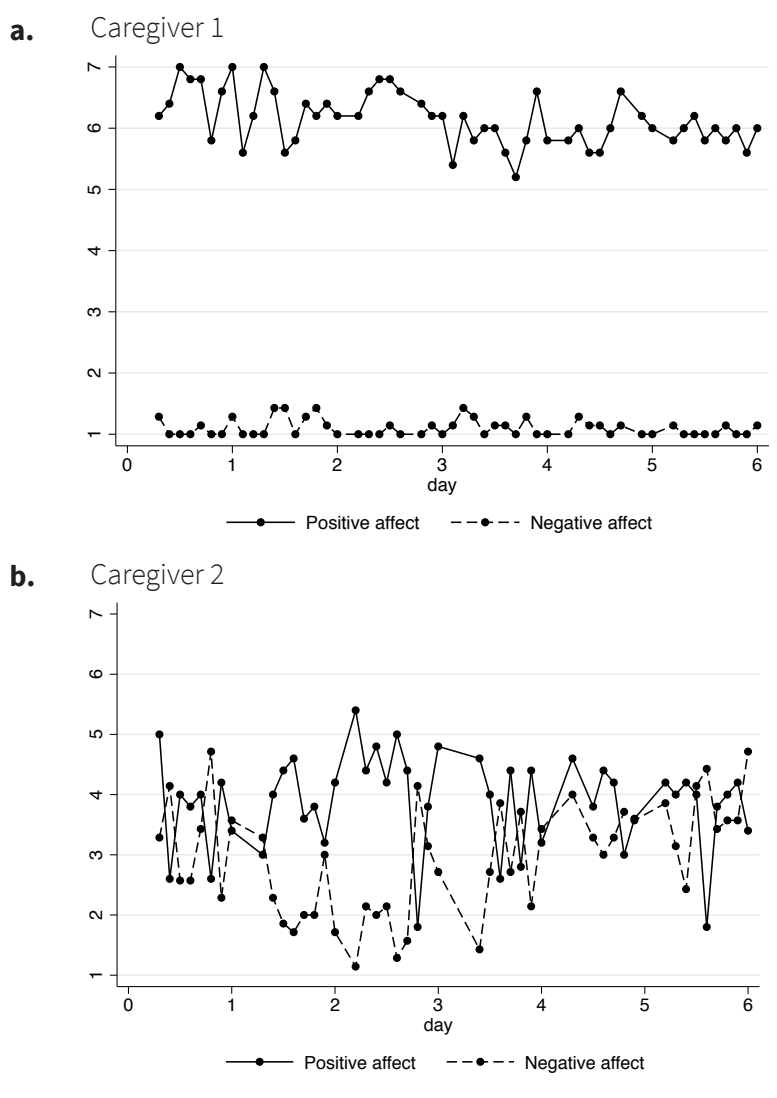


**b.** Caregiver 2



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

*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 3a). Subsequently, this contextual information can be linked to ESM data about the caregiver's mood state. Figure 3b 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.

**Activity**

**a.**



**Positive affect per type of activity**

**b.**
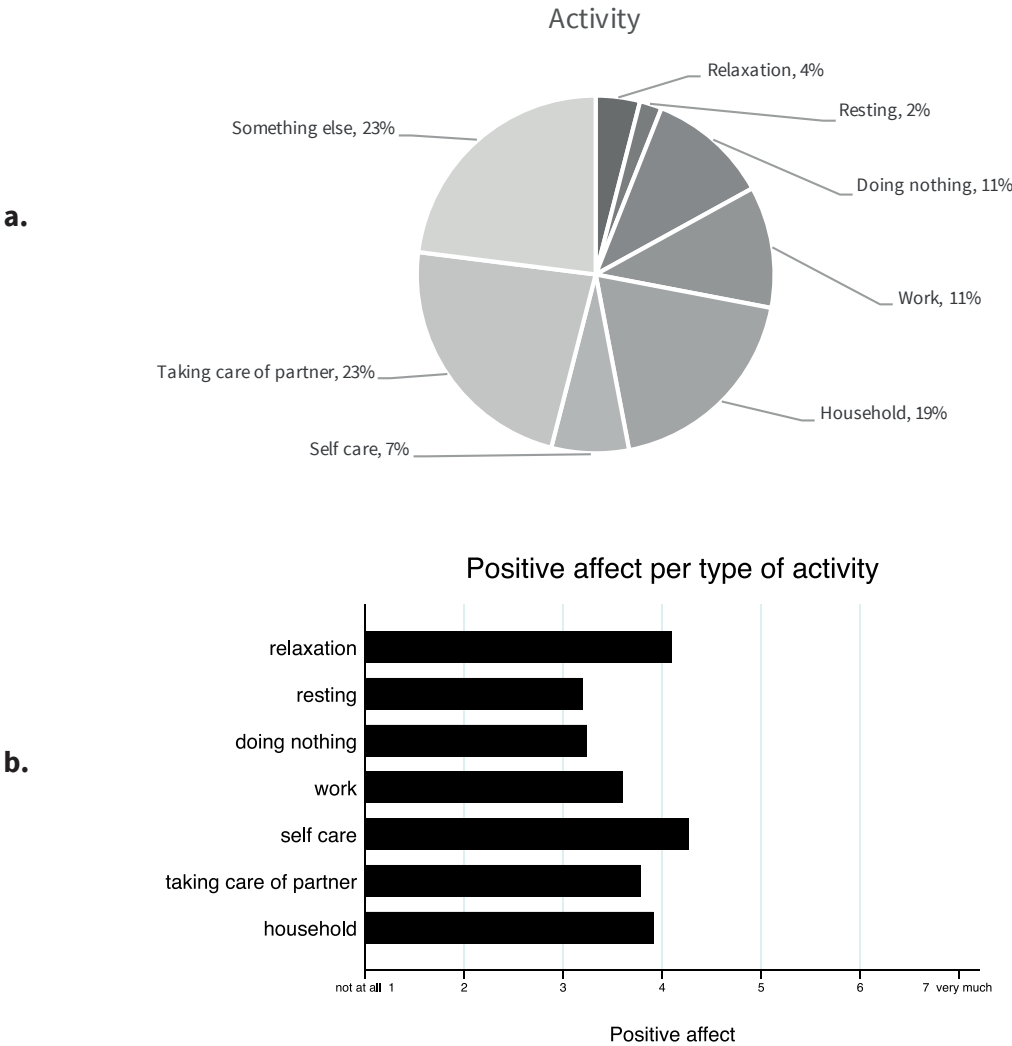


**Figure 3.** Individual data from one caregiver with regard to time spent on different activities in daily life (3a) and experienced levels of positive affect during different daily activities (3b)

## 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 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 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[16,17]. Poulin et al.[17] reported no dropouts during a seven-day ESM period, suggesting that participants did not find the ESM procedure too burdensome. Fonareva et al.[16] 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 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.[7] found that the intensity of the sampling density, i.e., 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[24]. 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[25].

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 hours a day and barely have time to pursue other interests and needs in their lives[26]. The ESM might be a valuable complement to standard retrospective questionnaires, since 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[27].

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 towards 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 care-taking 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[28]. 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[22].

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 towards 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[29]. 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.

**2**

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**2**

**Appendix 1.** 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 well-being | 17. I am tired | 7-point scale (1 'not at all' to 7 'very much') |
| | 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…? | Doing nothing; resting; work; household; self-care; 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 |

**Appendix 1.** (continued)

| Concept | Item | Rating scale |
|---|---|---|
| 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') |
| | 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 thing that happened is… | (take an event in mind before you continue) |
| | 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') |

**2**

# 3

An experience sampling study to assess caregivers' sense of competence and experienced positive affect in daily life

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**ABSTRACT**

**Objectives:** 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 six 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.

**Conclusions:** This study provides support for redirecting caregiver support interventions towards 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.

## INTRODUCTION

The number of people living with dementia worldwide is expected to increase substantially in the near future[1]. Due to 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 towards a more positive view of dementia and of health in general. Huber et al.[6] commented on the WHO 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 towards caregivers' capacities to cope with their loved one's chronic disease. Acceptance of the situation can lead to a better adaptation to the disease and a shift in focus towards 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

### Participants

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 (MUMC+), the Zuyderland Medical Center, and mental health care institutions in the southern Netherlands. The inclusion criteria were (1) being a spousal caregiver of a person with a diagnosis of dementia and (2) sharing a household with the PwD. The exclusion criteria were having (1) insufficient cognitive abilities to complete the daily life assessments and (2) severe health problems that limited study participation (both based on clinical judgment).

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

### Instruments

*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 5-point scale from 1 ('agree very strongly') to 5 ('disagree very strongly'). A total SSCQ sum score (range 7 to 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 (CDR) was used to assess the PwD's severity of dementia[18]. The researcher applied the CDR score using a 5-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, an electronic touchscreen device specifically developed for momentary assessments in clinical practice[20]. Recent results of our feasibility study, which are described in Chapter 2, showed that caregivers considered the PsyMate a user-friendly device in which they could accurately describe their feelings and experiences[21].

The PsyMate was pre-programmed to generate ten beeps (sound and vibration) daily at unpredictable times in a semi-random design between 7:30 AM and 10:30 PM. After each beep, short ESM reports of current context (e.g., location, activity, social company) and mood (i.e., positive and negative affect) were collected. ESM reports had to be completed within ten 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 feeling 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 α = 0.91 for the mean-centered scores). The items were rated on 7-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 one 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 α =

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 7-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 adhere to 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:

*(1) Introductory session*

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 day care 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 demo ESM questionnaire was completed to familiarize participants with the PsyMate. Participants were instructed to contact the researcher for any (technical) problems.

*(2) Daily life assessment period*

Participants were provided with a PsyMate for six 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.

*(3) 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 are described in detail in Chapter 2[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 (LR) 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 & daily) were uniquely associated with the two PA measures (levels of PA & 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, LR 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 day care attendance of the PwD).

**3**

## RESULTS

### Participants and descriptive statistics

Of the 31 caregivers in the study, one was excluded from the analyses for completing fewer than 20 valid reports (less than 33% of the total 60 ESM reports). The average number of completed ESM reports in the remaining 30 participants was 49.3±5.2 out of 60, indicating a completion rate of 81.1%. 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.

**Table 1.** Characteristics of caregivers and care recipients

| Variable | Caregivers (N = 30) | Care recipients (N = 30) |
|---|---|---|
| Age (M, SD, range) | 69.9 ± 5.8 (57-80) | 73.7 ± 6.2 (61-87) |
| Gender (n, %) | | |
| Male | 12 (40.0) | 18 (60.0) |
| Female | 18 (60.0) | 12 (40.0) |
| Level of education (n, %) | | |
| Low | 13 (43.3) | 16 (53.3) |
| Middle | 8 (26.7) | 6 (20.0) |
| High | 9 (30.0) | 8 (26.7) |
| Type of dementia (n, %) | | |
| 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 (n, %) | | |
| 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 (n, %) | | |
| Yes | | 11 (36.7) |
| No | | 19 (63.3) |
| Dementia day care hours per week (M, SD) | | 15.4 (6.8) |

M = mean; SD = standard deviation

**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% CI = 0.16-0.62, 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 (M = 2.06) and when measured retrospectively with the SSCQ (M = 1.81) (t(26) = -1.83, p = 0.078).

**Table 2.** Mean, standard deviation, and range for all variables utilized in the analyses

| Variable | No. of valid ESM reports | N | M (SD) | Range |
|---|---|---|---|---|
| Positive affect[a] | 1448 | 30 | 5.07 (0.89) | 2.97-6.46 |
| Variability in positive affect[b] | 1229 | 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 |

a. For each subject a mean was calculated over all beeps. The mean per subject was aggregated over the group to attain a group mean (SD).
b. Variability 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).
c. The 3 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 to 7 versus 1 to 5) and to be able to compare both scores. The sumscore of the 3 adjusted items is ranging from 0 to 3.
d. The retrospective SSCQ total score is not adjusted to the difference in scoring range between the daily and retrospective SSCQ. The sumscore of the SSCQ total score is ranging from 7 to 35.

**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-SD increase in SSCQ score was related to an increase of 0.36 in PA in each ESM report. The 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-SD 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 <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 = -0.18-0.43, SE = 0.16, z = 0.80, p = 0.425 for retrospective sense of competence. The sensitivity analysis 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 = -0.09-0.56, 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 = -0.13-0.05, 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 = -0.09-0.10, 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- -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 six 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 nonclinical 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 positive affect, 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, the 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 due to 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 pro-active 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 positive affect in daily life or whether positive affect 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., the 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.

**3**

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**3**

# 4

# Emotional reactivity to daily life stress in spousal caregivers of people with dementia

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**ABSTRACT**

**Objectives:** Caregivers differ in their emotional response when facing difficult situations during the caregiving process. Individual differences in vulnerabilities and resources could play an exacerbating or buffering role in caregivers' reactivity to daily life stress. This study examines which caregiver characteristics modify emotional stress reactivity in dementia caregivers.

**Methods:** Thirty-one caregivers of people with dementia collected experience sampling data to assess (1) appraised subjective stress related to events and minor disturbances in daily life, and (2) emotional reactivity to these daily life stressors, conceptualized as changes in negative affect. Caregiver characteristics (i.e. vulnerabilities and resources) were administered retrospectively.

**Results:** Caregivers who more frequently used the coping strategies 'seeking distraction', 'seeking social support', and 'fostering reassuring thoughts' experienced less emotional reactivity towards stressful daily events. A higher educational level and a higher sense of competence and mastery lowered emotional reactivity towards minor disturbances in daily life. No effects were found for age, gender, and hours of care and contact with the person with dementia.

**Conclusions:** Caregiver resources rather than vulnerabilities affect emotional reactivity to daily life stress. Interventions aimed at empowerment of caregiver resources, such as sense of competence, mastery, and coping, could help to reduce stress reactivity in dementia caregivers.

## INTRODUCTION

Providing years of extensive care for a person with dementia (PwD) is associated with increased levels of stress in the caregiver and a higher risk of developing depression and other adverse health problems[1-3]. Health problems in the caregiver are often overlooked and overshadowed by those of the PwD. However, caregiver well-being is important for both the caregiver and PwD, since it predicts the quality of care and timing of nursing home placement[4,5]. Caregivers differ in their emotional response when facing difficult situations during the caregiving process. According to the stress and coping model by Lazarus and Folkman[6], individual differences, such as vulnerabilities and resources, moderate relationships of stressors with distress. Vulnerabilities and resources can be distinguished according to their stability and changeability among pathways from stressors to illness. The term vulnerability refers to stable, hard-wired characteristics, such as age, gender, and race. In contrast, resources are more dynamic and mutable characteristics that are affected by interactions with the environment, such as coping and social support[7,8]. Previous studies have indicated several factors to play a role in experienced levels of caregiver distress. A recent systematic review reported that women and older caregivers generally have a higher risk of experiencing stress[9]. In addition, highly educated caregivers more often use effective caregiver management strategies, which suggests that these caregivers are better able to adapt to the care demands[4]. Besides these demographic characteristics, resource characteristics like caregivers' feelings of competence, mastery and applied coping strategies have been found to be important indicators of emotional distress[10,11]. Also, dynamic characteristics of the care recipient can affect caregiver outcomes[12]. The occurrence of problem behavior in the PwD can be unpredictable and is likely to fluctuate on a day-to-day basis[13]. Caregiver distress has been demonstrated to increase when neuropsychiatric problems are present and when dementia severity increases[14]. Due to an increase in care intensity caregivers' quality of life may be negatively impacted[10,15].

Most studies have used standard retrospective measures to examine determinants and levels of caregiver distress. However, caregivers' stress experiences are likely to fluctuate constantly during the day in response to the ebb and flow of dynamic care-related stressors[13]. Retrospective questionnaires are inadequate to capture moment-to-moment fluctuations in stress and rather take a snapshot of daily life. That is, data are mostly collected at only one occasion, and therefore only provide a global view of caregiver distress. Moreover, retrospective measures are highly susceptible to recall biases, which leads caregivers to over- or underestimate stress symptoms[16,17]. So far, very little research has been conducted to investigate caregiver well-being in-the-moment and in a natural setting. The experience sampling methodology (ESM) offers the possibility to assess subjective experiences in the

flow of daily life[18,19], and has been applied in several studies on stress-reactivity in psychiatric populations[20,21]. The ESM could provide valuable information on caregivers' sensitivity to daily stress, i.e. their emotional responses to daily stressors, and on factors that buffer or exacerbate reactivity to those stressors. It has been demonstrated in the general population that small daily events are important predictors of psychological symptoms and subjective distress[22,23]. Caregivers' emotional reactivity to daily stressors might constitute part of the underlying vulnerability for becoming overburdened in a later stage of the caring process. More insight into factors that influence caregivers' emotional reaction to day-to-day problems could help to identify the relevant elements to focus on in caregiver interventions[24]. Therefore, the current study aims to examine which specific caregiver characteristics, including resources and vulnerabilities, modify emotional reactivity to daily life stress in caregivers of PwD.

## METHODS

### Participants

Thirty-one informal caregivers participated in the study between February 2013 and February 2014. Caregivers were recruited in the Memory Clinic of the Maastricht University Medical Center Plus (MUMC+), the Zuyderland Medical Center, and in mental health care institutions in the southern Netherlands. Participants had to meet the following inclusion criteria: (1) being a spousal caregiver of a person diagnosed with dementia; (2) sharing a household with the PwD; and (3) informed consent obtained. Exclusion criteria were: (1) having insufficient cognitive abilities to engage in the ESM; and (2) being overburdened or having severe health problems, both based on clinical judgment.

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

### Procedure

The study protocol for each participant included:

*(1) Introductory session*

A demographic interview was conducted to assess caregiver and care recipient characteristics. Subsequently, participants received an electronic ESM device, the 'PsyMate', to collect data in their daily lives[25]. The feasibility of the 'PsyMate' in caregivers of PwD has been demonstrated in Chapter 2[26]. A 30-minute training session was provided to explain the ESM procedure and how to operate the 'PsyMate'.

*(2) ESM data collection*

Participants were asked to collect ESM data with the 'PsyMate' for six consecutive days, starting the day after the introductory session. The 'PsyMate' generated an alert (beep) at ten unpredictable moments per day between 7:30 AM and 10:30 PM. After every alert, participants were asked to immediately complete a questionnaire presented on the screen of the 'PsyMate' concerning their current context (location, activity, social company), appraisals of the situation, and mood.

*(3) Debriefing session*

After the ESM data collection participants were asked to complete retrospective questionnaires concerning their coping strategies, sense of competence and mastery, and the presence of neuropsychiatric symptoms in the PwD during the past week.

**Emotional stress reactivity assessment**

Based on previous ESM studies, emotional stress reactivity was conceptualized as negative mood reactivity to daily events (event-related stress) and minor disturbances that continually occur in the flow of daily life (activity-related stress)[20,27]. Mood and stress measures were derived from ESM reports as described below.

*Assessment of mood*

Caregivers' mood state reported after each beep was assessed with eight mood-related ESM items concerning their negative affect. The negative affect scale included the items 'insecure', 'lonely', 'anxious', 'irritated', 'down', 'desperate', and 'tensed' (Cronbach's α = .81). The item 'confident' had a low loading on the negative affect scale and was excluded.

*Assessment of stress*

Two different stress measures were computed:

*Event-related stress:* after each beep participants were asked to think about the most important event that happened between the current and the previous ESM report. This event could be either positive or negative, such as a pleasant phone call from a friend or a difficult situation with the PwD. Subsequently, participants had to rate on a 7-point bipolar Likert scale (-3 = 'very unpleasant', 0 = 'neutral', 3 = 'very pleasant') whether the event was perceived as pleasant. The negatively or neutrally (-3 to 0) rated events were used to create an event-related stress score that reflects caregivers' feelings of stress caused by daily events. Item scores were reversed, so that higher mean scores indicated higher levels of event-related stress.

*Activity-related stress:* after each beep participants had to judge their current activity (e.g. care task, household, relaxation) on four ESM items rated on a 7-point Likert scale (1 = 'not at all' to 7 = 'very'). The mean of the items 'I can do this well', 'I like doing this', 'I would rather do something else', and 'this is difficult for me' formed the activity-related stress score (Cronbach's α = .57). The first two item scores were reversed, so that higher mean scores indicated higher levels of activity-related stress. Compared to the event-related stress score, the activity-related stress score reflects momentary feelings of stress caused by minor disturbances that continually occur in the flow of daily life.

## Caregiver characteristics assessment

### Assessment of demographics & care intensity
Information regarding age, gender, education level, weekly hours of contact with and weekly hours of care for the PwD was obtained during a demographic interview with the caregiver.

### Assessment of sense of competence
The Short Sense of Competence Questionnaire (SSCQ) was used to assess the caregiver's sense of competence. The SSCQ assesses feelings of being capable to care for the PwD and contains seven items rated on a 5-point scale from 1 ('agree very strongly') to 5 ('disagree very strongly')[28]. All items were accumulated into a total SSCQ score (range 7-35). Higher scores indicate more sense of competence.

### Assessment of mastery
The Pearlin Mastery Scale (PMS) was used to assess the extent to which a caregiver perceives him- or herself to be in control of events and on-going situations, also known as mastery[29]. The scale contains seven items with scores varying from 0 ('complete agree') to 4 ('completely disagree'). Items were summed to form a total mastery score (range 0-28), with higher scores reflecting greater perceived control.

### Assessment of coping
The Utrecht Coping List (UCL) was used to measure seven coping strategies in the caregiver, including 'seeking distraction', 'expressing emotions', 'seeking social support', 'avoiding', 'fostering reassuring thoughts', 'passive coping', and 'active coping'[30]. Items were rated on a 4-point scale, ranging from 1 ('rarely or never use this strategy') to 4 ('very often use this strategy').

**Care recipient characteristics assessment**

*Assessment of disease severity and duration*

The Clinical Dementia Rating scale (CDR) was used to stage the severity of dementia in the PwD[31]. 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 from the caregiver. Additionally, the year of dementia onset was administered.

*Assessment of neuropsychiatric symptoms*

The Neuropsychiatric Inventory (NPI) was used to evaluate twelve neuropsychiatric symptoms in the PwD[32]. If a symptom is present, the caregiver rates its frequency and severity on a scale from respectively 1 ('rarely') to 4 ('very often'), and 1 ('mild') to 3 ('severe'). The score for each domain was computed by multiplying the frequency and severity score. Subsequently, a total NPI score was calculated by adding the domain scores together.

**Statistical analysis**

Participants with fewer than twenty valid ESM reports (less than 33% of the in total 60 ESM reports) were excluded from the analyses[33]. Multilevel modeling techniques were used to account for the hierarchical structure of ESM data, in which multiple observations (beep level 1) are nested within days (day level 2) and days are nested within individuals (individual level 3)[34]. Data were analyzed with the XTMIXED module in STATA 12.1 (StataCorp, College Station, TX). Analyses were conducted separately for the two stress measures (event- and activity-related stress). Negative affect was entered as the dependent variable. Ratings of stress (event- or activity-related stress), caregiver characteristics (age, gender, education level, hours of contact with and care for the PwD, sense of competence, mastery, and coping), and their interactions were entered as the independent variables, leading to the following model: mood = $\beta0 + \beta1$ stress + $\beta2$ caregiver characteristic + $\beta3$ (stress x caregiver characteristic) + residual. In addition, care recipient characteristics (i.e. disease severity and duration, and neuropsychiatric symptoms) were included as possible confounders. Post-hoc analyses were performed to test the overall effect of the categorical variables (gender and education level) and to separately test the effect of each categorical level. The interaction term was of most interest in the present study as the main question concerned which caregiver characteristics modify emotional stress reactivity. Stratified analyses were conducted in case of significant interaction effects to examine the direction of the effect in more detail. To this end, participants were classified into tertiles (low, middle, high) according to their score on the concerning caregiver characteristic. For each caregiver characteristic, emotional reaction to daily life stress was analyzed in the three groups separately according to the following model: mood = $\beta0 + \beta1$ stress + residual. Graphs were generated to illustrate the data in more detail.

## RESULTS

### Participants and descriptive statistics

Of the 31 caregivers who entered the study, one was excluded from the analyses due to insufficient ESM data. The remaining 30 caregivers completed on average 49.3 out of 60 valid reports (SD = 5.2). Table 1 contains the demographic and clinical characteristics of the 30 participating caregivers and their care recipients. Mean scores on negative mood, both stress measures, the remaining caregiver characteristics as well as its correlations are shown in Table 2.

**Table 1.** Demographic and clinical characteristics of the caregivers and care recipients

| Variable | Caregivers (N = 30) | Care recipients (N = 30) |
| --- | --- | --- |
| Age (M, SD, range) | 69.9 ± 5.8 (57-80) | 73.7 ± 6.2 (61-87) |
| Gender (n, %) | | |
|     male | 12 (40.0) | 18 (60.0) |
|     female | 18 (60.0) | 12 (40.0) |
| Level of education (n, %) | | |
|     low | 13 (43.3) | 16 (53.4) |
|     middle | 8 (26.7) | 6 (20.0) |
|     high | 9 (30.0) | 8 (26.6) |
| Type of dementia (n, %) | | |
|     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 (n, %) | | |
|     0,5 - very mild | | 11 (36.7) |
|     1 - mild | | 11 (36.7) |
|     2 - moderate | | 7 (23.3) |
|     3 - severe | | 1 (3.3) |

**Table 2.** Ratings and correlations of mood, stress, and caregiver characteristics (N=30)

| Measure | Score | | | Correlation (r)† | | | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Mean | SD | Range | Item 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 | 11 |
| Mood measure | | | | | | | | | | | | | | |
| Negative affect‡ | 1.9 | 0.8 | 1.0 to 4.4 | | | | | | | | | | | |
| Stress measures | | | | | | | | | | | | | | |
| 1. Event-related stress‡ | 0.7 | 0.5 | 0 to 1.8 | 1.00 | | | | | | | | | | |
| 2. Activity-related stress‡ | 2.7 | 0.7 | 1.5 to 3.9 | 0.20*** | 1.00 | | | | | | | | | |
| Caregiver characteristics | | | | | | | | | | | | | | |
| 1. Hours of contact with PwD per week§ | 153.3 | 12.4 | 126 to 168 | 1.00 | | | | | | | | | | |
| 2. Hours of care for PwD per week§ | 52.0 | 55.9 | 0 to 168 | .25*** | 1.00 | | | | | | | | | |
| 3. Sense of competence (SSCQ) | 25.7 | 6.5 | 8 to 35 | -.16*** | -.31*** | 1.00 | | | | | | | | |
| 4. Mastery (PMS) | 17.4 | 4.9 | 5 to 26 | -.16*** | -.54*** | .59*** | 1.00 | | | | | | | |
| Coping strategies | | | | | | | | | | | | | | |
| 5. Active coping | 20.2 | 4.3 | 13 to 28 | .37*** | -.18*** | .32*** | .61*** | 1.00 | | | | | | |
| 6. Passive coping | 10.0 | 2.8 | 7 to 18 | -.19*** | .34*** | -.41*** | -.74*** | -.59*** | 1.00 | | | | | |
| 7. Seeking distraction | 16.9 | 3.0 | 11 to 23 | -.05 | -.27*** | .21*** | .17*** | -.12** | .03 | 1.00 | | | | |
| 8. Expressing emotions | 5.5 | 1.0 | 3 to 7 | -.10* | -.02 | -.25*** | -.33*** | -.27*** | .26*** | .12*** | 1.00 | | | |
| 9. Seeking social support | 13.0 | 3.3 | 8 to 23 | .25*** | .04 | .05 | .22*** | .28*** | -.26*** | .30*** | .26*** | 1.00 | | |
| 10. Avoiding | 15.7 | 3.0 | 10 to 23 | .02 | .10* | .10* | -.24*** | -.06 | .31*** | .23*** | .10* | -.09 | 1.00 | |
| 11. Fostering reassuring thoughts | 11.6 | 2.8 | 4 to 19 | -.17*** | -.15*** | .07 | .17*** | .04 | -.01 | .38*** | -.08 | .09* | .45*** | 1.00 |

* p<0.05 ** p<0.01 *** p<0.001
†Pairwise correlations with Bonferroni correction
‡For each subject, a mean was calculated over all beeps. The mean per subject was aggregated over the group to attain a group mean (SD).
§PwD = person with dementia

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**Predictors of negative mood**

The multilevel model estimates of the interaction effects (stress x caregiver characteristic) on negative mood are reported in Table 3.

With respect to event-related stress, significant interaction effects on negative mood were found with the coping strategies 'seeking distraction', 'seeking social support', and 'fostering reassuring thoughts', indicating that these coping strategies modified the caregivers' emotional reaction to stress caused by daily events. Caregivers who scored high on these coping strategies experienced less negative affect in reaction to stressful daily events. No significant interaction effects were found with age, sense of competence, mastery, hours of contact with and care for the PwD, and the remaining coping strategies. In addition, post-hoc analyses showed non-significant results for the overall effect of gender ($\chi^2(1) = 3.43$, p = .064) and educational level ($\chi^2(2)$=2.73, p = .255).

With regard to activity-related stress, significant interaction effects on negative mood were found with education level, sense of competence, and mastery. A higher level of education, more sense of competence, and higher levels of mastery lowered caregivers' emotional reactivity to momentary feelings of stress caused by minor disturbances in daily life. A post-hoc analysis yielded a significant overall effect of education level ($\chi^2(2) = 7.48$, p = .024). The difference in stress reactivity was present between the low and highly educated caregivers (B = -.14, SE = .05, p = .006). No significant differences were found between the other levels of education (middle versus high: $\chi^2(1) = 3.18$, p = .075; low versus middle: B = -.05, SE = .04, p = .255). Moreover, no significant interaction effects were found with age, hours of contact with and care for the PwD, and coping strategies. In addition, the overall effect of gender was non-significant ($\chi^2(1) = .06$, p = .799).

**Table 3.** Analyses of the daily stress x caregiver characteristics interaction effect on negative mood

| Caregiver characteristic | Negative Mood | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| | Event-related stress | | | | Activity-related stress | | | |
| | B | SE | p | 95% CI | B | SE | p | 95% CI |
| Age | -.003 | .007 | .718 | -.016 - .011 | .003 | .003 | .316 | -.003 - .010 |
| Gender† | | | | | | | | |
| Male | .289 | .068 | <.001*** | .156 - .423 | .136 | .037 | <.001*** | .063 - .209 |
| Female | .132 | .051 | .011* | .031 - .232 | .125 | .026 | <.001*** | .074 - .175 |
| Education level† | | | | | | | | |
| Low | .126 | .058 | .031** | .012 - .241 | .172 | .028 | <.001*** | .117 - .227 |
| Middle | .283 | .075 | <.001*** | .136 - .429 | .126 | .029 | <.001*** | .069 - .183 |
| High | .200 | .103 | .053 | -.002 - .403 | .037 | .041 | .356 | -.042 - .117 |
| Sense of competence | -.005 | .009 | .564 | -.023 - .012 | -.011 | .004 | .002** | -.018 - -.004 |
| Mastery | -.005 | .010 | .605 | -.025 - .014 | -.010 | .004 | .008** | -.017 - -.003 |
| Hours of contact with PwD‡ | .003 | .003 | .338 | -.003 - .010 | .001 | .002 | .632 | -.003 - .005 |
| Hours of care for PwD‡ | .001 | .001 | .466 | -.001 - .002 | .000 | .000 | .384 | -.000 - .001 |
| Coping strategies: | | | | | | | | |
| Active coping | .016 | .010 | .113 | -.004 - .035 | -.007 | .005 | .141 | -.016-.002 |
| Passive coping | .006 | .015 | .664 | -.023 - .035 | .008 | .007 | .260 | -.006 - .021 |
| Seeking distraction | -.030 | .015 | .043* | -.058 - -.001 | .001 | .007 | .864 | -.013 - .016 |
| Expressing emotions | -.035 | .041 | .387 | -.116 - .045 | -.035 | .041 | .387 | -.116 - .045 |
| Seeking social support | -.028 | .014 | .046* | -.056 - -.000 | .004 | .007 | .592 | -.009 - .017 |
| Avoiding | -.001 | .017 | .966 | -.033 - .032 | -.003 | .007 | .702 | -.017 - .012 |
| Fostering reassuring thoughts | -.024 | .012 | .038* | -.046 - -.001 | -.008 | .007 | .235 | -.021 - .005 |

* p<0.05, ** p<0.01, *** p<0.001. †Effect sizes show the effect of stress on negative affect per stratum of the categorical variable (gender, education level).
‡PwD = person with dementia

Stratified analyses were conducted to further clarify the association between stress and mood in relation to sense of competence, mastery, and the coping subscales 'seeking distraction', 'seeking social support', and 'fostering reassuring thoughts'. Overall, the caregivers with the highest scores (third tertile) on sense of competence, mastery, and the three coping strategies showed a weaker emotional reaction to stress, with smaller increases in negative affect than the caregivers who had middle (second tertile) or low average scores (first tertile). As an example, graphs are included to illustrate the stratified data for sense of competence, mastery, and 'seeking social support' in more detail (Figure 1, 2 & 3).
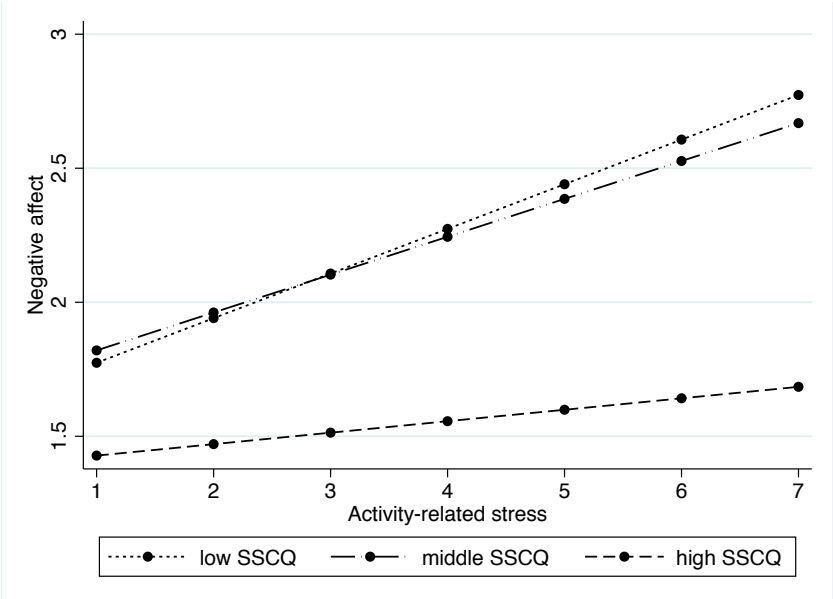


**Figure 1.** Stratified data illustrating the significant interaction between sense of competence and activity–related stress on negative mood. Data were stratified into three groups (low, middle, high) by means of tertiles.

**Figure 2.** Stratified data illustrating the significant interaction between mastery and activity–related stress on negative mood. Data were stratified into three groups (low, middle, high) by means of tertiles.



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**Figure 3.** Stratified data illustrating the significant interaction between the coping strategy 'seeking social support' and event–related stress on negative mood. Data were stratified into three groups (low, middle, high) by means of tertiles.

## DISCUSSION

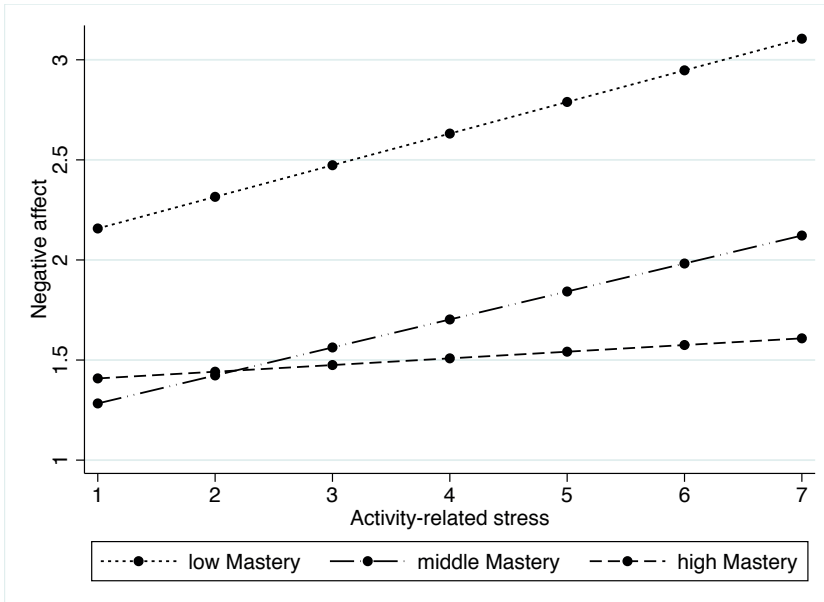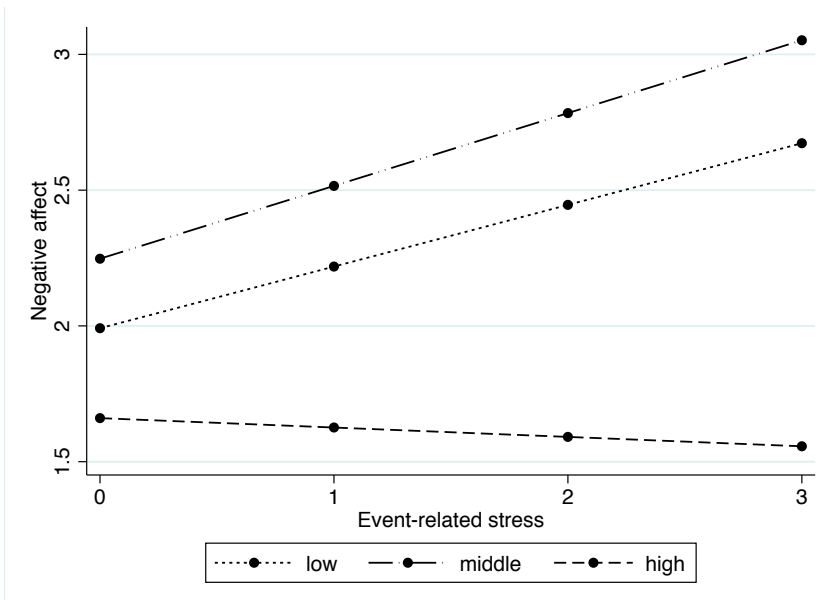In this study we examined which caregiver characteristics moderate the association between daily stress and negative affect in spousal caregivers of PwD. As suggested in Lazarus and Folkman's coping and stress model, personal characteristics (e.g. vulnerabilities and resources) may influence the direction of the stress process and play an exacerbating or buffering role in caregivers' emotional reactivity to daily life stress[6]. Results showed that caregivers who more frequently used the coping strategies 'seeking distraction', 'seeking social support', and 'fostering reassuring thoughts' reported less emotional reactivity to stressful daily events. In general, coping strategies can be divided into problem-focused (directed at actively altering or managing a problem) and emotion-focused strategies (directed at regulating emotional responses to a problem)[35]. Each form of coping is considered effective under different circumstances. However, problem-focused coping has been found to be conducive to psychological well-being when the stressor is perceived as changeable, whereas emotion-focused coping is more adaptive when the stressor is seen as uncontrollable[36]. It seems plausible that caregivers use both types of coping in response to stressors they encounter in daily life. Our results showed that primarily emotion-focused strategies reduced caregivers' emotional reactivity when facing stressful daily events. Stressful situations that occur within the presence of the PwD may be related to problem behavior of the PwD, which can be appraised by caregivers as difficult to manage and control[12]. Emotion-focused strategies might, therefore, be more adaptive in these circumstances. Previous studies already demonstrated that emotion-focused strategies could play a buffering role in reactivity to daily life stress. A study on associations between daily coping and end-of-day mood demonstrated that negative affect decreased when distraction and acceptance of the problem were used as coping strategies during times of stress[37]. Furthermore, a study investigating daily stress reactivity among caregivers for elder relatives found that caregivers who reported higher levels of available social support were less reactive to daily fluctuations in care recipient problem behavior[38]. Given that caregivers are at increased risk of becoming socially isolated and often lack social support, an important target in caregiver support interventions could be to stimulate caregivers in seeking social support[39]. In line with our finding that social support appears to be an important resource in buffering against stress reactivity, social support has been found to enhance caregivers' feelings of self-worth and self-esteem and to aid in resolving problems or losses[40].

Another finding of our study was that caregivers with a higher education level, more sense of competence, and higher levels of mastery appeared to be less prone to experiencing negative affect when they encountered minor disturbances in daily life. These caregiver characteristics especially seem to play a buffering role when dealing with momentary

stressors that continually occur in the flow of daily life. Higher educated caregivers tend to use more effective care management strategies, which may explain their reduced emotional reactivity towards momentary stressors[4]. Caregivers' sense of competence and mastery have been considered to influence the appraisal of stressful situations and the way in which caregivers cope with distress[29]. A study by Roepke et al.[41] found that caregivers with higher levels of mastery experienced less physical reactivity towards acute psychological stressors, suggesting that mastery also might serve as a resource to reduce emotional stress reactivity.

Overall, our results show that caregiver resources (i.e. dynamic characteristics, such as coping, sense of competence, and mastery) rather than vulnerabilities (i.e. hard-wired characteristic, such as age and gender) affect emotional reactivity to daily life stress. Differences in stress reactivity among caregivers might be due to the fact that dynamic caregiver characteristics have the capacity to influence the direction of the stress process and to blunt its impact on caregivers' negative mood state.

## Clinical implications

Our findings have important implications for clinical practice. An essential element in successful caregiver support interventions is the focus on personal characteristics and resources[24]. Intervention programs aimed at reinforcement of caregiver resources, i.e. enhancement of their sense of competence, mastery and coping strategies, could help to reduce caregivers' emotional stress reactivity. The ESM may be a useful tool to create interventions that are more person-tailored and that provide a more dynamic view of caregiver functioning. Recently, we developed an ESM-based intervention in which caregivers of PwD collect momentary data in their daily lives and receive personalized ESM-derived feedback to increase their sense of competence and mastery in dealing with the daily challenges of dementia[42]. Details on the design of this intervention are described in Chapter 5. A comparable ESM intervention has proven to be effective in increasing self-awareness and reducing depressive symptoms in persons with depression[43].

## Limitations

The results of this study should be viewed in the light of certain limitations. First, our study sample consisted primarily of caregivers of people with mild stages of dementia. Caregivers reported relatively low levels of negative affect and stress, which might be specific to caregivers who are not yet exposed to high care demands. Therefore, the generalizability of the results to a more heterogeneous caregiver population remains unknown. Second, in this study we examined caregivers' emotional reactivity towards daily stressors in general rather than towards specific care-related stressors. Zooming in to our data, we found that in 71.0% of the reported stressful events the PwD was present. A sensitivity-analysis including

only these stressful situations that occurred in the presence of the PwD yielded comparable results with respect to sense of competence, mastery, and seeking social support (results available on request). Finally, emotional stress reactivity has been defined in terms of emotional reaction to subjective stress. The cross-sectional nature of the data makes it impossible to establish causal relationships. The reverse may also be true in that a worse mood impacts the subjective appraisal of daily stressors. Either explanation, however, has clinical relevance.

## CONCLUSION

In this study an innovative approach was used to examine caregivers' stress experiences in the flow of daily life. The results provide evidence that empowerment of caregiver resources, such as sense of competence, mastery, and coping, may help to reduce daily stress reactivity among caregivers and could be an important target in caregiver interventions.

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# 5

## Effectiveness of the experience sampling method intervention 'Partner in Sight' for spousal caregivers of people with dementia: design of a randomized controlled trial

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## ABSTRACT

**Objectives:** There is an urgent need for psychosocial interventions that effectively support dementia caregivers in daily life. The experience sampling methodology (ESM) offers the possibility to provide a more dynamic view of caregiver functioning. ESM-derived feedback may help to redirect caregivers' behavior towards situations that elicit positive emotions and to increase their feelings of competence in the caretaking process. This paper presents the design of a study that evaluates the process characteristics and effects of the ESM-based intervention 'Partner in Sight'.

**Methods/design:** A randomized controlled trial with 90 spousal caregivers of people with dementia will be conducted. Participants will be randomly assigned to the experimental (six-week ESM intervention including feedback), pseudo-experimental (six-week ESM intervention without feedback), or control group (care as usual). Assessments will be performed pre- and post-intervention and at two-, and six-month follow-up. Main outcomes will be sense of competence, perceived control, momentary positive affect, and psychological complaints (depressive symptoms, perceived stress, anxiety, momentary negative affect). In addition to the effect evaluation, a process and economic evaluation will be conducted to investigate the credibility and generalizability of the intervention, and its cost-effectiveness.

**Discussion:** The potential effects of the ESM intervention may help caregivers to endure their care responsibilities and prevent them from becoming overburdened. This is the first ESM intervention for caregivers of people with dementia. The results of this study, therefore, provide a valuable contribution to the growing knowledge on m-health interventions for dementia caregivers.

## INTRODUCTION

Caregivers of people with dementia (PwD) are at great risk of becoming overburdened and of developing psychological and physical symptoms during the caretaking process[1]. This calls for psychosocial interventions that effectively support caregivers of PwD in daily life and help them handling their care responsibilities.

Various psycho-social interventions have been developed in recent years for caregivers of PwD, including psycho-education, emotional support, practical assistance, cognitive-behavioral therapy, and multi-component interventions[2]. Overall, research has shown significant but small effects of current interventions on caregiver outcomes. A common feature in these studies is that outcome measures include retrospective self-assessments that are highly susceptible to emotional and cognitive biases[3]. Moreover, retrospective methods do not provide information about fluctuations in subjective experiences over time and across situations that caregivers of PwD may face due to constantly changing care demands.

The experience sampling methodology (ESM) is an innovative approach in assessing subjective experiences in real-time within the flow of daily life. The ESM consists of a structured diary method in which repeated self-assessments are electronically recorded the moment they occur, in their natural setting[4,5]. The ESM offers the possibility to provide a more accurate and detailed view of caregiver functioning, since it enables daily fluctuations in subjective experiences to be explored and it minimizes retrospective recall biases[6,7]. Therefore, the ESM might be a valuable addition to standard retrospective methods, particularly in older populations with an increased incidence of memory deficits[8].

Recently, there has been growing interest in adapting the ESM to clinical practice. By using modern technology, such as personal digital assistants (PDAs) and apps, momentary data are immediately available to both caregivers and professionals. This creates the opportunity to develop ESM interventions that provide explicit visualized feedback on implicit dynamic patterns of feelings, experiences, and behavior[9,10]. Receiving feedback on behavior can result in emotional and behavioral change, something already known from the field of behavioral therapy[11,12]. The feedback may help caregivers redirect their behavior towards situations that are conducive to positive emotional experiences. In this way, the ESM offers the opportunity to actively involve caregivers in their own empowering process and to provide more personally tailored support[13]. Both these aspects have been demonstrated to be essential in effective psychosocial interventions[14,15].

A focus on positive experiences facilitates a more positive interaction between the caregiver and the PwD and increases positive emotions in both the parties[16]. According to the 'broaden-and-build theory', positive emotions elevate the ability to cope with stressful situations and might consequently help to increase caregivers' feelings of being capable of caring for the PwD[17,18]. Positive emotions could thus be an important target in caregiver support interventions, increasing caregiver well-being and reducing long-term negative impacts, such as stress and burden[19,20].

In a recent study, ESM-derived feedback on positive affect was provided to persons with depression during a 6-week intervention period. Its results showed that personalized feedback increased self-awareness and resulted in a significant decline in depressive symptoms[9]. In another ESM study, in which depressed individuals collected ESM data for scientific purposes but without receiving feedback, some participants reported that responding to the ESM questionnaires had already 'helped them' and enhanced awareness of their daily functioning[21]. So far, few studies have applied the ESM in caregivers of PwD in the context of research[22,23]. Recent evidence suggests that the ESM is a feasible method for use with this often elderly and vulnerable population (Chapter 2)[24]. However, to date, no ESM interventions have been developed to support caregivers of PwD in dealing with daily challenges associated with dementia. This paper describes the design of a randomized controlled trial (RCT) to evaluate the effects of the ESM-based intervention program 'Partner in Sight' for spousal caregivers of PwD.

**Study aims**
The specific objectives of the current study are:

1. *Process evaluation* to investigate the internal and external validity of the intervention based on sampling quality (recruitment, randomization, and reach) and intervention quality (relevance, feasibility, and performance according to protocol). The process evaluation will be conducted prior to the effect evaluation in order to provide essential information about credibility and generalizability[25].
2. *Effect evaluation* to assess whether 'Partner in Sight' is superior to a pseudo-intervention and control group in terms of producing a clinically significant increase in subjective well-being, as proven by an increase in caregivers' sense of competence, perceived control, momentary positive affect, and a decrease in psychological complaints (depression, anxiety, stress, and momentary negative affect). A follow-up evaluation will be conducted to examine whether the effects have lasted two and six months after the intervention.

3. *Economic evaluation* to assess the cost-effectiveness of 'Partner in Sight' by estimating the impact of the intervention on resource use, costs, and health outcomes.

## METHODS AND DESIGN

The study is a randomized controlled trial with three treatment arms. The experimental condition in which caregivers participate in the ESM intervention 'Partner in Sight' (ESM data collection including feedback) will be compared with a pseudo-experimental condition (ESM data collection without feedback) and a control group (care as usual). Data will be collected pre- and post-intervention and at two- and six-months follow-up (Figure 1).



**Figure 1.** CONSORT Flow diagram
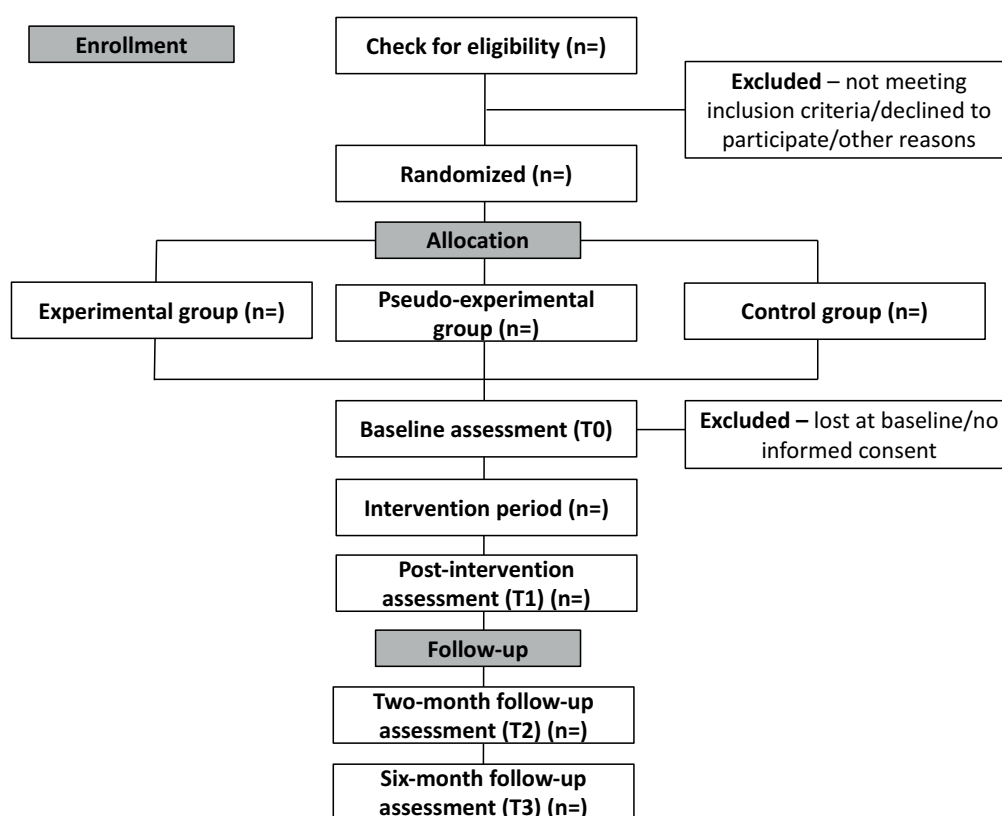
## Study population

The study population will consist of spousal caregivers of community dwelling people with all subtypes and stages of dementia. No age limit will be applied. Participants will be recruited in memory clinics (Maastricht University Medical Center+ (MUMC+), Zuyderland Medical Center), ambulatory mental health care institutions (Virenze-RIAGG Maastricht, Lionarons

GGZ), dementia day care centers (Sevagram, NOVIzorg, Orbis Glana, Proteion, care farm Ransdalerveld), and caregiver support services (Hulp bij Dementie, Steunpunt Mantelzorg) in the southern region of the Netherlands, and via the website of the Dutch Alzheimer Society. The clinician or care counselor who is involved in the treatment of the PwD will approach caregivers to participate in the study. Subsequently, potential participants will be contacted and screened by the researcher to make sure that they fully meet the following inclusion criteria: (1) being a spousal caregiver of a person with a diagnosis of dementia; (2) sharing a household with the PwD; and (3) informed consent obtained. Exclusion criteria will be: (1) insufficient cognitive abilities to engage in the ESM; (2) being overburdened or having severe health problems based on clinical judgment of a knowledgeable practitioner; (3) taking care of a PwD caused by Human Immunodeficiency Virus (HIV), acquired brain injury, Down syndrome, chorea related to Huntington's disease or alcohol abuse.

**Randomization**
Caregivers will be randomly assigned to the experimental group, pseudo-experimental group, or control group. Randomization will be computer-generated and conducted by an independent statistician. Block randomization will be performed to diminish the risk of an unbalanced assignment to the three treatment arms. Randomly permuted blocks with variable block sizes (three, six, and nine) will be used, by which the block size and specific order will be chosen randomly at the beginning of each block. This reduces the risk of predicting group assignment and keeps research staff blind to the randomization process. The design of this study is single-blind. An independent research assistant, who is being blinded to the treatment allocation, will conduct the baseline, post-intervention and follow-up assessments, and will be asked to evaluate success of blinding and reasons for possible unmasking on the Case Record Form.

**Experience sampling method procedure**
The ESM will be carried out using the PsyMate, an electronic touchscreen device that is specifically designed to monitor experiences and behavior in daily life and that offers the possibility to provide immediate ESM-derived feedback (www.psymate.eu). The PsyMate has been extensively studied and refined in several studies concerning psychiatric populations (e.g. psychosis and depression)[10,13]. In a recent ESM study with spousal caregivers of PwD, the PsyMate was considered to be a user-friendly and easily accessible device (Chapter 2)[24].

The PsyMate will be programmed to generate ten beeps (sound and vibration) per day at random intervals between 7:30 AM and 10:30 PM. The ESM will be used as an assessment tool during the baseline assessment (three consecutive days = 30 beeps in total) and the post assessment (three consecutive days = 30 beeps in total) to evaluate the effectiveness of the

intervention. Furthermore, the ESM will be used as an intervention tool during the six-week intervention period (three consecutive days per week = 10x3x6 = 180 beeps in total). In order to include different days of the week, the PsyMate will beep alternately on Friday, Saturday, and Sunday, or Tuesday, Wednesday, and Thursday during the intervention period.

After each beep, caregivers will be asked to complete a questionnaire presented on the screen of the PsyMate, including current affect (four positive affect and eight negative affect items), self-esteem (four items), physical well-being (four items), as well as current context and activities (daily life activities, social company, location and events). At the end of each questionnaire, caregivers will have to indicate whether the beep disturbed them. Answering all questions will take approximately three minutes per beep (Chapter 2)[24]. Additionally, the PsyMate will be programmed to generate a morning and evening questionnaire at the beginning and end of each day. The morning questionnaire consists of six items regarding their sleep quality during the previous night and their current level of energy. The evening questionnaire contains 25 items concerning caregivers' daily sense of well-being and competence, and neuropsychiatric symptoms in the PwD during that day. Responses will be rated on 7-point Likert scales (ranging from 1 'not at all' to 7 'very much'), bipolar scales (ranging from -3 'very unpleasant/very unimportant' to +3 'very pleasant/very important'), a Visual Analogue Scale (ranging from 0 'worst imaginable health' to 100 'best imaginable health'), and box-checking formats. Responses cannot be corrected afterwards. An overview of the ESM items with corresponding response choices and concepts is presented in Appendix 1. The specific items of the ESM questionnaires were developed and selected according to information available from previous ESM studies[26,27], knowledge about the experiences and situations that caregivers of PwD could be expected to encounter in daily life, and the guidelines for item development created by ESM experts[28]. Moreover, the ESM questionnaires were recently tested in a feasibility study that yielded positive results (Chapter 2)[24].

**Study procedure**

*(1) Baseline assessment (T0)*
After the randomization procedure, a baseline assessment (T0) will take place in the caregivers' home or at the MUMC+ according to their preference. Participants will be asked by the research assistant to sign the informed consent before continuation of the study procedure. Next, a demographical interview will be conducted to assess caregiver and care recipient characteristics. Additionally, caregivers will be asked to participate in a three-day ESM baseline measurement, starting the day after the baseline assessment. A 30-minute briefing will be provided during the baseline assessment to ensure that they fully understand the procedure and how to operate the PsyMate. A demo questionnaire will be presented

to familiarize caregivers with the device and a leaflet containing all relevant information regarding the use of the device will be handed out. Finally, the caregivers will be asked to complete a number of retrospective questionnaires at their own convenience as part of the effect evaluation.

*(2) Intervention period*

*Experimental group*

Caregivers in the experimental group will participate in the six-week intervention 'Partner in Sight' and collect ESM data for three consecutive days a week. Every two weeks they will receive ESM-derived feedback in a face-to-face session with a coach in their home or at the MUMC+ according to their preference. This sums up to a total of three feedback sessions. The aim of the feedback sessions is to provide an overview of the caregivers' everyday functioning, including their mood (i.e. levels of positive affect), daily life activities, and social interactions. The focus will be on positive rather than negative emotional experiences and how these relate to specific daily contexts. In this way, we try to stimulate caregivers to redirect their behavior towards situations that elicit positive emotions.

At the beginning of each feedback session average levels of positive affect experienced during the past two weeks will be presented. Subsequently, a feedback module on daily activities and/or social interactions in daily life will be discussed with the caregiver. Feedback modules are based on an existing ESM intervention, which has proven to be effective in people with depression[9]. During the first feedback session the module 'daily activities' will be discussed with the caregiver. The data may, for example, illustrate that positive emotions increase during moments of active relaxation, while the caregiver is actually spending the least amount of time on active relaxation activities. The coach will stimulate caregivers to think about the findings and to implement new insights into their daily lives. In the second feedback session the module 'social interactions in daily life' will be added. A caregiver might state, for example, that he prefers to spend his time alone, without any company. The feedback, however, may show that positive emotions are experienced particularly while being in company instead of when being alone. This finding might induce an increase in social interactions, which in turn may lead to increased positive emotions. The third session will combine both modules. At the end of each session the weekly progress in levels of positive affect yielded by daily activities and/or social interactions will be evaluated. A more detailed description of the feedback modules is presented in Table 1.

The coach will present all feedback verbally and graphically (in clear pie charts and bar graphs) to the caregiver according to a standardized protocol. Before the start of the study all

coaches will receive training with clear instructions on how to provide feedback. After each session both the caregiver as well as the involved clinician or care counselor will be provided with a written copy of the feedback.

At the end of each feedback session there will be a debriefing concerning the use of the PsyMate, e.g. difficulties operating the device, technical problems, items that are unclear, and reasons for missing measurements. Furthermore, the participant will be reminded and encouraged to fill out the PsyMate during the following two weeks as accurately as possible conform the instructions given by the coach. During the third feedback session the coach will additionally conduct an unstructured interview to assess the feasibility of the intervention.

**Table 1.** Feedback modules of the experience sampling method intervention 'Partner in Sight'

| Session | Feedback module | Description |
|---|---|---|
| 1 | 1 Daily activities | - Pie chart of the average time spent on different activities (e.g. caring for partner, household, active relaxation, passive relaxation, resting, self care) during the past two weeks |
| | | - Graph demonstrating the relationship between different kind of activities and experienced levels of positive affect |
| | | - Pie chart of the average time spent on active relaxation in the presence and absence of the PwD |
| | | - Graph showing experienced levels of positive affect during active relaxation in the presence and absence of the PwD |
| | | - Pie chart of the average time spent on passive relaxation in the presence and absence of the PwD |
| | | - Graph showing experienced levels of positive affect during passive relaxation in the presence and absence of the PwD |
| 2 | 1 & 2 Social interactions | Added: |
| | | - Pie chart of the average time spent in different kinds of company (e.g. partner, friends, family, colleagues, alone) during the past two weeks |
| | | - Graph demonstrating the relationship between different types of social company and experienced levels of positive affect |
| 3 | 1 & 2 | See description above |
| 1,2,3 | General graphs | - Graph including information on average levels of positive affect during the past two weeks |
| | | - Graph demonstrating the weekly progress in levels of positive affect during the course of the intervention |
| | | - Graph demonstrating the weekly progress in levels of positive affect yielded by daily activities |
| | | - Graph demonstrating the weekly progress in levels of positive affect yielded by social interactions |

PwD = person with dementia

*Pseudo-experimental group*

A pseudo-experimental group is added to the study design to investigate whether the ESM-derived feedback adds value to the use of the PsyMate without receiving any direct feedback. Repeated self-assessments might already increase caregivers' self-awareness and redirect their behavior accordingly[21].

Caregivers in the pseudo-experimental group will participate in a six-week pseudo-intervention and collect ESM data for three days a week. Every two weeks they will receive a face-to-face session with a coach. However, during these sessions they will not be provided with feedback on their daily recordings. Alternatively, a semi-structured interview on their well-being during the past two weeks will be performed to prevent any effects of different duration of contact with the coach.

At the end of each session caregivers will, similar to the participants in the experimental group, be provided with a debriefing concerning the use of the ESM-device.

*Control group*

Caregivers in the control group will receive care as usual during the six-week intervention period. Care conditions will differ among caregivers and will be registered carefully at baseline. In general, care as usual includes low-frequent sessions with a clinician from the memory clinic or counselor from a caregiver support service.

*(3) Post-intervention assessment (T1)*

After the intervention period a post-intervention assessment will be executed in the caregivers' home or at the MUMC+ according to their preference. As part of the post-intervention assessment, caregivers will be asked to participate in a three-day ESM post measurement. They will be shortly briefed with respect to the procedure. Afterwards, all participants will be asked to complete a questionnaire concerning their general experiences with the ESM device during the complete study period. Based on their answers a semi-structured interview will be conducted to discuss the questionnaire. Finally, caregivers will be asked again to complete a number of retrospective questionnaires at their own convenience as part of the effect evaluation.

*(4) Follow-up assessments (T2 & T3)*

A two- and six-month follow-up assessment will be administered in which participants receive a number of retrospective questionnaires by post and are asked to return them after completion.

**Retention**

Participants will be provided with periodic newsletters to inform them about the current status of the study, plans for the next phase, as well as to acknowledge their support.

**Instruments**

For an overview of the instruments used during the baseline, post-intervention and follow-up assessments see Table 2.

*Primary outcome measures*

*Sense of competence*: caregivers' subjective feelings of competence will be assessed with the Short Sense of Competence Questionnaire (SSCQ), a shortened version of the 27-item Sense of Competence Questionnaire (SSQ)[29]. The SSCQ consists of seven items, rated on a 5-point scale from 1 ('agree very strongly') to 5 ('disagree very strongly'). The items reflect three domains of caregivers' feelings of being capable to care for the PwD: satisfaction with their own performance as a caregiver (two items), satisfaction with the PwD as a care recipient (three items), and consequences of involvement in care for personal life of the caregiver (two items). A total sum score (range 7-35) will be calculated for each participant. Higher sum scores represent higher levels of sense of competence. The scale displayed good content and construct validity in previous research[29].

*Perceived control:* the extent to which a person perceives him- or herself to be in control of events and on-going situations, also known as mastery, will be measured with the Pearlin Mastery Scale (PMS)[30]. The scale contains seven items with scores varying from 0 ('completely agree') to 4 ('completely disagree'). Items are summed to form a total mastery score (range 0-28), with higher scores indicating greater perceived control. The psychometric properties of the PMS are good according to previous research[31].

*Secondary outcome measures*

*Depressive symptoms:* the Center for Epidemiological Studies Depression Scale (CES-D) will be used to assess depressive symptoms among caregivers[32]. It includes twenty items that rate the frequency of symptoms during the past week. Item scores range from 0 ('rarely or none of the time present' [less than 1 day]) to 3 ('most or all of the time present' [5-7 days]). The total sum score ranges from 0 to 60, with higher scores indicating more depressive symptoms. Items depict major components of depressive symptomatology, such as depressed mood, feelings of guilt and worthlessness, feelings of helplessness and hopelessness, psychomotor retardation, loss of appetite, and sleep disturbance. The CES-D has been widely used in research on caregiving and has proven to be sensitive to changes in caregiver depressive symptoms after intervention[14].

**5**

**Table 2.** Flowchart of measures used during the assessments

| | Pre-test | Intervention period | | | Post-tests | | |
|---|---|---|---|---|---|---|---|
| | T=0 | FB1 | FB2 | FB3 | T=1 | T=2 | T=3 |
| **Primary outcome measures RCT** | | | | | | | |
| - Sense of competence: SSCQ | X | | | | X | X | X |
| - Perceived control: PMS | X | | | | X | X | X |
| **Secondary outcome measures RCT** | | | | | | | |
| - Depressive symptoms: CES-D | X | | | | X | X | X |
| - Perceived stress: PSS | X | | | | X | X | X |
| - Anxiety symptoms: HADS-A | X | | | | X | X | X |
| **ESM outcome measures RCT** | | | | | | | |
| - Momentary positive affect | X | | | | X | | |
| - Momentary negative affect | X | | | | X | | |
| **Additional measures RCT** | | | | | | | |
| - Demographic variables | X | | | | | | |
| - Neuropsychiatric symptoms in PwD: NPI-Q | X | | | | X | X | X |
| - Quality of the relationship: 4 items of the University of Southern California Longitudinal Study of Three- Generation Families measures of positive affect | X | | | | X | X | X |
| - Coping: UCL | X | | | | X | X | X |
| - Personality: subscale neuroticism of NEO-FFI | X | | | | X | X | X |
| **Outcome measures process evaluation** | | | | | | | |
| - Subjective experiences with intervention: quantitative questionnaire & qualitative semi-structured interview | | | | X | | | |
| - Subjective experiences with the use of the ESM device: quantitative questionnaire | | | | | X | | |
| - Subjective experiences with ESM procedure: quantitative questionnaire | | X | X | X | X | | |
| **Outcome measures economic evaluation** | | | | | | | |
| - Resource use: RUD-lite | X | | | | X | X | X |
| - Quality of life: EQ-5D | X | | | | X | X | X |

RCT = randomized controlled trial; SSCQ = Short Sense of Competence Questionnaire; PMS = Pearlin Mastery Scale; CES-D = Center for Epidemiological Studies Depression Scale; PSS = Perceived Stress Scale; HADS-A = Hospital Anxiety and Depression Scale - Anxiety subscale; PwD = person with dementia; NPI-Q = Neuropsychiatric Inventory Questionnaire; UCL = Utrecht Coping List; NEO-FFI = NEO Five-Factor Inventory; ESM = Experience Sampling Methodology; RUD-lite = Resource Utilization in Dementia - shortened version; EQ-5D = EuroQoL-5D

*Perceived stress:* the Perceived Stress Scale (PSS) will be used to measure the degree to which situations in one's life are appraised as stressful[33]. The PSS consists of ten items, rated on a 5-point scale from 0 ('never') to 4 ('very often'), regarding unpredictability, control, and overload. Total sum scores on the PSS range from 0 to 40, with higher scores representing higher levels of stress. Adequate validity and reliability has been demonstrated in previous research[33].

*Anxiety symptoms:* the 7-item anxiety subscale of the Hospital Anxiety and Depression Scale (HADS) will be employed to assess the severity of anxiety symptoms in caregivers[34]. Item scores range from 0 ('not at all') to 3 ('a great deal of the time') and will be accumulated to produce a total sum score (range 0-21), with higher scores indicating more anxiety. The HADS has frequently been used in caregivers of PwD and has shown good reliability rates[35].

### ESM outcome measures
*Momentary positive and negative affect:* the ESM data collected during the three-day ESM baseline measurement and three-day ESM post measurement will be used to assess caregivers' momentary positive and negative affect. Positive affect will be defined as the mean score of the items: 'I feel cheerful', 'I feel relaxed', 'I feel enthusiastic', and 'I feel satisfied'. Negative affect will be defined as the mean score of the items ' I feel insecure', 'I feel lonely', 'I feel anxious', 'I feel irritated', 'I feel down', 'I feel desperate', 'I feel tensed', and 'I feel confident'. A mean positive and negative affect score will be calculated for each completed beep during the day, with higher scores indicating higher levels of positive and negative affect.

### Additional measures
*Demographics:* demographic variables, including age, sex, and level of education of both the caregiver and the care recipient, will be assessed during a demographical interview with the caregiver. Furthermore, information about the type, severity, and duration of dementia, caregiver hours of contact with the PwD, caregiver hours of caring for the PwD, and PwD hours spent in a dementia day care setting will be collected. The Clinical Dementia Rating scale (CDR) will be used to stage the severity of the dementia[36]. The CDR score is rated on a 5-point scale: 0 = 'normal'; 0.5 = 'very mild dementia'; 1 = 'mild dementia'; 2 = 'moderate dementia'; and 3 = 'severe dementia'. The CDR has become widely accepted in the clinical setting as a reliable and valid global assessment measure of dementia[37].

*Neuropsychiatric symptoms in the PwD:* the Neuropsychiatric Inventory Questionnaire (NPI-Q), a brief form of the Neuropsychiatric Inventory (NPI), will be used to evaluate neuropsychiatric symptoms in the PwD and associated caregiver distress[38]. The NPI-Q evaluates twelve neuropsychiatric domains, including: delusions, hallucinations, agitation/

aggression, dysphoria/depression, anxiety, euphoria, apathy, disinhibition, irritability, aberrant motor behavior, nighttime behavioral disturbances, and appetite and eating abnormalities. For each domain, the caregiver answers a screening question to indicate whether the symptom is present or not. If present, the severity is rated on a scale from 1 ('mild') to 3 ('severe'). Total sum scores range from 0 to 36. Additionally, a caregiver distress score is rated for each domain on a 6-point scale, ranging from 0 ('not emotionally stressful') to 5 ('extremely stressful'). The Dutch version of the NPI-Q has been investigated and appears to be a valid instrument[39].

*Quality of the relationship:* quality of the relationship will be assessed using four items of the University of Southern California Longitudinal Study of Three-Generation Families measures of positive affect[40]. The items represent: general closeness, communication, similarity of views on life, and degree of getting along with each other. Answer scales range from 1 ('not at all') to 4 ('very'). Caregivers will answer these items in terms of the current situation and to what extent the relationship changed since illness onset (1 = 'much better', 5 = 'much worse'). Summed scores will be used as an index of the change in relationship quality. A previous study found good internal reliability[41].

*Coping*: The 44-item Utrecht Coping List (UCL) will be used to measure seven different coping strategies in the caregiver, including seeking distraction (eight items), expressing emotions (three items), seeking social support (six items), avoiding (eight items), fostering reassuring thoughts (five items), passive coping (seven items), and active coping (seven items). Items are rated on a 4-point scale, ranging from 1 ('rarely or never use this strategy') to 4 ('very often use this strategy'). The reliability and validity has been found sufficient despite some inconsistencies in the literature[42].

*Personality:* The 12-item Neuroticism domain of the NEO Five-Factor Inventory (NEO-FFI) will be used to identify caregivers who are susceptible to psychological distress [43]. This domain measures six traits: anxiety, hostility, depression, self-consciousness, impulsiveness, and vulnerability. Item scores will be rated on a 5-point scale, ranging from 0 ('strongly disagree') to 4 ('strongly agree'), and will be accumulated to generate a total sum score (range 0-48). The reliability and internal consistency of the Dutch version of the NEO-FFI is good[43].

### Outcome measures in the process evaluation
As part of the process evaluation, sampling quality and intervention quality will be evaluated to determine the internal and external validity of the intervention program and to reveal facilitators and barriers for the intervention.

*Sampling quality*: will be evaluated by describing (1) the recruitment and randomization procedure; (2) the informed consent and allocation procedure; and (3) barriers and facilitators to the recruitment of caregivers. Reach will be established by the proportion of caregivers participating and the number of institutions involved in the intervention.

*Intervention quality:* will be evaluated by determining (1) the relevance of the intervention; (2) the feasibility of the intervention; and (3) the extent to which the intervention was performed according to protocol.

Required data will be collected from the research database and during the sessions with the coach and the post-intervention assessment. Objective measures of compliance with respect to the ESM procedure (number of completed beeps) and the intervention (number of drop-outs) will be examined. Technical problems with the PsyMate will be logged. Subjective experiences with respect to the intervention (i.e. clearness, relevance, usability, impact on daily functioning, satisfaction with procedure and time burden, suggestions for improvement, and recommendations to other caregivers) will be assessed by means of a quantitative questionnaire and a qualitative interview with the caregiver during the third feedback session. In addition, subjective experiences with the PsyMate and ESM procedure (e.g. difficulties operating the device, clearness items, readability of the items on the screen, interference with daily activities, and reasons for missed beeps) will be examined.

Performance of the intervention according to protocol will be evaluated with a structured registration form, which includes protocol deviations and duration of each face-to-face session during the intervention period.

### Economic evaluation

The economic evaluation will involve a cost-effectiveness analysis (CEA) and includes the assessment of costs as well as outcomes of the intervention.

*Resource use and costs:* the Resource Utilization in Dementia - shortened version (RUD-lite) will be used to map the utilization of resources for both the PwD and the caregiver[44]. The RUD-lite assesses both formal and informal resource use, making it possible to calculate costs from a societal point of view. Costs will be calculated by multiplying the quantity of resource use by the cost price per resource unit and will include the period from the baseline assessment until the last follow-up assessment (six months). All relevant costs will be determined according to the Dutch guidelines for cost calculations in health care[45].

*Intervention costs:* intervention costs will include the amount of time spent on briefing the caregivers regarding the PsyMate and ESM procedure, the feedback sessions with the coach, administration (e.g. writing short feedback reports), telephone contact, the training session for the coach on how to provide the feedback, and costs of required materials (e.g. PsyMate). The coach will register the duration of the feedback sessions, administration, and telephone contact with the caregiver on a structured registration form.

Incremental cost effectiveness ratios (ICER) will be calculated by dividing the difference in total costs between the treatment arms by the difference in average effect size.

*Quality of life:* caregivers' health related quality of life will be measured with the EuroQol-5D (EQ-5D) and consists of five items representing the following dimensions: mobility, self-care, usual activities, pain/discomfort, and anxiety/depression[46]. Respondents indicate their health state by rating each dimension on a three-level scale, including 1 'no problems', 2 'moderate problems', or 3 'severe problems'. In addition, the EQ-VAS will be used to record caregivers' self-rated health status on a Visual Analogue Scale, anchored at 'the best health you can imagine' (100) and 'the worst health you can imagine' (0). The EuroQol demonstrates a good test-retest reliability[47]. For the cost-effectiveness analysis, quality-adjusted life-years (QALYs) will be calculated according to the Dutch EuroQol tariff[48].

**Sample size**

The calculation of the sample size will be based on previous studies using the Sense of Competence Questionnaire (SCQ) as outcome measure in intervention studies for caregivers of PwD, the use of repeated measures, within-between interaction with a mean effect size of 0.8[49], and the following assumptions: alpha 0.05, 80% power, and 25% loss to follow up. Accordingly, we aim to enrol 90 participants in the study (30 participants per group).

**Statistical analyses**

*Primary and secondary outcome measures*
Data will be entered twice to guarantee data integrity. Before the analyses, data will be checked for missing values and handled according to their distribution (missing completely at random, missing at random, or not missing at random), and the 'intention-to-treat' principle. Additionally, data will be checked for outliers, and normality. Non-parametric tests will be used in case of non-normality after data transformation. Possible baseline differences in group characteristics will be tested with t-tests for continuous and $\chi^2$-tests for categorical variables.

To investigate changes in the primary and secondary outcomes for each group during the intervention period, an analysis of covariance (ANCOVA) will be performed with outcome at post-intervention as the dependent variable, group (experimental, pseudo-experimental, control) as the between-subject factor, and outcome at baseline and potential confounders (e.g. demographic variables, coping, personality, and quality of the relationship) as covariates. Separate analyses will be conducted for each outcome variable. Group differences in the post-intervention outcome, adjusted for the baseline value, will be examined to test the effectiveness of the intervention.

To examine changes in the primary and secondary outcomes for each group during the total study period, a linear mixed model (LMM) for repeated measures will be conducted. Analyses will be performed with group as a fixed between-subject factor (three levels: experimental, pseudo-experimental, and control group) and time as fixed within-subject variable (four levels: baseline, post-intervention, two-month follow-up, and six-month follow-up) and first-order interactions as additional fixed factors. The LMM will estimate fixed effects (regression slopes) for change in the intervals during (T0-T1) and after (T1-T2, T2-T3) the intervention period. The intervals will be entered as a categorical dummy variable (three levels). Potential confounders will be added to the model as covariates.

All data will be analysed using STATA 12.1 (StataCorp, College Station, TX). Tests of significance will report mean change and will be two tailed with α set at 0.05.

*ESM outcome measures*
Subjects have to complete at least 33% of the ESM beeps in order to be included in the ESM data analysis[4]. To investigate changes in momentary positive and negative affect between the three-day ESM baseline and post measurement for each group, an LMM will be performed for both outcome measures. LMMs are ideally suited for ESM data, since these models take into account the hierarchical data structure in which multiple ESM observations (beep level 1) are nested within days (day level 2), and days are nested within subjects (subject level 3). The XTMIXED command in STATA 12.1 (StataCorp, College Station, TX) will be used to conduct analyses with group (three levels: experimental, pseudo-experimental, and control group), time (two levels: baseline and post-intervention), and the two-way interaction between group and time as fixed factors. Random slopes, representing positive or negative affect, will be added at the subject, day, and beep level. Potential confounders will be included in the model as covariates.

*Process evaluation*

Descriptive analyses will be conducted to summarize response rates, overall experiences regarding the ESM intervention and the PsyMate, and additional findings with respect to the sampling and intervention quality.

## Confidentiality

All study-related information will be stored securely at the study site. All participant information will be identified by a coded ID number to maintain participant confidentiality. The principal investigators and project team members will be able to access the data. All records that contain names or other personal identifiers (e.g. informed consent forms) will be stored separately from study records identified by code number. All datasets will be password protected.

## Monitoring and participant safety

The study will be monitored externally by the trial monitoring committee of the MUMC+ (Clinical Trial Center Maastricht). The trial monitoring committee is independent of the study organizers. All adverse events (AEs) and serious adverse events (SAEs) that occur during the study will be recorded during the (feedback) sessions, the post-intervention assessment, and the two- and six-month follow-up assessment. SAEs will be reported to the accredited Medical Ethical Committee that approved the protocol.

## Withdrawal of participants

Participants can leave the study at any time without justification and without any consequences.

## Ethics approval and consent to participate

The Medical Ethical Committee of the MUMC+ approved this study (#143040). All participants gave informed consent to participate in the study.

## Protocol amendments

Important protocol modifications, which may impact on the conduct of the study or may affect participant safety, including changes in study objectives, study design, study population, sample sizes, study procedures, or significant administrative aspects will require a formal amendment to protocol. Substantial amendments will be notified to the principal investigators and approved by the Medical Ethical Committee of the MUMC+ prior to implementation. Minor changes to the protocol that have no effect on the way the study is conducted will not be notified to the Medical Ethical Committee of the MUMC+, but will be recorded and filed by the investigators.

## DISCUSSION

The current paper presents the study protocol of an RCT to evaluate the effectiveness of an ESM intervention to improve caregivers' sense of competence and control and psychological well-being. The potential effects of the intervention may help caregivers to keep on caring and prevent them from developing (more) health problems and becoming overburdened. This study contains several unique aspects. To our knowledge, this is the first ESM intervention for caregivers of PwD. ESM might be a promising tool in both research and clinical practice, since it offers the possibility to provide more detailed information on caregiver functioning in the flow of daily life. In this study we will use ESM as an intervention tool, but also as an assessment tool to evaluate the effects of the intervention. Therefore, an important advantage is that the results of this study represent a high level of ecological validity. Another unique aspect is that our intervention focuses on positive rather than negative experiences during the caretaking process. Positive emotions are important facilitators of adaptive coping and might increase caregivers' feelings of being capable to care[18,50]. The ESM intervention might enhance caregivers' self-awareness and redirect their behavior to situations that are conducive to positive emotional experiences. Moreover, the intervention includes ESM-derived feedback that is tailored to the caregivers' personal situation and actively involves them in their own empowering process. Both are known to be important aspects of effective caregiver support interventions[14]. The inclusion of a pseudo-experimental condition in our study design allows us to unravel the added value of the ESM-derived feedback to the use of the PsyMate in general. Caregivers might benefit from the use of the PsyMate without receiving any feedback, since repeated self-assessments may lead people to pay more attention to their internal states and own behavior[21]. Lastly, the intervention program will be delivered in daily practice and offers the possibility to be integrated in future clinical practice. The additional process and economic evaluation will provide valuable information on potential facilitators and barriers to implementation, and on the cost-effectiveness of the intervention.

Certain limitations need to be acknowledged in advance. There is a possibility of sample bias. Although participants will be recruited in a wide range of different institutions, the group that agrees to participate in the study might differ from the group that refuses to participate. In general, participants are expected to be relatively young, more highly educated, and more pro-active in seeking for support[51]. Moreover, recent results from our feasibility study, in which caregivers were asked to collect ESM data for only six consecutive days, showed that a large number of caregivers refused to participate because of a too busy time schedule (Chapter 2)[24]. The even more time-intensive nature of the current study might, therefore, cause a selection bias towards caregivers that are not yet facing extreme difficulties in the caregiving process. It is also expected that a number of participants will drop out of the

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ESM intervention prematurely. In this specific population, it is likely that participants drop out for specific disease related reasons, such as institutionalization or death of the PwD. In a previous ESM study with persons with depression, 15% of the participants did not complete the six-week ESM intervention period[9]. The face-to-face sessions with a coach and the delivery of personalized feedback, however, might increase caregivers' motivation to participate given that usual care for dementia caregivers often does not, or very infrequent, include counseling[52].

In conclusion, the results of this study will provide a valuable contribution to the growing knowledge on m-health interventions for caregivers of PwD. Our ESM intervention 'Partner in Sight' is expected to be effective in terms of caregiver well-being and might be an innovative approach to support caregivers of PwD in managing daily challenges during the course of the disease.

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**Appendix 1.** Description of the experience sampling method concepts, items and response choices in the daily, morning, and evening questionnaire

**Daily questionnaire**

| 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 well-being | 17. I am tired | 7-point scale (1 'not at all' to 7 'very much') |
| | 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; caring for partner; active relaxation; passive relaxation; something else |
| | 22. And also? | Doing nothing; resting; work; household; self care; caring for partner; active relaxation; passive relaxation; something else |
| | 23. And…? | Doing nothing; resting; work; household; self care; caring for partner; active relaxation; passive 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 |

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**Appendix 1.** (continued)

**Daily questionnaire**

| Concept | Item | Rating scale |
|---|---|---|
| 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 of others | 7-point scale (1 'not at all' to 7 'very much') |
| | 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 thing that happened is… | (take an event in mind before you continue) |
| | 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') |

**Morning questionnaire**

| | | |
|---|---|---|
| | 1. I slept well | 7-point scale (1 'not at all' to 7 'very much') |
| | 2. How long did it take before I fell asleep | 0-5 min; 5-15 min; 30-45 min; 45-60 min; 1-2h; 2-4h; >4h |
| | 3. How often did I wake up last night | 1 time; 2 times; 3 times; 4 times; 5 times; more than 5 times |
| | 4. My partner disturbed my sleep | 7-point scale (1 'not at all' to 7 'very much') |
| | 5. I feel rested | 7-point scale (1 'not at all' to 7 'very much') |
| | 6. I feel apprehensive about today | 7-point scale (1 'not at all' to 7 'very much') |

**Evening questionnaire**

| | | |
|---|---|---|
| | 1. This was an ordinary day | 7-point scale (1 'not at all' to 7 'very much') |
| | 2. If I had not had the device, I would have done different things today | 7-point scale (1 'not at all' to 7 'very much') |
| | 3. I generally felt well today | 7-point scale (1 'not at all' to 7 'very much') |
| | 4. I generally felt tired today | 7-point scale (1 'not at all' to 7 'very much') |
| | 5. I generally felt tensed today | 7-point scale (1 'not at all' to 7 'very much') |

**Appendix 1.** (continued)

**Evening questionnaire**

| Concept | Item | Rating scale |
|---|---|---|
| | 6. I generally worried a lot today | 7-point scale (1 'not at all' to 7 'very much') |
| | 7. I generally felt able to manage today | 7-point scale (1 'not at all' to 7 'very much') |
| | 8. My health state was good today | Visual Analogue Scale (0 'worst imaginable health' to 100 'best imaginable health') |
| | 9. How many hours did you spend on caring for your partner today (incl. supervision) | 0h; 1h; 2h; 3h; 4h; 5h; >5h |
| | 10. Today I felt strained in the interactions with my partner | 7-point scale (1 'not at all' to 7 'very much') |
| | 11. Today I felt stressed due to my care responsibilities | 7-point scale (1 'not at all' to 7 'very much') |
| | 12. Today I felt that the situation with my partner did not allow me as much privacy as I would have liked | 7-point scale (1 'not at all' to 7 'very much') |
| | 13. Today I had enough time for myself | 7-point scale (1 'not at all' to 7 'very much') |
| | 14. Today I was in need of support | 7-point scale (1 'not at all' to 7 'very much') |
| | 15. Today I received enough support | |
| | Today, to what extent did your partner suffer from: | |
| | 16. Being sad or depressed | 7-point scale (1 'not at all' to 7 'very much') |
| | 17. Being anxious our nervous | 7-point scale (1 'not at all' to 7 'very much') |
| | 18. Acting impulsively or embarrassing | 7-point scale (1 'not at all' to 7 'very much') |
| | 19. A loss of interest in activities/other people | 7-point scale (1 'not at all' to 7 'very much') |
| | 20. Being irritated or impatient | 7-point scale (1 'not at all' to 7 'very much') |
| | 21. Being too cheerful for no reason | 7-point scale (1 'not at all' to 7 'very much') |
| | 22. Being restless | 7-point scale (1 'not at all' to 7 'very much') |
| | 23. Agitation/aggression | 7-point scale (1 'not at all' to 7 'very much') |
| | 24. Beliefs that you know are not true | 7-point scale (1 'not at all' to 7 'very much') |
| | 25. Seeing false visions or hearing false voices | 7-point scale (1 'not at all' to 7 'very much') |

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# 6

## Process evaluation of the experience sampling method intervention 'Partner in Sight' for spousal caregivers of people with dementia

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**ABSTRACT**

**Objectives:** This study describes the process evaluation of the experience sampling method (ESM) intervention 'Partner in Sight' for spousal caregivers of people with dementia. The aim was to determine internal and external validity of the intervention and provide information for future implementation in clinical practice.

**Methods:** Qualitative and quantitative data on sampling quality (recruitment and randomization, reach) and intervention quality (relevance and feasibility, adherence to protocol) were evaluated using descriptive statistics and conventional content analysis.

**Results:** The participation rate included 31.4%. Due to recruitment difficulties and time constraints the original goal to include 90 caregivers was not met. The intervention was largely performed according to protocol and well received by the participants. Overall, the ESM-derived feedback was considered supportive and increased participants' awareness of their feelings and behavior. A large variance was found in the extent to which caregivers applied the feedback into their daily lives. The importance of the personal coach to provide face-to-face feedback and stimulate caregivers to implement new insights into their daily lives was emphasized. Suggestions for improvement were to reduce the time intensity of the program, to better tailor the program content to one's personal situation, and to improve the ESM device.

**Conclusions:** Although recruitment barriers were encountered, results indicate that future implementation of the ESM intervention 'Partner in Sight' is likely to be feasible in regular health care. If the intervention turns out to be (cost-) effective, a fine-tuned version of the program could be a valuable addition to the current health care system.

## INTRODUCTION

The prevalence of people with dementia is increasing rapidly as a consequence of the global ageing of the population. Dementia is associated with intense need for care and has a huge economic and societal impact[1]. The current labor force will not be capable of dealing with such an increased future demand. Therefore, the care for persons with dementia (PwD) will depend increasingly on informal caregivers in the upcoming years. Caring for a PwD puts one at risk of becoming overburdened and of developing psychological and physical symptoms[2]. Yet, caregivers differ in their emotional response when dealing with daily challenges of dementia. Caregiver resources, such as sense of competence and mastery, play an important role in reducing caregivers' emotional reactivity to daily life stressors (Chapter 4)[3]. Moreover, positive emotions have been found to positively impact feelings of competence to care for the PwD (Chapter 3)[4]. Existing psychosocial interventions mostly focus on the negative consequences of the caregiving process and do not account for individual differences among caregivers[5]. Therefore, the experience sampling method (ESM) intervention 'Partner in Sight' for spousal caregivers of people with dementia was developed, aimed at empowerment of positive caregiver experiences, and tailored to the individual caregiver. To evaluate the effectiveness of the intervention with respect to caregiver sense of competence, mastery, momentary positive and negative affect, and psychological complaints, a randomized controlled trial (RCT) was performed.

While RCTs are considered as the 'gold standard' to study the effectiveness of interventions on prespecified outcomes, in-depth information on the internal and external validity of the intervention is essential for the interpretation and generalizability of the results[6]. A process evaluation can be used to explore the context, implementation, and receipt of an intervention. Key elements of a process evaluation are the evaluation of sampling quality (recruitment of participants and reach) and intervention quality (the extent to which the intervention was performed and perceived)[6]. Process data not only help to understand possible intervention effects, but also provide necessary information for replication studies and implementation of the intervention in health practice[7].

Several frameworks for conducting a process evaluation have been proposed, covering numerous elements that can be used for different aims[6]. In this study we apply a previously used model[6] to evaluate process data about sampling and intervention quality of the experience sampling method intervention 'Partner in Sight' prior to the effect analyses.

## METHODS

### Study design

The process evaluation is a descriptive mixed methods study in which both quantitative and qualitative data were gathered alongside an RCT with three treatment arms[8]. As part of the RCT, participants were randomly assigned to the intervention group ('Partner in Sight': ESM data collection with feedback); pseudo-intervention group (ESM data collection without feedback); or control group (care as usual). The pseudo-intervention group was included to examine whether the feedback added any extra value to the collection of ESM data on its own. In the process evaluation we only focused on the participants who were allocated to the intervention group and followed the program 'Partner in Sight'. Detailed information on the study design and the intervention are described in Chapter 5[8]. A brief description is presented below.

The Medical Ethics Committee of the Maastricht University Medical Center Plus approved this study (#143040).

### Intervention

The intervention program 'Partner in Sight' consists of ESM data collection for six consecutive weeks and three face-to-face sessions in which ESM-derived feedback is provided by a personal coach. The ESM is a repeated self-assessment approach to assess subjective experiences and context in the flow of daily life[9-11]. The 'PsyMate', a palmtop, was used to digitally collect momentary assessments and to provide visualized feedback on daily life situations that elicit positive emotions[12]. The feasibility of the 'PsyMate' in caregivers of PwD has recently been demonstrated[13]. During the six-week intervention period, the 'PsyMate' was programmed to generate ten alerts (sound and vibration) per day for three consecutive days per week (6x10x3 = 180 beeps in total). Alerts were emitted at random intervals between 7:30 AM and 10:30 PM. After each alert, participants were asked to digitally complete a brief questionnaire on the screen of the 'PsyMate', including current mood (e.g. positive and negative affect) as well as current context (e.g. social company, activities, location, and important events). Every two weeks participants received ESM-derived feedback from a personal coach (psychologist) according to a standardized protocol. Feedback was provided both graphically and verbally and contained information on experienced levels of positive affect and their relationship with daily activities and social interactions in daily life. Participants were encouraged to implement new insights into their daily lives. Before the start of the study, all coaches received training with detailed instructions on how to provide the feedback.

## Process data

Process data were evaluated prior to the effect analyses. Data on sampling and intervention quality should be evaluated at an early stage to further fine-tune the effect analyses and to provide essential information about credibility and generalizability of the results[6]. Table 1 shows how the components sampling quality (recruitment and randomization, barriers and facilitators for recruitment, and reach) and intervention quality (relevance and feasibility, and adherence to protocol) were operationalized and measured in the current process evaluation.

The sampling quality was based on information recorded digitally by the researchers throughout the intervention period (Da). Information on barriers and facilitators for recruitment was provided by clinicians and dementia case managers during the recruitment process and stored digitally by the researchers (Da).

The intervention quality was based on data collected from the participants in the intervention group who completed the intervention (N=20). Information on the relevance and feasibility of the intervention was collected during the last intervention contact through a questionnaire (Qli) and a semi-structured interview, conducted by the personal coach (Ili). General experiences with the ESM were gathered from a questionnaire completed by the participants and discussed with their coach, during each intervention contact (Qi). In addition, user experience with the 'PsyMate' was evaluated by means of a questionnaire during the post-intervention assessment (Qp). Multiple-choice items in the self-administered questionnaires were rated on 7-point Likert scales (1 = 'not at all' to 7 = 'very much'). Answers to open-ended questions and the semi-structured interview were categorized in order to identify relevant themes. Compliance with the 'PsyMate' was recorded electronically during the intervention period. Finally, protocol deviations with respect to total duration of the intervention, frequency and duration of the feedback sessions, and structure of the feedback sessions, were registered to evaluate adherence to protocol.

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**Table 1.** Components and subcomponents of process evaluation and ways of measurement

| Components and subcomponents | Operationalization | Measurement | | | | |
|---|---|---|---|---|---|---|
| | | Da | Qi | Qli | Qp | Ili |
| *Sampling quality* | | | | | | |
| - Recruitment and randomization | Number of caregivers approached | X | | | | |
| | Number of caregivers randomized | X | | | | |
| | Reasons for refusal | X | | | | |
| - Barriers and facilitators for recruitment | Information from clinicians/ dementia case managers regarding recruitment procedure | X | | | | |
| - Reach | Number of caregivers from different institutions | X | | | | |
| *Intervention quality* | | | | | | |
| - Relevance and feasibility | Experiences with intervention (program content, program structure, advantages for participants) | | | | X | X |
| | Experiences with ESM in general (ESM device, ESM content, ESM structure) | | | X | | X |
| - Performance according to protocol | Total duration of intervention | X | | | | |
| | Reasons for variance in intervention period | X | | | | |
| | Duration and structure of feedback sessions | X | | | | |
| | Compliance | X | | | | |

Da = Data recorded by researchers during intervention period, Qi = Questionnaire completed by participant per intervention contact, Qli = Questionnaire completed by participant during last intervention contact, Qp = Questionnaire completed by participant during post-intervention assessment, Ili = semi-structured interview conducted by coach during last intervention contact

## Data analysis

Quantitative data were analyzed by means of descriptive statistics (STATA version 12.1). Qualitative data were analyzed with a conventional content analysis, in which an open coding approach was applied to attain a codebook with categories derived from the data at hand without preconceived categories[14]. The emerging categories were merged into relevant themes by the authors RvK and CS. Three themes were identified with respect to the intervention 'Partner in Sight' (program content, program structure, advantages for participants) and three themes were identified with respect to the ESM procedure in general (ESM device, ESM content, ESM structure).

## RESULTS

### Sampling quality

*Recruitment and randomization*
Informal caregivers (N=295) were recruited from memory clinics (Maastricht University Medical Center+, Zuyderland Medical Center), ambulatory mental health care institutions (Virenze-RIAGG Maastricht, Lionarons GGZ), dementia day care centers (Sevagram, NOVIzorg, Orbis Glana, Proteion, care farm Ransdalerveld), caregiver support services in the southern Netherlands, and via dementia case managers ('Hulp bij Dementie') and the Dutch Alzheimer Association. Of the 295 caregivers, 242 met the in- and exclusion criteria and were eligible to participate. If interested, caregivers (N=172) received a detailed information letter. Informed consent (IC) was signed by 44.1% (76/172). Reasons for declining to receive the information letter or to sign the IC after more detailed information were: no need for support (N=57), intervention considered as too burdensome (N=53), too time-consuming (N=24) or too confronting (N=5), worries that the intervention will cause agitation or suspicion in the care recipient (N=10), feeling unfamiliar with technological devices (N=9), care recipient almost institutionalized (N=6), or restrictions to participate due to hearing loss (N=2). The overall participation rate of eligible caregivers was 31.4% (76/242). The original aim to enroll a total of 90 participants was not accomplished due to recruitment difficulties and time constraints.

After the baseline assessment, 76 caregivers were randomly assigned to the intervention ('Partner in Sight': ESM including feedback) (N=26), pseudo-intervention (ESM without feedback) (N=24), or control group (N=26). Allocation to the three groups was conducted by a researcher (RvK) who was not involved in the assessments. Research assistants blinded to allocation performed the assessments and recorded success of blinding. In total, 84.2% of the caregivers (N=64) completed the post-intervention assessment. The number of dropouts included 6 in the intervention group, 4 in the pseudo-intervention group, and 2 in the control group. Blinding of the researchers for group allocation was intact for 37.5% (24/64), unsuccessful for 14.1% (9/64), and for 48.4% (31/64) a conjecture of allocation was reported.

*Barriers and facilitators for recruitment*
Clinicians and dementia case managers involved in the recruitment of participants frequently mentioned that their caseload comprised lots of people with dementia that were living alone without a registered partner. Other recruitment barriers included concerns that the intervention would be too time-consuming and burdensome for caregivers in the moderate to severe stages of dementia, worries that the technical ESM device would be too difficult for older caregivers, and involvement in other caregiver support interventions. Clinicians and

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dementia case managers reported that a mild stage of dementia severity in the care recipient and familiarity with technological devices were facilitators for program recruitment.

*Reach*

Caregivers were approached to participate by the clinician who treated their partner with dementia (N=120), their dementia case manager (N=104), their care counselor (N=8), or by the day care center of their partner (N=41). Others were informed about the intervention by the Dutch Alzheimer Association (N=8); requested information based on editorials in local newspapers, information brochures, or information stands in the southern Netherlands (N=10); or knew caregivers who already participated in the intervention (N=4). The Dutch Alzheimer Association promoted the intervention program via (1) Alzheimer Cafés for people with dementia and their caregivers, (2) a digital newsletter, and (3) their website.

**Intervention quality**

*Relevance and feasibility*

*Experience sampling method intervention*
*Program content.* Overall, participants were satisfied with the content of the feedback sessions and indicated on a 7-point Likert scale that the feedback was easy to understand (M = 6.5, SD = 0.8). They appreciated getting the feedback in the form of pie charts and graphs (M = 6.6, SD = 1.0) and found it easy to understand the information in the graphs (M = 6.1, SD = 1.4). Most participants indicated that the amount of feedback was sufficient (M = 6.1, SD = 1.070, but some suggested to add information on problem behavior of the care recipient, and to elaborate more on time spent on different care tasks:

> *"Caregiving entails so many different aspects – next to assistance in activities of daily living, I spend a lot of my time on supervision and providing emotional support to my partner [person with dementia]. It could be valuable to differentiate between these different levels of care during the feedback sessions." [P174]*

Participants did not feel like they needed more specific advice following the feedback that was given (M = 2.8, SD = 2.4). One participant, however, stressed that he would have preferred to receive more practical advice to help him applying the suggestions from the feedback in daily life.

*Program structure.* The program structure of blending ESM data collection with face-to-face contacts with a personal coach was experienced positively. Participants appreciated that the personal coach was available to explain and discuss the feedback and indicated that the coach was able to answer their questions well (M = 6.6, SD = 0.8).

> *"She [coach] made me feel at ease and encouraged me to talk about my feelings. A digital coach would have depersonalized the program." [P113]*

Moreover, the written summary of the feedback provided by the coach at the end of each session, was seen as a useful addition (M = 6.5, SD = 0.8) and was considered to be easy to understand (M = 6.8, SD = 0.6).

Participants reported that the duration of contact for the feedback sessions was suitable (M = 6.5, SD = 0.5). Overall, the frequency of the sessions was considered to be sufficient. Two participants suggested including weekly sessions in the program instead of one session every two weeks, and two participants would have preferred fewer sessions. The overall duration of the intervention (six weeks) was considered to be rather long. When being asked if participants would have preferred to prolong the program, only two out of twenty confirmed. Proper information about the total time investment before the start of the program was emphasized to be essential. Lastly, participants appreciated the possibility to situate the sessions in their own homes.

*Advantages for participants.* The feedback was considered supportive and increased awareness of both positive and negative feelings and behavior. Participants reported to gain more insight into their own situation and felt stimulated by the coach to talk about it.

> *"The situation with my partner [person with dementia] always felt 'normal' to me. I never really took the time for self-reflection. The feedback was like a mirror and wake-up call to me." [P138]*

Some participants mentioned that the feedback was not new to them, but a confirmation and acknowledgement of their feelings.

> *"I have always tried to continue spending time on relaxation next to my care task. The feedback gave me more insight into my daily activity pattern and confirmed that my life is perfectly balanced at the moment." [P129]*

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Participants differed with respect to the extent to which they tried to apply the suggestions from the feedback in their daily lives (M = 4.6, SD = 2.3). Some felt that the feedback was not applicable to their personal situation, as they already believed to be sufficiently aware of their daily functioning. Others indicated that the intervention would be more relevant in the future, since they did not experience any difficulties in the caretaking process yet.

*Experience sampling method in general*
*Experience sampling method device.* Participants indicated the 'PsyMate' to be user-friendly and easy to operate (M = 6.9, SD = 0.2). They were satisfied with the instructions provided verbally by the research assistant (M = 6.2, SD = 1.7) and in written by means of a leaflet (M = 6.7, SD = 0.6). In general, participants reported that they were able to hear the alerts (M = 5.9, SD = 1.5) and read the text on the screen clearly (M = 6.1, SD = 1.2). However, participants with hearing or vision loss experienced difficulties due to a too weak alert sound and vibration, or too small letters on the screen of the device. Problems particularly arose when being in a noisy environment or outside in bright sunlight. In total, 9 participants experienced technical issues with the 'PsyMate' due to software problems (N=7), an empty battery (N=1), or a defective touchscreen (N=1).

*Experience sampling method content.* A few items in the ESM questionnaire were mentioned to be difficult or unclear with respect to content or phrasing. In addition, some participants were struggling with the classification of their answers into one of the response categories. However, most indicated to experience few difficulties during completion of the items (M = 2.4, SD = 1.6). Generally, participants felt able to accurately describe their feelings and experiences in the ESM questionnaire (M = 5.4, SD = 1.1). Yet, reflecting on their emotions and expressing them quantitatively was considered to be challenging. Participants often mentioned that they would have preferred to explain their answers in more detail.

> *"I find it rather difficult to rate on a scale whether I feel down or not. The situation with my husband [person with dementia] makes me feel sad. However, it is like I got used to these negative feelings." [P127]*

Participants reported having made several mistakes while completing the ESM questionnaire (M = 3.2 SD = 1.2), which was primarily due to the change in positively and negatively formulated items, answering items too rapidly, or being distracted by other activities (e.g. care task, shopping, driving, social interactions).

*"I regularly gave the wrong answer when I got distracted by my partner [person with dementia] who kept asking questions. I missed an option in the 'PsyMate' to correct my answers afterwards." [P132]*

The content of the ESM questionnaire was considered to be rather negative. Some participants could not identify themselves with items such as 'I feel desperate' and 'I am ashamed of myself'. They also mentioned that certain items (e.g. 'I am in pain' and 'I have problems in walking') were not applicable to them. It was suggested to adjust the ESM questionnaire conform the positive focus of the feedback sessions and to tailor it to one's personal situation.

*Experience sampling method structure.* In general, participants did not experience the ESM procedure as too aggravating or stressful with respect to the number of alerts per day (M = 1.9, SD = 1.3), the time it took to answer the questions for a single alert (M = 2.1, SD = 1.8), and the sound volume of the alert (M = 1.8, SD = 1.5), nor did they feel that the ESM interfered with their daily lives. Participants reported the ESM to affect their mood (M = 2.2, SD = 1.6), activities (M = 2.1 SD = 1.5), and contact with other people (M = 1.8, SD = 1.5) to a minimum extent. Both positive and negative influences were mentioned.

*"Carrying the 'PsyMate' with me all the time makes me feel better. It feels like a buddy that is always there for me." [P130]*

*"In the beginning I found it rather confronting to answer all these questions repeatedly. It forced me to dig into my own feelings." [P140]*

Moreover, it was mentioned that the repeated assessments increased self-awareness in some participants.

*"The diary made me realize that I spend most of my time at home. Now I see that I became more isolated due to the situation with my wife [person with dementia]." [P152]*

*"At times of the alert I noticed that I was often in company of friends or family. I became more aware of the good social network we have and of the importance to maintain it." [P154]*

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However, some participants indicated to get annoyed by the repeated nature of the ESM in which the same questions were asked persistently. The time between two succeeding alerts was perceived as too short and it was suggested to decrease the number of alerts per day.

> *"Answering the same questions over and over again made me feel bored and sometimes even irritated. Especially when two alerts followed each other so quickly, I had the feeling that I was giving the same answers twice." [P168]*

*Adherence to protocol*

Intervention adherence to protocol contained: ESM data collection for six weeks, three face-to-face feedback sessions (session 1: 30 minutes; session 2 & 3: 45 minutes), and a written summary of the feedback after each session.

In total, 76.9% of the participants allocated to the intervention group completed the intervention (20/26). Five dropped out after completing the baseline assessment and before the actual start of the intervention. Reasons for withdrawal were health problems (N=1), institutionalization of the care recipient (N=1), difficulties with the ESM device due to vision loss (N=1), and considering the intervention as too time-intensive (N=2). One participant dropped out during the third feedback session due to institutionalization of the care recipient.

Total intervention time ranged from six to eight weeks (M = 6.5, SD = 0.7). Deviations in intervention time were reported for eight participants: one week longer for six participants and twee weeks longer for two participants. Reasons for intervention period variance were: busy schedules, holidays, and technical problems with the 'PsyMate'. The duration of each feedback session varied from 45 to 150 minutes (M = 89.1, SD = 23.1). All feedback sessions, except for one, lasted longer than initially planned in the study protocol. The average duration of session 1, 2, and 3 were respectively 95 minutes (SD = 21.8, range: 60-135), 81 minutes (SD = 22.9, range: 45-120, and 92 minutes (SD = 23.2, range: 60-150). Coaches reported adherence to protocol during all sessions with respect to the structure of the feedback sessions and the delivery of a written summary of the feedback after each session.

Compliance during the ESM data collection was high, with an average response rate of 74.9% (2695/3600) to the alerts. During the course of the intervention no fatigue effect was present according to response rates examined after two weeks (73.5%; 882/1200), four weeks (72.9%; 875/1200), and six weeks (78.2%; 938/1200). Reasons for missing alerts were: not having heard the alert, not having been able to read the text when being outside, having forgotten the 'PsyMate' at home, and inconvenient circumstances (e.g. car driving, church visits, funerals, swimming, sleeping, sports, care task).

## DISCUSSION

This study reveals process data about sampling and intervention quality of the ESM intervention 'Partner in Sight' for spousal caregivers of people with dementia.

### Sampling quality

Data on sampling quality showed an overall participation rate of 31.4% (76/242). Since many participants refused to participate, the inclusion rate was lower than expected and the original goal to include 90 participants was not met. In general, response rates in caregiver studies vary widely as selection criteria, recruitment methods, and the content of research projects differ between studies[15]. To the best of our knowledge, this is the first ESM intervention for caregivers of people with dementia and cross study comparisons are, therefore, not possible. A recent study in which a comparable ESM intervention was provided to persons with depression also reported recruitment difficulties (only 102 instead of 120 participants were included)[16]. As a consequence of the smaller sample size, statistical power might be too low to establish significant effect size differences between groups in the effect analyses.

Main recruitment barriers in our study included no need for additional support and considering the intervention as too time-consuming or burdensome. Previous research has indicated that informal caregivers may struggle with a stigma associated with the term dementia, which could make them refuse to participate in research that places emphasis on the care recipient's diagnosis[17]. Furthermore, advanced age, research skepticism, and the perception that the intervention will lack direct personal benefit, may have influenced decisions about study participation[18]. Finally, the intrusive nature of the ESM could have withheld caregivers from participating in the study. Especially caregivers who spent a lot of time on caregiving, or who experience high levels of burden, might have been more inclined to reject study participation[19]. Also, a bias in recruitment is highly likely, because clinicians and case managers had a substantial impact on who was recruited. This might challenge the external validity of the study results, since it negatively impacts the generalizability of the results[20,21]. Future analyses on the sample characteristics in the effect study are important to reveal whether our sample was representative of the general caregiver population.

At post-intervention assessment (N=64), blinding of the researchers for group allocation was intact for only 37.5% (24/64) of the participants. Blinding is an important safeguard against bias, particularly when assessing subjective outcomes[22]. However, blinding in psychosocial research is challenging and maintenance of blinding has seldom been described[23]. The complexity of our study design, including alternate visits from either the coach or researcher, hindered complete masking from group allocation.

**Intervention quality**

Overall, participants considered the intervention program 'Partner in Sight' acceptable and feasible. Participants were satisfied with the respect to the content and structure of the program. The ESM-derived feedback was considered supportive and increased participants' awareness of their feelings and behavior. However, there was a large variance in the extent to which participants tried to apply the feedback into their daily lives. The feedback was not always considered to be applicable to one's personal situation, as participants were already sufficiently aware of their daily functioning or did not experience any difficulties in the caregiving process yet. Participants emphasized the importance of the personal coach in providing face-to-face feedback and encouraging them to implement new insights into their daily lives. This finding is supported by a systematic review on internet-based interventions, in which guidance by a personal coach has proven to be a noteworthy extension to online interventions for informal dementia caregivers[24]. Exchanges with a coach might increase commitment to the intervention and boost confidence to implement the provided feedback into one's daily life[25]. Participant compliance to the intervention was high (76.9%), which could be explained by the motivational aspect of having a coach[26]. However, participants indicated the overall duration of the program (six weeks) to be rather long. Although the ESM data collection was not considered to be overly burdensome and the average response rate to the alerts was high (74.4%), it was suggested to decrease the number of alerts per day. A study from Stone et al. [27] demonstrated that perceived burden reduced by choosing a less intensive sampling density. Lowering the time-investment might facilitate recruitment and future implementation of the intervention in clinical practice. Other suggestions for improvement of the program were to tailor the ESM questionnaire more to one's personal situation and to formulate items in a more positive rather than negative way to create a better link with the positive focus of the feedback sessions. Moreover, it was recommended to improve readability and audibility of the ESM device in order to be easier to use for elderly persons.

Considering the intervention adherence to protocol, results showed that the protocol was largely followed. Variances in total intervention time were reported and may influence the effectiveness of the intervention[28]. However, reasons for protocol deviations were not uncommon for informal caregivers (e.g. time constraints) and for ESM studies in general (e.g. technical problems). Furthermore, feedback sessions lasted considerably longer than initially planned in the study protocol. Given that more face-to-face contact with a personal coach might benefit caregivers, the longer duration of the sessions may influence the results and should be taken into consideration in the effect analyses.

**Strengths and weaknesses**

To our knowledge, no other study has reported process evaluation outcomes of an ESM intervention for caregivers of people with dementia. The application of the ESM in the field of dementia care is still in its infancy[13]. Our study, therefore, provides valuable information for future implementation of the ESM as a supportive tool in clinical practice. However, several limitations of this study need to be considered. First, protocol deviations were mainly measured based on data directly collected from the coaches who were responsible for delivering the intervention. No measurements were available to examine adherence to protocol more objectively, for example through independent observations. Previous research has shown large discrepancies between self-report measures and ratings based on tape-recordings, indicating that professionals might not always be aware of their treatment fidelity[29]. Second, participants' satisfaction with the program was measured by the coach during the last intervention visit. Therefore, participants may have given socially desirable answers and might not have had enough time to reflect on the relevance and feasibility of the intervention. A follow-up measurement on participants' satisfaction with the program would have been useful to examine whether they actually implemented the feedback into their daily lives. At last, intervention quality was only determined from the perspective of participants in the intervention group. Process data on relevance of the pseudo-intervention (i.e. ESM data collection and three face-to-face sessions with a coach without receiving ESM-derived feedback) would have been useful to evaluate the extent to which the collection of ESM data in itself increased self-awareness and elicited behavioral changes. In the intervention group some participants also mentioned that the repeated assessments led them to pay more attention to their internal states and behavior. The effect analyses may provide more insight into the potential benefits of ESM data collection in itself and the added value of the ESM-derived feedback.

**Conclusion**

The ESM intervention 'Partner in Sight' was generally well performed and received by spousal caregivers of people with dementia. Overall, participants were satisfied with the program and considered it to be supportive. Suggestions for improvement were provided to reduce the time intensity of the program and to better tailor the program content to one's personal situation. Although recruitment barriers were encountered, results indicate that future implementation of ESM interventions is likely to be feasible in regular health care for caregivers of people with dementia. If the ESM intervention 'Partner in Sight' proves to be (cost-) effective, it could be a valuable addition to the current health care system.

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# 7

Effectiveness of the experience sampling method intervention 'Partner in Sight' for spousal caregivers of people with dementia: results of a randomized controlled trial

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**ABSTRACT**

**Objectives**: There is a call for interventions that effectively support caregivers of people with dementia in daily life. Ecological momentary interventions integrated with real-life assessments using the experience sampling method (ESM) could be promising to tailor interventions more toward the specific needs of the caregiver and toward those moments when support is most needed. The current study evaluates the effectiveness of the ESM intervention 'Partner in Sight' for dementia caregivers.

**Methods**: A randomized controlled trial with 76 spousal caregivers of community-dwelling people with dementia was performed. Participants were randomly assigned to the experimental group (six-week intervention 'Partner in Sight' consisting of ESM self-monitoring and personalized feedback), pseudo-experimental group (six-week pseudo-intervention consisting of ESM self-monitoring without feedback), or control group (usual care). Effects were evaluated pre- and post-intervention, and at two-months follow-up using retrospective measures of caregiver sense of competence, mastery, and psychological complaints (depression, anxiety, and perceived stress). Complementary, ESM measures of positive and negative affect were collected pre- and post-intervention.

**Results**: Both the experimental and pseudo-experimental group showed a significant increase in retrospectively measured sense of competence and a decrease in retrospectively measured perceived stress at two-months follow-up. Immediately after the intervention the experimental group showed a decrease in momentary negative affect compared to the pseudo-experimental and control group. No effects were found for retrospective mastery, depression, and anxiety, and for momentary positive affect.

**Conclusions**: ESM interventions could be an important asset to increase caregiver resources that could help to better adapt and manage difficult situations, and to protect caregivers against negative emotions.

## INTRODUCTION

Providing care to a family member with dementia can have a substantial impact on mental and physical health of the caregiver[1]. There is a need for interventions that effectively support caregivers in everyday life and help to prevent or delay institutionalization of the person with dementia (PwD). Existing psychosocial interventions, including psycho-education, emotional support, cognitive-behavioral therapies, and multi-component interventions have demonstrated positive effects on caregiver outcomes, but effects are in general small and the methodological quality of most studies is limited[2]. Recently, researchers have started to examine the effectiveness of technology-based interventions for caregivers using computers, personal digital assistants (PDAs), smartphones, and the Internet to provide support and information[3]. Rapid technological advances provide new opportunities to extend interventions beyond the clinical setting into people's everyday lives. These interventions, in which support is provided in real time and in the real world, are also referred to as ecological momentary interventions (EMIs)[4,5]. So far, EMIs have proven useful in the treatment of various patient groups, including persons with diabetes, asthma, and severe mental illness[5,6]. However, to the best of our knowledge, no study has yet investigated the potentials and the efficacy of EMIs for supporting caregivers of people with dementia.

There are several reasons to assume that EMIs could contribute to ongoing efforts to enhance the effectiveness of psychosocial interventions in the field of dementia care. An EMI approach, in which caregiver experiences and behavior are assessed repeatedly in real-time and within daily life, as based on the experience sampling method (ESM)[7,8], could provide both the caregiver and the clinician with detailed information on caregiver well-being. Monitoring caregiver functioning in real life might help clinicians to detect at what moments support is most needed[4] and could help to prevent high levels of burden in a later stage. Moreover, EMIs offer the opportunity to actively involve caregivers in their own empowering process[9]. Self-monitoring may promote awareness of adaptive and dysfunctional patterns of emotions and behavior, and may induce behavioral change accordingly[10]. For example, caregivers could learn to become more aware of and to engage more in behaviors that elicit positive emotions, such as relaxation and social activities. Positive emotions may enhance the ability to cope with stressful situations[11] and increase feelings of competence in caring for the PwD[12]. To ultimately induce behavioral change, personalized feedback based on self-monitoring reports and tailored to the specific needs of the caregiver could be provided as part of the intervention[13]. A recent randomized controlled trial (RCT) in persons with depressive disorder demonstrated that adding personalized feedback on positive affect experience resulted in more lasting effects compared to self-monitoring without feedback[14]. Based on this study and the results from a recently performed study on the feasibility of the ESM in caregivers of PwD

(Chapter 2), we developed the EMI program 'Partner in Sight' for spousal caregivers of PwDs and examined its effectiveness in an RCT with three arms: ESM self-monitoring including feedback, ESM self-monitoring without feedback, and care as usual. Effects were evaluated using retrospective measures of caregiver sense of competence, mastery and psychological symptoms (depression, anxiety, and stress). Complementary, ESM measures of positive and negative affect were collected pre- and post-intervention to capture changes in moment-to-moment fluctuations in emotional experiences, providing a more detailed rather than global view of caregiver functioning[8,15].

## METHODS

### Participants and design

From December 2014 to June 2016, informal caregivers of community dwelling people with dementia of all subtypes and stages were recruited from memory clinics and other relevant care institutes in the southern Netherlands, and via the digital newsletter and website of the Dutch Alzheimer Association. Participants were included if they were a spousal caregiver of a PwD, shared a household with the PwD, and provided written informed consent. Caregivers with insufficient cognitive abilities to engage in the ESM or who felt overburdened or had severe health problems as based on clinical judgment of a knowledgeable practitioner, were excluded from study participation.

A single-blinded RCT was conducted with three treatments arms. Following the baseline assessment, participants were randomly assigned to the experimental, pseudo-experimental, or control group. The experimental group participated in an ESM procedure (ESM self-monitoring for three days per week over a six-week period) and received standardized ESM-derived feedback on personalized patterns of positive affect every two weeks during a face-to-face session with a coach. The pseudo-experimental group also participated in the ESM procedure (ESM self-monitoring for three days per week over a six-week period), but without receiving feedback. The control group received usual care, consisting of non-frequent counseling.

Randomization was performed using a computerized sequence generator for block randomization with variable sizes of three, six, and nine. An independent research assistant who was blinded to treatment allocation conducted the assessments at baseline, post-intervention, and two-months follow-up.

The study was approved by the Medical Ethics Committee of the MUMC+ (#143040) and registered in the Dutch Trial Register (NTR4847). More detailed information on the study design is presented in Chapter 5[16].

## Procedure

The study protocol consisted of a telephone screening to check for study eligibility, a baseline assessment (T0), a six-week intervention period, a post-intervention assessment (T1), and a two-month follow-up assessment (T2).

### *Intervention*

The experimental group participated in the EMI program 'Partner in Sight', consisting of ESM data collection for 6 consecutive weeks and three face-to-face feedback sessions with a personal coach (psychologist). Feedback sessions immediately followed after every two weeks of ESM data collection. The feedback was provided both verbally and graphically according to a standardized protocol and presented levels of positive affect in the context of daily life activities (Figure 1a and 1b) and social situations. Additionally, the feedback showed changes in the level of positive affect over the course of the EMI (Figure 1c). A written copy of the feedback was provided to both the participant and the involved clinician after each session.

The pseudo-experimental group was similar in procedure to the experimental group, except that no ESM-derived feedback was provided during the intervention sessions. Alternatively, a semi-structured interview concerning participant's well-being during the previous two weeks was conducted to prevent any effects of different duration of the sessions.
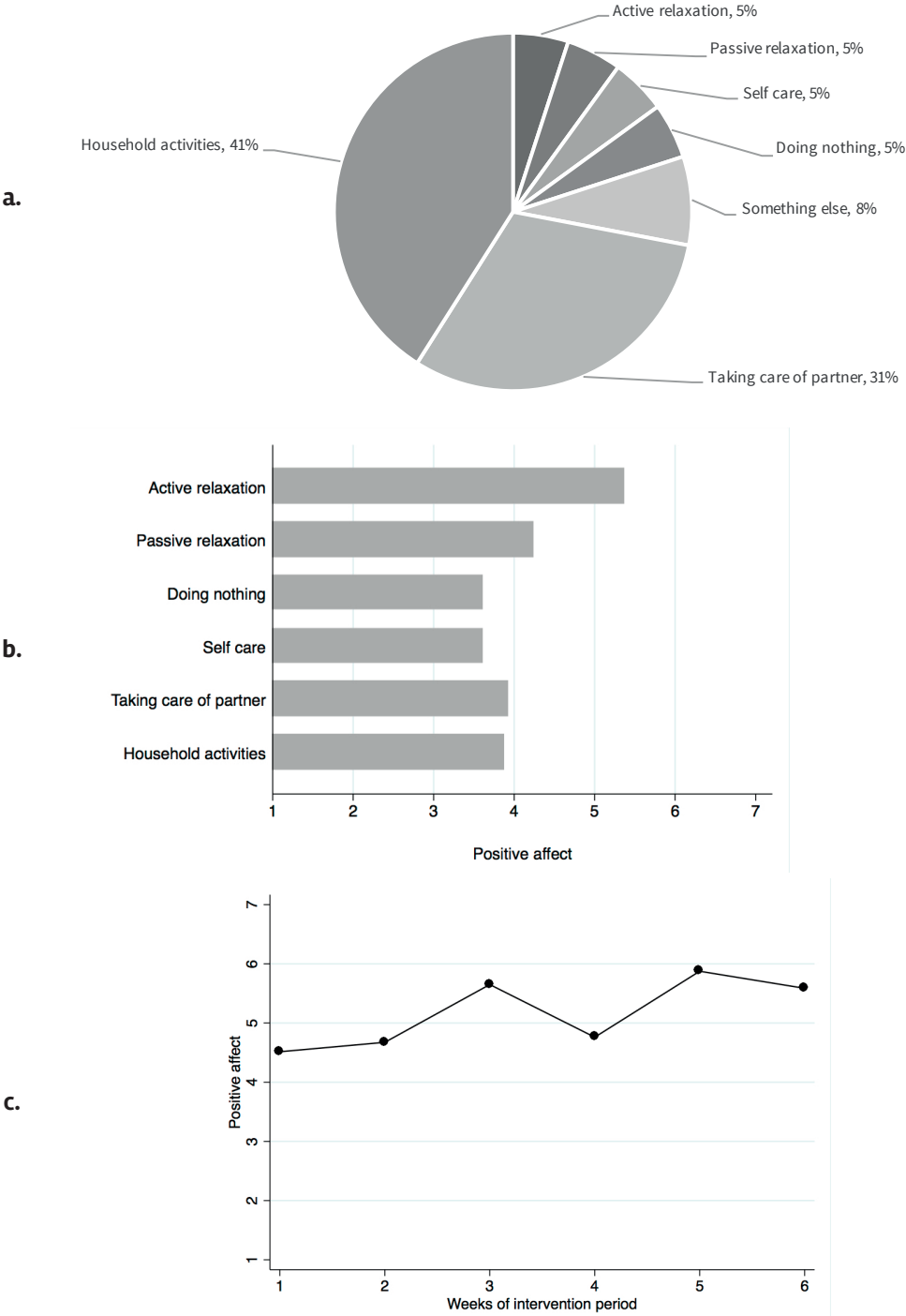
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**Figure 1.** Examples of ESM–derived feedback graphs. (a) Amount of time spent doing different types of activities, (b) Amount of positive affect experienced per type of activity, (c) Mean level of positive affect over the six–week intervention period.

*Experience sampling methodology (ESM)*

The ESM was carried out according to previous ESM studies[17,18]. The 'PsyMate', a palmtop, was used to digitally collect momentary assessments and to provide ESM-derived feedback[13]. The feasibility of the 'PsyMate' in caregivers of PwD has recently been demonstrated (Chapter 2)[19]. The 'PsyMate' was programmed to generate ten beeps (sound and vibration) per day at random intervals between 7:30 AM and 10:30 PM. At each beep, participants were asked to immediately complete a brief questionnaire on the screen of the 'PsyMate', including current mood (four positive affect items and seven negative affect items) as well as current context (e.g. social company, activities, location, and important events).

The ESM was used as an assessment tool during the baseline assessment (T0) and the post-intervention assessment (T1), and as an intervention tool throughout the six-week intervention period. During the three-day ESM baseline assessment and three-day ESM post-intervention assessment, ten beeps were generated per day (10 x 3 = 30 beeps in total for both the ESM baseline and post-intervention assessment). During the six-week intervention period, participants completed ten beeps per day for three consecutive days per week (10 x 3 x 6 = 180 beeps in total).

The ESM procedure was explained in a thirty-minute briefing during the baseline assessment and a demo questionnaire was presented to ensure that participants understood the questions and device. Participants' general experiences with the ESM procedure and the ESM-derived feedback were evaluated through a quantitative questionnaire and a semi-structured interview. These findings are described in Chapter 6[20].

**Instruments**

Primary outcomes were retrospective measures of caregiver sense of competence and mastery. Sense of competence was measured with the Short Sense of Competence Questionnaire (SSCQ) that consists of seven items and reflects caregivers' feelings of being capable to care for the PwD[21]. Total scores range from 7-35. Feelings of mastery were measured with the 7-item Pearlin Mastery Scale (PMS)[22]. Total scores range from 0-28. Secondary outcomes were retrospective measures of depressive symptoms, perceived stress, and anxiety symptoms. The 20-item Center for Epidemiological Studies Depression Scale (CES-D) was used to assess depressive symptoms[23]. Total scores range from 0-60. Perceived stress was measured with the 10-item Perceived Stress Scale (PSS), with total scores ranging from 0-40[24]. The 7-item anxiety subscale of the Hospital Anxiety and Depression Scale (HADS-A) was used to rate the severity of anxiety symptoms in caregivers[25]. Total scores range from 0-21.

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Caregiver and care recipient (socio-) demographics, including age, gender, education level, severity of dementia, caregiver hours of contact with and care for the PwD, and PwD hours spent in a dementia day care setting were obtained during the baseline assessment. The Clinical Dementia Rating Scale (CDR) was used to rate the severity of dementia on a 5-point scale from 0 'normal' to 3 'severe dementia'[26]. Additional retrospective measures on quality of the relationship, emotional instability, coping, and neuropsychiatric symptoms in the PwD were assessed to control for potential confounding effects. Quality of the relationship was measured with four items of the University of South Carolina Longitudinal Study of Three-Generation Families measures of positive affect[27]. The 12-item Neuroticism domain of the NEO Five-Factor Inventory (NEO-FFI) was used to assess emotional instability[28]. Total scores range from 0-24. The 44-item Utrecht Coping List (UCL) was used to measure seven different coping strategies, including seeking distraction, expressing emotions, seeking social support, avoiding, fostering reassuring thoughts, passive coping, and active coping[29]. Neuropsychiatric symptoms in the care recipient were evaluated with the Neuropsychiatric Inventory Questionnaire (NPI-Q)[30]. Total scores range from 0 to 36.

ESM measures of momentary positive and negative affect were assessed during a three-day ESM baseline assessment and three-day ESM post-intervention assessment. Positive affect was indexed by the mean score of the items 'I feel cheerful', 'I feel relaxed', 'I feel enthusiastic', and 'I feel satisfied' (Cronbach's $\alpha = 0.86$ for the mean-centered scores). Negative affect was defined by the mean score of the items 'I feel insecure', 'I feel lonely', 'I feel anxious', 'I feel irritated', 'I feel down', 'I feel desperate', and 'I feel tensed' (Cronbach's $\alpha = 0.80$ for the mean-centered scores). Responses were rated on 7-point Likert scales (ranging from 1 'not at all' to 7 'very much').

**Statistical analysis**
Statistical analyses were conducted using STATA 12.1 (StataCorp, College Station, TX). Before analysis, data were checked for missing values, outliers, and normality. Potential baseline differences between the three treatment arms were tested with t-tests for continuous variables and $\chi^2$-tests for categorical variables. Non-parametric tests were used in case of non-normality. Baseline characteristics were added as potential confounders in the analyses in case of significant group differences.

To examine the impact of treatment allocation on the course of retrospective measures of caregiver sense of competence, mastery, depressive symptoms, perceived stress, and anxiety symptoms, linear mixed models (LMM) for repeated measures were performed with treatment allocation (experimental, pseudo-experimental, control group) as a fixed between-subject factor, time (baseline, post-intervention, two-months follow-up) as a fixed within-

subject factor and their first-order interaction as additional fixed factor. The covariance was set to unstructured. Post-hoc analyses were performed to calculate estimated between-group effects. Bonferroni corrections were applied to correct for multiple testing. All tests of significance reported mean change and were two-tailed with $\alpha$ set at 0.05. The LMM allows use of all data without requiring imputation of missing data[31].

To examine changes in momentary measures of positive and negative affect between baseline and post-intervention assessment for each group, an LMM was performed separately for each outcome measure. LMMs account for the hierarchical structure of the ESM data in which multiple observations (beep level 1) are nested within days (day level 2) and days are nested within individuals (subject level 3)[32]. Treatment allocation (experimental, pseudo-experimental, control group), time (baseline, post-intervention), and their two-way interaction were entered as fixed factors in the model. Random intercepts and slopes, representing positive and negative affect, were added at the subject, day, and beep level. The covariance was set to unstructured.

## RESULTS

### Participants and descriptive statistics

A total of 295 caregivers were approached to participate in the study. After the screening procedure, 242 caregivers remained eligible to participate. In total 76 caregivers signed informed consent and were randomly assigned to the experimental group (N=26), pseudo-experimental group (N=26), or control group (N=24). Reasons for declining participation are described in Chapter 6[20]. Of the 76 randomized participants, 64 completed the post-intervention assessment and 61 completed the two-month follow-up assessment. Figure 2 presents the participant flow throughout the study.

The baseline characteristics of the included caregivers are shown in Table 1. There were no significant differences in socio-demographic characteristics, outcome measures, and additional measures between the groups. Therefore, none of these variables were included as potential confounders in the analyses.
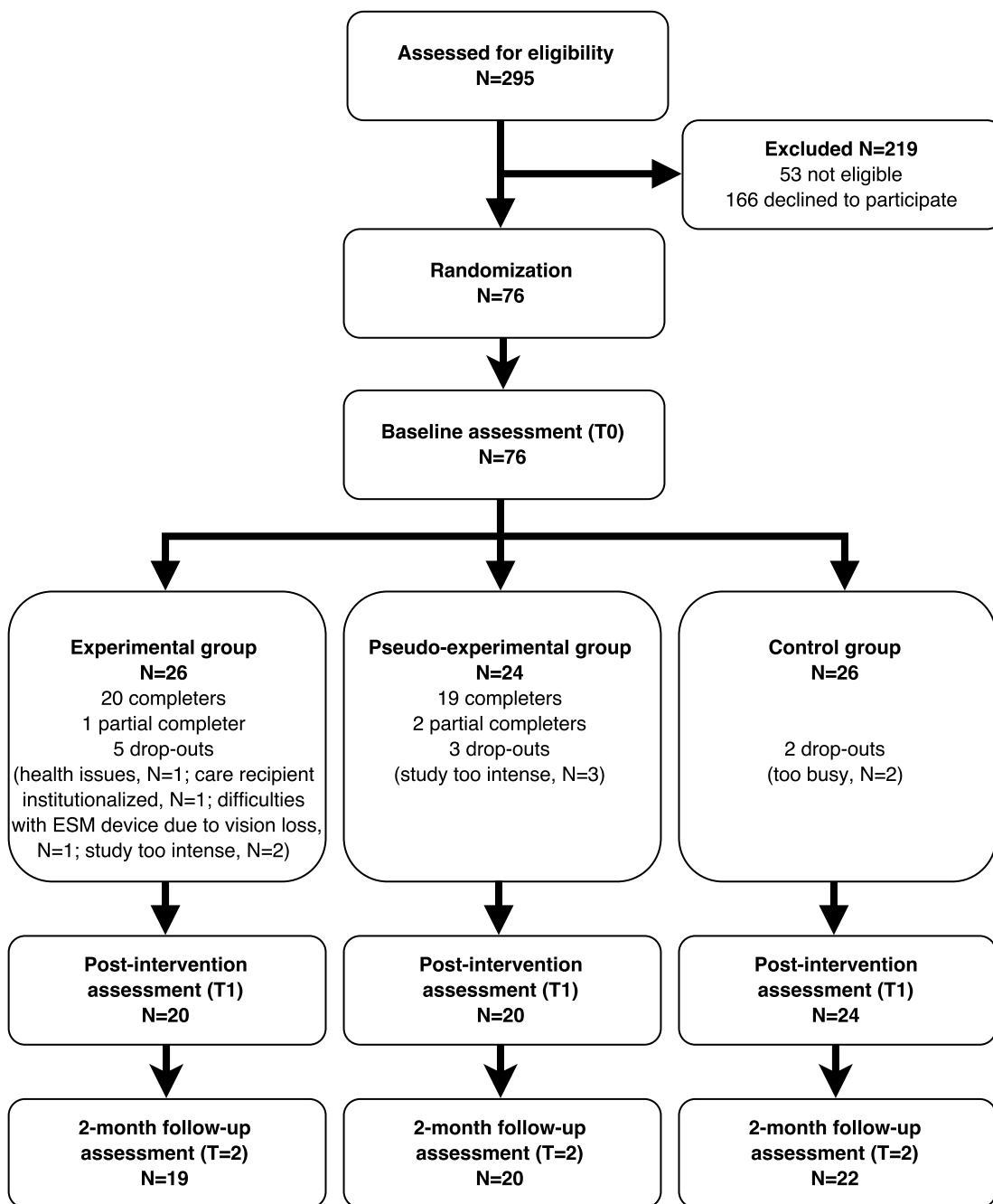
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**Figure 2.** Study flowchart

**Table 1.** Baseline characteristics of the study sample

| | Total (N=76) | Experimental (N=26) | Pseudo-experimental (N=24) | Controls (N=26) | Test value | df | P |
|---|---|---|---|---|---|---|---|
| **Socio-demographics** | | | | | | | |
| Age, mean±SD | 72.1±8.4 | 71.7±8.4 | 71.1±7.3 | 73.2±9.4 | F=0.42 | 2;73 | 0.662 |
| Gender, N (%) | | | | | $\chi^2$=1.08 | 2 | 0.583 |
| Male | 25 (32.9) | 10 (38.5) | 6 (25.0) | 9 (34.6) | | | |
| Female | 51 (67.1) | 16 (61.5) | 18 (75.0) | 17 (65.4) | | | |
| Education level, N (%) | | | | | $\chi^2$=1.76 | 4 | 0.779 |
| Low | 39 (51.3) | 13 (50.0) | 14 (58.3) | 12 (46.2) | | | |
| Middle | 15 (19.7) | 5 (19.2) | 3 (12.5) | 7 (26.9) | | | |
| High | 22 (28.9) | 8 (30.8) | 7 (29.2) | 7 (26.9) | | | |
| Hours of contact per week, mean±SD | 150.8±11.4 | 149.3±11.1 | 151.6±12.9 | 151.5±10.5 | F=0.31 | 2;73 | 0.737 |
| Hours of caring per week, mean±SD | 93.8±59.7 | 93.0±59.9 | 89.7±62.6 | 98.3±58.8 | F=0.13 | 2;73 | 0.878 |
| Care recipient severity of dementia, (CDR), N (%) | | | | | $\chi^2$=5.90 | 6 | 0.435 |
| 0.5 – very mild | 13 (17.3) | 4 (15.4) | 5 (21.7) | 4 (15.4) | | | |
| 1 - mild | 28 (37.3) | 9 (34.6) | 10 (43.5) | 9 (34.6) | | | |
| 2 - moderate | 25 (33.3) | 7 (26.9) | 7 (30.4) | 11 (42.3) | | | |
| 3 – severe | 9 (12.0) | 6 (23.1) | 1 (4.3) | 2 (7.7) | | | |
| Care recipient hours of dementia day care per week, mean±SD | 11.0±12.0 | 10.6±10.3 | 9.2±10.7 | 13.0±14.4 | F=0.66 | 2;73 | 0.518 |
| **Primary outcomes** | | | | | | | |
| Sense of competence (SSCQ), mean±SD | 25.2±5.2 | 26.1±4.8 | 24.8±5.4 | 24.7±5.5 | F=0.50 | 2;67 | 0.608 |
| Mastery (PMS), mean±SD | 16.7±5.7 | 17.2±6.8 | 15.8±5.1 | 16.9±5.1 | F=0.37 | 2;66 | 0.695 |

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**Table 1.** (continued)

| | Total (N=76) | Experimental (N=26) | Pseudo-experimental (N=24) | Controls (N=26) | Test value | df | P |
|---|---|---|---|---|---|---|---|
| **Secondary outcomes** | | | | | | | |
| Depressive symptoms (CES-D), mean±SD | 13.9±8.9 | 13.0±9.8 | 14.2±8.5 | 14.4±8.7 | F=0.17 | 2;67 | 0.845 |
| Perceived stress (PSS), mean±SD | 14.9±6.5 | 14.3±7.8 | 14.9±5.1 | 15.6±6.3 | F=0.25 | 2;67 | 0.782 |
| Anxiety symptoms (HADS-A), mean±SD | 6.5±4.0 | 5.9±4.2 | 6.5±3.9 | 7.0±4.1 | F=0.47 | 2;67 | 0.630 |
| **ESM outcomes** | | | | | | | |
| Positive affect | 4.7±1.1 | 4.6±1.1 | 4.8±1.2 | 4.7±1.1 | F=0.08 | 2;71 | 0.923 |
| Negative affect | 1.9±0.9 | 1.8±0.7 | 2.0±1.1 | 2.0±0.9 | F=0.25 | 2;71 | 0.777 |
| **Additional measures** | | | | | | | |
| Neuroticism (NEO-FFI), mean±SD | 16.9±8.6 | 16.0±9.5 | 17.1±7.8 | 17.6±8.6 | F=0.20 | 2;67 | 0.822 |
| Quality of the relationship, mean±SD | 10.9±2.3 | 11.1±2.5 | 11.0±1.9 | 10.7±2.6 | F=0.15 | 2;67 | 0.861 |
| Coping (UCL), mean±SD | | | | | | | |
| Active coping | 19.0±3.8 | 20.0±4.4 | 19.1±3.1 | 17.8±3.4 | F=2.18 | 2;67 | 0.121 |
| Passive coping | 11.0±3.1 | 11.0±3.2 | 11.3±3.4 | 10.9±2.9 | F=0.09 | 2;67 | 0.915 |
| Seeking distraction | 18.1±3.6 | 18.9±3.8 | 18.3±2.8 | 17.1±3.8 | F=1.55 | 2;67 | 0.220 |
| Expressing emotions | 6.0±1.3 | 6.1±1.4 | 6.1±1.2 | 5.8±1.4 | F=0.29 | 2;67 | 0.750 |
| Seeking social support | 12.9±3.2 | 13.7±3.5 | 13.2±3.0 | 12.0±3.0 | F=1.91 | 2;67 | 0.155 |
| Avoiding | 15.6±3.2 | 16.4±3.4 | 15.7±3.2 | 14.8±3.0 | F=1.58 | 2;67 | 0.214 |
| Fostering reassuring thoughts | 12.5±2.5 | 13.3±2.6 | 12.3±2.1 | 12.0±2.6 | F=2.02 | 2;67 | 0.141 |
| Neuropsychiatric symptoms in the care recipient (NPI-Q), mean±SD | 11.1±6.5 | 12.2±6.4 | 9.2±6.8 | 11.8±6.3 | F=1.37 | 2;66 | 0.261 |

CDR = Clinical Dementia Rating Scale, SSCQ = Short Sense of Competence Questionnaire, PMS = Pearlin Mastery Scale, CES-D = Center for Epidemiological Studies Depression Scale, PSS = Perceived Stress Scale, HADS-A = Hospital Anxiety and Depression Scale, NEO-FFI = NEO Five-Factor Inventory, UCL = Utrecht Coping List, NPI-Q = Neuropsychiatric Inventory Questionnaire.

## Compliance

Of the 50 participants allocated to the experimental or pseudo-experimental group, 39 (78.0%) fully completed the six-week intervention period, including 6 x 3 ESM assessment days and three corresponding face-to-face sessions. Compared to the completers (M=16.1), the non-completers took care for PwDs who were spending significantly more hours in a dementia day care setting (M=8.2) (t(48)=-2.34, p=0.02). Other baseline characteristics were similar between participants who fully completed the intervention period and those who did not. The average number of completed beep-questionnaires in these 39 participants was 137.4±20.2 out of 180, indicating a completion rate of 76.4%. There was no significant difference between the experimental versus the pseudo-experimental group in the mean number of completed beep-questionnaires over the entire intervention period (t(37)=0.54, p=0.59), or the number of participants who completed all three intervention sessions ($\chi^2(1)$=0.04, p=0.85). Feedback sessions lasted significantly longer (M=89.1±23.1 min, range=45-150 min) compared to the pseudo-experimental sessions (M=57.4±10.7 min, range=30-90 min) (t(115)=9.44, p>0.001).

## Primary outcomes

Multilevel regression analyses showed a significant overall interaction effect between treatment allocation and time on retrospectively measured sense of competence (F(4,62)=3.57, p=0.01), indicating that SSCQ scores differed between the three groups over the course of the study (Figure 3a). SSCQ scores differed between groups at two-months follow-up: both the experimental and the pseudo experimental group had significantly higher SSCQ scores compared to the control group (respectively B=4.35, 95%CI [1.97, 6.73], p=0.001, and B=2.71, 95%CI [0.34, 5.09], p=0.026). SSCQ scores of the experimental and pseudo-experimental group were not different at two-months follow-up (B=1.63, 95%CI [-0.82, 4.09], p=0.188). The overall interaction effect between treatment allocation and time on retrospective feelings of mastery was non-significant (F(4,62)=0.94, p=0.446), indicating that there were no significant differences in PMS scores between the three groups over the course of the study.

## Secondary outcomes

With respect to the secondary outcomes, results yielded a significant overall interaction effect on retrospectively measured perceived stress (F(4,61)=3.35, p=0.015), indicating that PSS scores differed between the three groups over the course of the study (Figure 3b). Between-group comparisons demonstrated that the difference in PSS scores became significant at post-intervention between the pseudo-experimental and control group (B=-3.93, 95%CI [-7.23, -0.63], p=0.020). At two-months follow-up both the pseudo-experimental and experimental group displayed significantly lower perceived stress compared to the control group (respectively B=-4.72, 95%CI [-7.86, -1.58], p=0.004 and B=-4.65, 95%CI [-7.80, -1.50], p=0.004). There was no significant difference in PSS scores between the experimental

and pseudo-experimental group (B=0.07, 95%CI [-3.18, 3.32], p=0.967). The overall interaction effect between treatment allocation and time on retrospectively measured symptoms of anxiety was non-significant (F(4,59)=1.46, p=0.226).
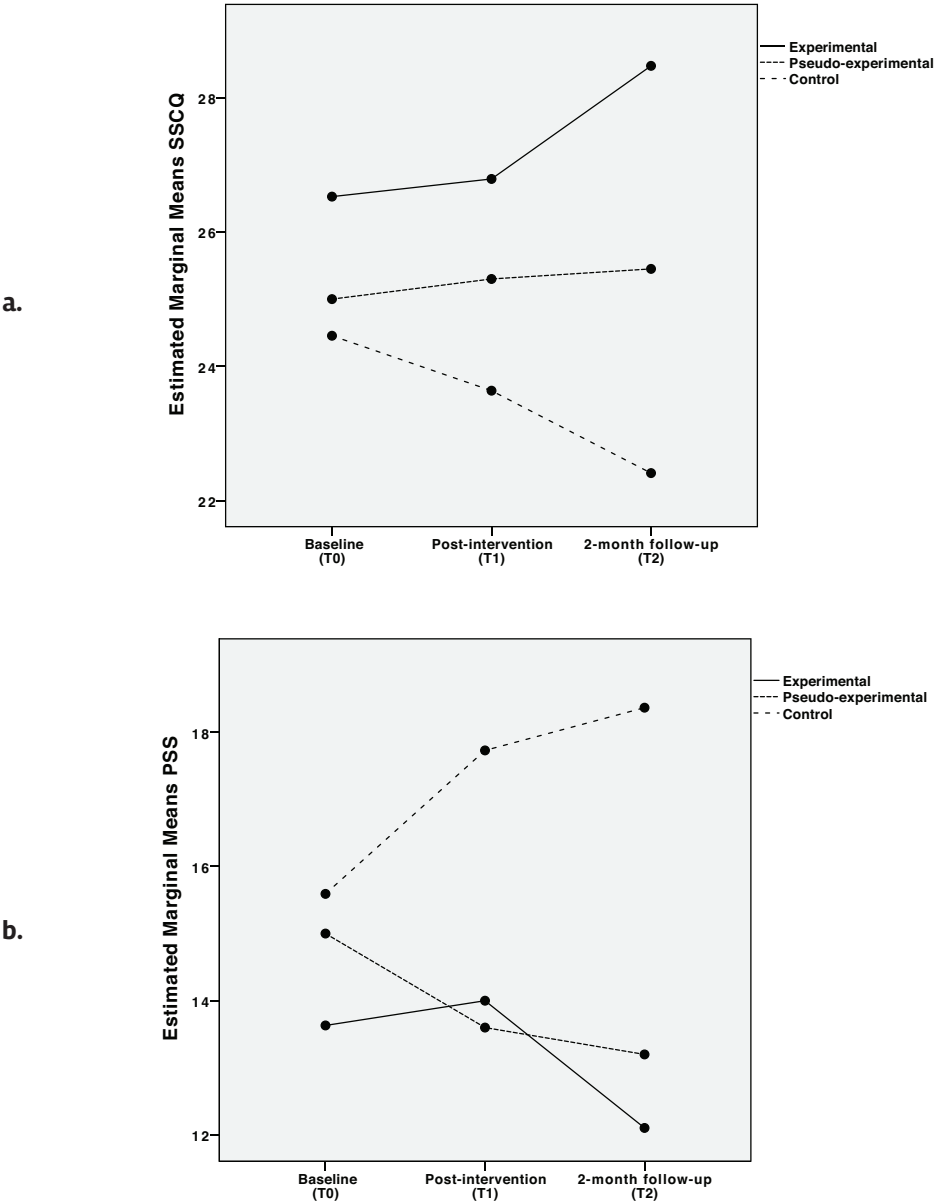
**a.**

**b.**

**Figure 3.** Mean sense of competence and perceived stress scores over time. (a) Short Sense of Competence Questionnaire (SSCQ), (b) Perceived Stress Scale (PSS).

**ESM outcomes**

With regard to the ESM outcomes, results of the multilevel regression analyses showed a significant overall interaction effect between treatment allocation and time on momentary negative affect ($\chi^2(2) = 14.69$, p<0.001), indicating that negative affect scores differed between the three groups over the course of the intervention period. Between group comparisons revealed that the experimental group experienced significantly lower levels of negative affect at post-intervention compared to the pseudo-experimental (B=0.17, 95%CI [0.05-0.29], p=0.007) and control group (B=0.22, 95%CI [0.10-0.34], p<.001). The pseudo-experimental and control group did not significantly differ on levels of negative affect over time ($\chi^2(1)=0.76$, p=0.384). No significant overall interaction effect between treatment allocation and time was found for momentary levels of positive affect ($\chi^2(2)=2.51$, p=0.285).

## DISCUSSION

This study is the first to examine the effectiveness of an EMI program to support spousal caregivers of PwDs in daily life. Allocation to both the experimental group (ESM self-monitoring and feedback) and the pseudo-experimental group (ESM self-monitoring without feedback) was associated with increased levels of sense of competence and decreased levels of perceived stress after two months compared to the usual care group. The difference between the experimental and pseudo-experimental group was non-significant, suggesting that caregivers evenly benefited from self-monitoring without receiving any direct feedback. The repeated self-assessments could have led caregivers to pay more attention to their internal states and behavior, which increases the availability of adequate information to make more adaptive responses[10,33]. An RCT that previously examined the effectiveness of an EMI in persons with depressive disorder yielded comparable results: at two-months follow-up both the experimental and pseudo-experimental group showed a significant decline in depressive symptoms compared to the control group. However, only in the experimental group effects persisted until the last follow-up six months later[14]. This suggests that personalized feedback adds value when it comes to achieving sustainable changes in behavior rather than short-term compensation for deficits[34]. In the current study, a longer follow-up period is needed to establish whether the effects in the experimental and pseudo-experimental group will remain in the long-term. Six-month follow-up assessments are still ongoing and could provide important information on the potential added value of personalized feedback to accomplish sustainable change.

Differences between groups on sense of competence and perceived stress particularly emerged two months after the intervention period. Transferring new insights into everyday

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life and changing behavioral habits takes time[10], which might explain why effects on these retrospective measures were not yet present at post-intervention. However, effects on momentary measures of negative affect did appear immediately after the intervention period: caregivers in the experimental group demonstrated significantly lower levels of momentary negative affect compared to the pseudo-experimental and control group. Contrary to retrospective assessments, momentary assessments provide a more fine-grained view of caregiver functioning and could reveal subtle changes that occurred within individuals during or immediately after the intervention[8]. Moreover, ESM allows for capturing in-the-moment experiences that caregivers may not be consciously aware of[35]. It is plausible to assume that the ESM-derived feedback provoked implicit positive effects immediately after the intervention, which eventually became explicit to participants after a longer time period. Results of our process evaluation, described in Chapter 6[20], support this idea: several participants reported not to be aware of the personal benefits of the intervention when being asked explicitly at the end of the intervention period. Surprisingly, despite the focus of the intervention on empowerment of positive caregiver experiences, effects on momentary positive affect did not differ among groups. This finding suggests that the intervention is particularly an important asset to reduce negative feelings in caregivers and to help them better adapt to and deal with the daily challenges of dementia. Caregiving is an ambivalent process that has a considerable impact on everyday life and might leave minimal room for enhancement of positive emotions. On the other hand, our study results highlight that a focus on positive caregiver experiences and caregivers' ability to cope with the care situation could lead to a better adaptation, as evidenced by an increase in caregiver sense of competence, and help to regulate negative emotions, as proven by a decrease in momentary negative affect and perceived stress[36]. This positive approach is in line with recent trends to view dementia and health in general from a more positive perspective[37].

**Strengths and weaknesses**

This study has several methodological strengths, including its randomized controlled design and the combination of both retrospective and momentary outcome measures to evaluate intervention effects. Traditional retrospective measures are susceptible to recall biases[38] and do not take into account fluctuations in emotional experiences that occur over time and across situations in daily life. Adding momentary outcomes, results in a higher ecological validity and generalizability of the results to caregivers' normal daily environment[8]. Yet, certain limitations of the study need to be acknowledged. First, recruitment was more challenging than expected, resulting in a lower inclusion rate and a smaller study sample (N=76) than initially planned in the study protocol (N=90). A selection bias might be present toward caregivers that are not yet exposed to extreme care demands and high levels of stress and burden. Furthermore, the study might have been underpowered to detect smaller

treatment effects that may be clinically relevant[39]. Second, the possibility cannot be fully excluded that the effects found in the experimental and pseudo-experimental group are a result of the study procedure, including face-to-face sessions with a coach that might have had a soothing or activating effect. Finally, the longer duration of the feedback sessions in the experimental group (approximately 30 minutes per session) may have had an impact on the results.

**Clinical implications and future research**

Introducing EMI in dementia care offers possibilities to bridge the gap between the clinician's office and caregivers' everyday life. The results of this study show that EMIs, consisting of ESM self-monitoring with and without personalized feedback, may be a useful add-on tool to gain insight in caregivers' everyday functioning and to promote behavioral changes that could positively affect emotional well-being. Moreover, this study highlights the importance of focusing on positive rather than negative caregiver experiences to enhance adaptation and reduce negative feelings in the caregiver.

Incorporating EMIs in dementia care seems to be promising, but the barriers to further implementation in clinical practice should be carefully considered. Future research is needed to increase the acceptability of EMIs among caregivers and to make EMIs more accessible and attractive to implement with respect to time and costs. A cost-effectiveness analysis could provide valuable information on whether the costs of setting up and implementing EMIs outweigh the benefits. Such information could help researchers, clinicians, and policy makers to make more informed decisions about the most appropriate allocation of resources.

**CONCLUSION**

This study demonstrates that EMIs are promising in the field of dementia care to strengthen caregivers in the caretaking process. However, the application of EMIs in the field of dementia care is still in its early stages and future research is needed for further fine-tuning and implementation in clinical practice.

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# 8

General discussion

## INTRODUCTION

This thesis pioneers the use of the experience sampling method (ESM) within an intervention to support spousal caregivers of people with dementia in daily life. In the first part, we conducted an exploratory study to investigate how such an intervention should look like. As part of this exploratory study, we examined the feasibility and usability of the ESM in this vulnerable and often elderly population (Chapter 2). In addition, we examined the relationship between caregivers' sense of competence and experienced positive affect (PA) in daily life (Chapter 3), and the relationship between individual caregiver characteristics and emotional reactivity to daily life stress (Chapter 4), to define the relevant elements to focus on in our intervention. In the second part of this thesis, we described the design of the newly developed experience sampling method intervention 'Partner in Sight' (Chapter 5) and performed a randomized controlled trial (RCT) to evaluate its process characteristics and effects on retrospective measures of caregiver sense of competence, mastery, and psychological complaints (depression, anxiety, and stress) and on momentary measures of positive and negative affect (Chapter 6 & 7).

In this last chapter, we will provide an overview of the main findings and discuss their implications for scientific and clinical practice. In addition, some methodological considerations and directions for future research will be addressed.

## MAIN FINDINGS

### *Is the ESM a feasible method in spousal caregivers of PwD and how can it be used in clinical practice? (Chapter 2)*

With respect to the feasibility of the ESM, results of the exploratory study showed a high compliance rate and positive experiences with the ESM in 31 spousal caregivers of PwD[1]. The ESM procedure, including six days of ESM data collection and ten random alerts per day, was experienced as time-intensive, yet still feasible. Participants stressed that a longer ESM period would have been too burdensome. Moreover, a large number of caregivers did not want to participate because of a too busy time schedule. Given that our study sample consisted of relatively young and healthy caregivers who mainly cared for people with mild stages of dementia, it is questionable whether our findings are representative for an older, more vulnerable caregiver population that has to deal with extreme care demands. With regard to the usability of the ESM for scientific and clinical practice, results demonstrated the potential of individual ESM data to reveal personalized patterns of emotions and behavior in a daily life context[1]. The ESM data provide both the caregiver and clinician with unique

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detailed information, which could not have been captured using conventional retrospective methods.

*What is the relationship between caregivers' sense of competence and their experienced positive affect in daily life? (Chapter 3)*
In order to answer this question, we used both traditional retrospective assessments and ESM measures to evaluate the relationship between caregivers' sense of competence in caring for the PwD and the amount of positive affect that they experienced. The results showed that a higher sense of competence was related to more positive emotions in the caregiver. The cross-sectional nature of our study made it impossible to demonstrate causal relationships, but it is reasonable to assume that a reciprocal relationship exists between sense of competence and positive emotions, i.e. that they reinforce one another.

Compared to retrospective measures, daily measures of sense of competence were stronger predictors of caregiver levels of positive affect in daily life. Only daily sense of competence showed a significant relationship with variability in PA in daily life. A higher daily sense of competence appeared to be associated with a more stable PA pattern, and could, thus, help to maintain mental stability.

*Which caregiver characteristics modify emotional reactivity to daily life stress? (Chapter 4)*
A further exploration of the ESM data retrieved from the exploratory study described in Chapter 2, revealed that a higher education level, higher sense of competence, higher levels of mastery, and more use of the coping strategies 'seeking distraction', 'seeking social support', and 'fostering reassuring thoughts' play a buffering role in caregivers' emotional reactivity to daily life stress. These results indicate that caregiver resources (i.e. dynamic characteristics, such as coping, sense of competence, and mastery) rather than vulnerabilities (i.e. hard-wired characteristic, such as age and gender) affect how caregivers react to daily hassles, and could protect caregivers by reducing their negative emotional reaction in stressful situations.

The above-mentioned results from the exploratory study were used to develop a new ESM intervention, called 'Partner in Sight'. The intervention consisted of six consecutive weeks of ESM self-monitoring including personalized feedback on daily life situations (i.e. daily activities and social interactions) that elicit positive emotions. Receiving feedback might promote behavioral changes towards situations that are conducive to positive emotional experiences and could consequently strengthen caregivers with respect to their sense of competence and feelings of mastery throughout the caretaking process. The intervention was compared with a usual care condition and a pseudo-intervention, consisting of ESM self-monitoring without feedback, to examine the unique value of the personalized feedback[2]. A

detailed description of the study design has been provided in Chapter 5. Next, we describe the main findings on the process characteristics and effects of the intervention 'Partner in Sight'. The process evaluation was conducted prior to the effect evaluation to be able to better interpret treatment effects with respect to credibility and generalizability[3].

*What are the process characteristics of the experience sampling method intervention 'Partner in Sight'? (Chapter 6)*

The process evaluation demonstrated an overall participation rate of 31.4% among the recruited caregivers, resulting in a total of 76 participants in the study. Recruitment for this study was more challenging than we anticipated, and therefore, the original aim to include 90 participants was not met. Main recruitment barriers included no need for additional support, and considering the intervention as too time-consuming or burdensome. As mentioned in Chapter 2, the intrusive nature of the ESM could have been a major concern in many caregivers, especially in the ones who spent a lot of time on caregiving or experience high levels of burden[4].

Overall, participants were satisfied with respect to the content and structure of the ESM intervention 'Partner in Sight'. The ESM-derived feedback was considered supportive and increased participants' awareness of their feelings and behavior. However, a large variance was found in the extent to which caregivers applied the feedback into their daily lives. Participants emphasized the importance of the personal coach in providing face-to-face feedback and encouraging them to implement new insights into their daily lives. Participants indicated that the intervention was too time-intensive, with respect to the overall duration (six weeks) and the number of ESM alerts per day (ten alerts). Other suggestions for improvement were to better tailor the program content to one's personal situation and to make use of a more advanced ESM device to increase readability and audibility in elderly persons.

*What are the effects of the experience sampling method intervention 'Partner in Sight' on retrospective measures of caregiver sense of competence, mastery, and psychological complaints (depression, anxiety, and stress) and on momentary measures of positive and negative affect? (Chapter 7)*

An RCT was conducted to demonstrate the effects of the ESM intervention 'Partner in Sight'. Results showed a significant increase in retrospective measures of sense of competence and a decrease in perceived stress in both the intervention (ESM including feedback) and pseudo-intervention group (ESM without feedback) after two months, compared to the usual care group. The difference between the intervention and pseudo-intervention group was non-significant, indicating that the repeated self-assessments already could have increased caregivers' self-awareness. Effects on momentary measures of negative affect

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appeared immediately after the intervention: caregivers in the intervention group showed a decrease in momentary negative affect compared to the pseudo-intervention and usual care group. ESM assessments provide a more detailed view of caregiver functioning compared to retrospective assessments, which offers the opportunity to uncover smaller treatment effects that arose during or immediately after the intervention[5]. Unexpectedly, no effects were found for momentary positive affect. The focus of our intervention on empowerment of positive caregiver experiences, thus, proved to be particularly important to protect caregivers against negative feelings.

## METHODOLOGICAL CONSIDERATIONS

This thesis has several methodological strengths and weaknesses, which will be discussed below.

### Strengths

The effects of the ESM intervention 'Partner in Sight' were evaluated in an RCT design, which is considered 'the gold standard' for providing convincing evidence. A multi-method approach was used, including retrospective and momentary outcome measures to examine intervention effects. This approach allowed for collection of both global and detailed self-reports of the outcomes we were interested in. Moreover, adding momentary outcomes will have increased the ecological validity and generalizability of our results to caregivers' normal daily environment[6]. Another strength of this thesis is that we performed a process evaluation alongside the effect evaluation. Next to determining the effects of an intervention, it is of great importance to understand how an intervention is actually being delivered and perceived. Information on sampling and intervention quality is crucial to make well-informed decisions about further implementation of an intervention into clinical practice[3].

### Limitations

First, a selection bias might be present in our studies. A large number of caregivers refused to participate due to a too busy time-schedule or considering the ESM procedure as too time-intensive, which might have led to a selective participation of caregivers who are not yet exposed to extreme care demands and high levels of caregiver burden. Moreover, clinicians and dementia case managers are likely to have made a selection when recruiting caregivers, with caregivers that experience less strain and are more familiar with technological devices being more easily recruited. Although caregivers were recruited in a wide range of different institutions, it is conceivable that many caregivers were overlooked because of not being familiar with the care parties involved in recruitment. Many informal caregivers experience

difficulties accessing formal care services or decline formal care due to a fear of stigma[7]. This could have resulted in a highly motivated sample that is more open to and pro-active in seeking support. It remains, therefore, unknown how the results of this thesis generalize to the general caregiver population.

Second, recruitment difficulties resulted in a smaller sample size than initially planned in the study protocol to obtain a power of >0.80. Therefore, the study might have been underpowered to detect smaller effects that may be clinically relevant[8]. This may, however, be partly compensated by including ESM outcomes complementary to the standard retrospective outcomes, which offered the possibility to capture subtle changes in momentary experiences.

Third, it cannot be ruled out that the positive effects found in the intervention group (ESM including feedback) and pseudo-intervention group (ESM without feedback) have been the result of the attention provided by the coach, which might have had a soothing or activating effect. Adding an extra treatment condition in which participants only collect ESM data without receiving face-to-face sessions with a coach would have been an alternative, but it is questionable whether participants would have been compliant to the ESM procedure without a coach to motivate them. Previous research suggests that direct communication with a personal coach increases caregivers' commitment to therapy[9].

Finally, the application of the ESM in the field of dementia care is still in its infancy and standardized criteria for sampling protocols and sets of ESM items are not yet available. The design of our studies was, therefore, based on previous ESM studies in psychiatric populations[6], guidelines from ESM experts[10], and clinical knowledge about caregiver experiences. Future research is recommended to validate the content of our ESM questionnaire and to test different time sampling protocols that are less time-intensive. Another aspect that requires further exploration is the potential problem of reactivity in ESM studies, i.e. the potential for experiences to change as a result of the repetitive nature of the ESM measurements[11]. The repeated assessments may have led caregivers to pay unusual attention to their internal states and behavior, which might have impacted their retrospective recall of emotions. So far, only few studies have addressed reactivity effects of experience sampling and findings are inconsistent[12]. More research is needed and can lead to guidelines for testing procedures to minimize the risk of reactivity. In our studies, we included a random time schedule and a high sampling load to desensitize caregivers to the ESM procedure and reduce preoccupation with the method.

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## CLINICAL IMPLICATIONS

This thesis is the first to present the process characteristics and effects of an ESM intervention for caregivers of PwD. Its results, therefore, provide new and valuable information for clinical practice.

### Focus on positive experiences

This thesis showed that targeting on positive aspects of caregiving might be a promising direction in future caregiver interventions. Existing interventions often focus on negative experiences in order to reduce negative caregiver outcomes, such as feelings of stress and burden. The results of our thesis, however, demonstrate that targeting on positive rather than negative aspects can be beneficial to increase caregiver resources, such as feelings of competence and mastery. This new focus is supported by the broaden-and-build theory of positive emotions, which states that positive emotions have the ability to broaden people's momentary thought-action repertoire[13]. A broadened mindset enables more flexible and creative thinking, which might facilitate coping with stress and negative emotional experiences and help to build enduring personal resources to manage future threats. A focus on adaptation and positive aspects of caregiving also fits the new concept of health, which emphasizes people's capacity to self-manage their life and engage in society, despite their medical condition or that of their loved ones[14]. The results of this thesis, nonetheless, highlight that we should be careful not to tip the balance towards a too positive approach. Caring for a PwD can be an extremely stressful and demanding process, leaving minimal room for enhancement of positive emotions. Caregiver interventions might not be able to transform caregiving into a pleasant process, but they could learn caregivers to better adapt to and manage difficult situations.

### The experience sampling method for detailed information on caregiver functioning

The ESM is a feasible and valuable tool for assessment and screening in the field of dementia care. ESM assessments are a useful complement to standard retrospective questionnaires and clinical interviews, as they take into account fluctuations in caregivers' experiences throughout the caretaking process and, therefore, provide a more comprehensive and dynamic view of caregiver functioning. Another major advantage of ESM assessments is that experiences are examined in real-life and, therefore, represent higher ecological validity compared to retrospective assessments. Moreover, ESM assessments capture experiences in-the-moment, while retrospective assessments often cover a larger time period and are subject to various recall biases[15]. Thus, ESM data are rich and might include information that might normally have been overlooked or forgotten. The use of the ESM in dementia care,

therefore, should be stimulated as it might allow for a more accurate screening of caregiver functioning, which might also be useful when setting goals for treatment[16].

## The experience sampling method as an intervention tool

This thesis showed that the ESM could be a valuable intervention tool in dementia care. The ESM intervention 'Partner in Sight' aimed at empowerment of caregiver resources by providing feedback on positive affect experience, proved to be successful to support caregivers of PwD in daily life. The pseudo-intervention also demonstrated positive effects on caregiver outcomes. The term pseudo-intervention basically indicates a surrogate intervention, which might not do justice to the significant value of self-monitoring without receiving feedback, which appeared to be an effective intervention in itself. A previous study examining the efficacy of ESM self-monitoring with and without personalized feedback in persons with depressive disorder, showed that the feedback was particularly important to achieve sustainable changes in behavior[17]. Longer follow-up periods are, therefore, needed to more clearly establish the long-term effects of ESM interventions[18].

The ESM offers the possibility to tailor caregiver interventions more to the specific situation of the caregiver. Previous studies confirmed caregiver interventions to be more effective if they are tailor-made and meet the needs of the caregiver[19,20]. Tailored information is more personally relevant, which increases the likelihood of thoughtful consideration and helps to initiate behavioral change[21]. Moreover, ESM actively involves caregivers in their own empowering process, which is considered as another important aspect in effective psychosocial interventions. However, despite these advantages and the positive effects of our ESM intervention on caregiver outcomes, this thesis illustrates that ESM interventions still need further fine-tuning to become successfully implementable in clinical practice. Better understanding and addressing recruitment barriers appears to be necessary to make ESM interventions accessible to a wider range of caregivers and more feasible to implement.

## FUTURE RESEARCH DIRECTIONS

Overall, this thesis showed that ESM interventions are promising in the field of dementia care. However, future research is needed to make ESM interventions more accessible and attractive to implement.

## Enhancing the acceptability of experience sampling method interventions

One of the biggest challenges with ESM interventions is that they demand a lot of time and commitment from participants, which may lead to recruitment difficulties and attrition.

Especially in caregivers of PwD this is a problem, since they often face time constraints due to the complex care situations they are involved in. Lowering the time-investment of ESM interventions by adapting the duration and intensity of time sampling might be an important first step to increase acceptability in caregivers of PwD.

**Personal coaching in experience sampling method interventions**

Following the growing interest in remote support for dementia caregivers[22-24], we should consider to provide digitalized and automated ESM-derived feedback in future ESM interventions. Providing feedback in face-to-face contact sessions with a coach makes an ESM intervention even more time-consuming and intensive. Also, reflecting on one's feelings anonymously and in one's personal environment might be easier and more accessible to a wider range of caregivers. However, the importance of the personal coach was stressed in this thesis and the high compliance rates and positive intervention effects might have been (partly) attributed to the motivational aspect of the personal coach. Previous studies support the value of a blended care format to increase adherence and effectiveness of a treatment[25,26]. A digital coach, who is available for online questions and provides motivational messages to stimulate engagement in the ESM and making behavioral changes, might be a worthy alternative to reduce the time-intensity of ESM interventions. Different approaches for delivering ESM interventions in caregivers of PwD remain to be determined and are an important area for future research.

**Adapting experience sampling method devices to the needs of elderly**

Another important avenue of research concerns the development of ESM devices that are better adjusted to elderly people. The use of PDAs in daily life is intrusive, and requires caregivers to become familiar with a novel device that they would otherwise not carry with them. In addition, software and programming expertise is required from professionals and detailed instructions need to be given on how to operate the device. Introducing an ESM platform or application ('app') that can be installed on smartphones would be ideal, since it offers the possibility for people to use their own devices[27] and it allows for advanced interfaces that take into account sensory or motor deficits that might be present in older adults (e.g. with a larger font, clearly labeled push buttons, and higher volume settings). Moreover, previous work on mobile technology already demonstrated the potential of apps to expand the ability to directly intervene within people's everyday lives in order to foster positive change in behavior[28]. Future studies are needed to test whether newly developed ESM platforms and apps are more suitable for elderly caregivers and could facilitate further implementation of ESM interventions in dementia care practice.

**The experience sampling method as a supportive tool in existing psychological treatments**

ESM interventions have been effectively implemented in a wide variety of health behaviors and psychological symptoms and can take many forms. ESM interventions can be implemented on their own, as demonstrated in this thesis, or could supplement existing interventions or ongoing psychological treatments[18]. For example, in cognitive behavioral therapy the ESM could help to increase awareness of negative thoughts and behavioral patterns and could be used to encourage skill building between treatment sessions. More recently, the ESM was used in acceptance and commitment therapy to transfer skills and new insights into the practice of daily life[29]. Integrating real-life assessments and existing psychological therapies might also be promising in the field of dementia care, as the effectiveness of any therapy targeting psychological mechanisms is likely to be greater if delivered in real life, outside the clinician's office. Future research is recommended to examine the added value of such an integrated approach.

**Combining experience sampling method data with other personal data**

The content in this thesis was typically restricted to momentary assessments of subjective caregiver experiences, including ratings of emotions and behavior. Recent technological advances provide new opportunities for PDAs and smartphones to collect audio, video, geographical positioning, and, with the help of biosensors and other attachments, even physiological data (e.g. heart rate, blood pressure, or blood glucose). Coupling this information with ESM data could provide an even more comprehensive picture of caregivers' emotional, psychological, behavioral, and physical functioning in a real-life environment[18]. These types of interventions have yet to be developed and evaluated, but as technology continues to become more sophisticated, using physiological or environmental cues becomes a possibility. Nevertheless, we should be aware of privacy and confidentiality concerns that might arise when sophistication of technology continues to improve.

**The experience sampling method to measure behavioral changes in daily life**

Most studies examine the effectiveness of interventions by focusing on changes in symptoms or behavior before and after the intervention. However, ESM data collected during the intervention could also be used to provide important information on actual changes in daily life behaviors over time. In addition, these data can be used to explore associations between daily life behaviors and caregivers' emotional well-being over the course of the intervention and to examine daily within-person associations[30]. Future research addressing these more nuanced research questions could be useful to better understand the factors that influence the efficacy of ESM interventions.

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**Cost–effectiveness of experience sampling method interventions**

Finally, future studies on the cost-effectiveness of ESM interventions for caregivers of PwD should be conducted to inform researchers, clinicians, and policy makers about the costs of setting up and implementing ESM interventions and its potential benefits.

## CONCLUSION

The research presented in this thesis showed that the ESM is a promising tool in the field of dementia care, but the barriers to adoption in clinical practice should be carefully considered. Future research is essential to make ESM interventions less time-consuming and accessible to a wider range of caregivers.

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# SUMMARY

The rising prevalence of people with dementia will make a growing appeal to informal caregivers to engage in the caretaking process. Providing care to a person with dementia (PwD) poses great demands and puts caregivers at risk for mental and physical health problems. There is a need for interventions that effectively support caregivers in daily life and help them to adequately adapt and respond to the daily challenges of dementia. Recent technological developments provide new opportunities to extend interventions beyond the clinical setting into people's everyday lives. These interventions, in which support is provided in real time and in the real world, are also referred to as ecological momentary interventions (EMIs). As part of this thesis, we developed and evaluated an EMI based on the experience sampling method (ESM). The ESM is a structured diary method that can be used to self-monitor experiences and behavior within daily life. This method has been applied with success in a wide range of health-related areas. However, its application in the field of dementia care is still novel and requires further exploration.

The main aim of this thesis was to explore the use of the ESM within an intervention to support spousal caregivers of people with dementia in daily life. A general introduction, including the study rationale, research questions, and outline of this thesis, is provided in **Chapter 1**.

The first part of this thesis describes the results of an exploratory study, which was conducted to pioneer the use of the ESM within caregivers of people with dementia and to investigate which relevant elements to focus on in our intervention.

**Chapter 2** describes the feasibility of the ESM in spousal caregivers of people with dementia and the usability of ESM data for clinical practice. Results showed a high compliance rate and positive experiences with the ESM in 31 dementia caregivers, who collected ESM data for six consecutive days. In general, caregivers experienced the ESM as time-intensive and recommended to take this into account when developing our ESM intervention. With regard to the usability of the ESM for clinical practice, the results demonstrated the potential of individual ESM data to reveal personalized patterns of mood and behavior in the flow of daily life.

In **Chapter 3** the relationship between caregivers' sense of competence and their positive affect experience in daily life was examined, by using both traditional retrospective measures and ESM measures. Results showed a higher sense of competence to be related to more positive emotions in the caregiver. Compared to retrospective measures, daily measures of sense of competence were stronger predictors of the amount of positive emotions

experienced in daily life. Only daily sense of competence predicted variability in positive emotions over time; caregivers with a higher daily sense of competence experienced more stable patterns of positive emotions. This finding highlights that momentary assessments are a valuable addition to standard retrospective measures as they enable a more dynamic view of caregiver functioning.

In **Chapter 4** ESM data derived from the exploratory study were analyzed to examine which caregiver characteristics modify emotional reactivity to daily life stress. Caregivers with a higher education level, higher sense of competence, higher levels of mastery, and caregivers who more frequently used the coping strategies 'seeking distraction', 'seeking social support', and 'fostering reassuring thoughts', experienced less negative emotions in reaction to stressful daily events. No effects were found for age, gender, and hours of contact with and care for the person with dementia. These results indicate that caregiver resources (i.e. dynamic characteristics, such as coping, sense of competence, and mastery) rather than vulnerabilities (i.e. hard-wired characteristic, such as age and gender) affect how caregivers react to daily hassles, and are an important target in caregiver support interventions.

In the second part of this thesis, the above-mentioned results of the exploratory study were used to develop the ESM intervention 'Partner in Sight'. The intervention consists of six weeks of ESM self-monitoring including personalized feedback from a coach on daily life situations that elicit positive emotions.

**Chapter 5** describes the study design of a randomized controlled trial to evaluate the process characteristics and effects of the ESM intervention 'Partner in Sight' on retrospective measures of sense of competence, mastery, and psychological complaints (stress, depression, and anxiety), and on momentary measures of positive and negative affect. The intervention was compared with a usual care condition and a pseudo-intervention, consisting of ESM self-monitoring without feedback, to examine the unique value of the personalized feedback.

**Chapter 6** provides the results of a process evaluation to examine the internal and external validity of the ESM intervention 'Partner in Sight' and to provide information for future implementation in clinical practice. Recruitment was more challenging than expected and resulted in a participation rate of 31.4%. Main recruitment barriers included no need for support and considering the intervention as too time-consuming or burdensome. Overall, participants were satisfied with the content and structure of the ESM intervention. The ESM-feedback was considered supportive and increased caregivers' awareness of their feelings and behavior. Caregivers emphasized the importance of the personal coach in providing face-to-face feedback and encouraging them to implement new insights into their daily

lives. Participants indicated that the intervention was too time-intensive, with respect to the overall duration and the number of ESM alerts per day. Other suggestions for improvement were to better tailor the intervention content to one's personal situation and to make use of a more advanced ESM device to increase readability and audibility in elderly persons.

**Chapter 7** describes the effectiveness of the ESM intervention 'Partner in Sight' for spousal caregivers of people with dementia. The results demonstrated a significant increase in retrospective measures of sense of competence and a decrease in perceived stress in both the intervention and pseudo-intervention group after two months, compared to the usual care group. The difference between the intervention and pseudo-intervention group was non-significant, indicating that the repeated self-assessments already could have increased caregivers' self-awareness. Effects on momentary measures of negative affect appeared immediately after the intervention: caregivers in the intervention group showed a decrease in momentary negative affect compared to the pseudo-intervention and usual care group. Unexpectedly, no effects were found for momentary positive affect. The focus of our intervention on empowerment of positive caregiver experiences, thus, proved to be particularly important to protect caregivers against negative feelings.

In **Chapter 8** the main findings are discussed together with methodological considerations, implications for clinical practice, and recommendations for future research.

## SAMENVATTING

Als gevolg van het toenemende aantal mensen met dementie, zal er in de toekomst een steeds groter beroep worden gedaan op informele mantelzorgers. De zorg voor iemand met dementie legt een grote druk op mantelzorgers en verhoogt het risico op mentale en fysieke gezondheidsproblemen. Er is behoefte aan effectieve interventies om mantelzorgers te ondersteunen in het dagelijks leven en hen te helpen omgaan met dagelijkse uitdagingen gedurende het zorgproces. Recente technologische ontwikkelingen bieden nieuwe mogelijkheden om hulp aan te bieden in het dagelijks leven van de mantelzorger in plaats van in een klinische setting. Interventies waarbij ondersteuning wordt aangeboden 'in het moment' en in de 'dagelijkse leefomgeving' worden ook wel aangeduid als ecological momentary interventies (EMIs). In dit proefschrift werd een EMI ontwikkeld op basis van de experience sampling methode (ESM). De ESM is een gestructureerde dagboekmethode die kan worden gebruikt om gevoelens en gedrag te monitoren in het dagelijks leven. De methode is reeds succesvol gebleken in diverse klinische populaties. Echter, de toepassing van de ESM in het dementieveld is nog nieuw en dient nader onderzocht te worden.

Het doel van dit proefschrift was om het gebruik van de ESM in een interventie te onderzoeken om partners van mensen met dementie te ondersteunen in het dagelijks leven. Een algemene inleiding, bestaande uit de rationale, vraagstellingen en opzet van dit proefschrift, wordt beschreven in **Hoofdstuk 1**.

In het eerste deel van dit proefschrift worden de resultaten van een exploratieve studie beschreven met als doel het gebruik van de ESM in het dementieveld te verkennen en relevante informatie te verzamelen voor de ontwikkeling van een ESM interventie.

**Hoofdstuk 2** beschrijft de uitvoerbaarheid van de ESM bij mantelzorgers van mensen met dementie en de bruikbaarheid van ESM gegevens voor de klinische praktijk. De resultaten toonden een hoge mate van compliance en positieve ervaringen met de ESM in een studie met 31 partners van mensen met dementie, die gedurende zes achtereenvolgende dagen ESM gegevens verzamelden. Over het algemeen werd de ESM door mantelzorgers als tijdrovend ervaren en werd aanbevolen hier rekening mee te houden bij de ontwikkeling van de ESM interventie. Met betrekking tot de bruikbaarheid van ESM gegevens voor de klinische praktijk, gaven de resultaten inzicht in de mogelijkheden van ESM om individuele stemmings- en gedragspatronen aan het licht te brengen.

In **Hoofdstuk 3** werd de relatie tussen gevoelens van competentie van mantelzorgers en hun ervaring van positieve emoties in het dagelijks leven onderzocht. Hierbij werd gebruik

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gemaakt van zowel traditionele retrospectieve metingen als ESM metingen. Mantelzorgers met meer gevoelens van competentie bleken meer positieve emoties te ervaren in het dagelijks leven. Dagelijkse metingen van gevoelens van competentie bleken in vergelijking met retrospectieve metingen een sterkere voorspeller van de hoeveelheid ervaren positieve gevoelens. Enkel dagelijks gemeten gevoelens van competentie voorspelden variabiliteit van positieve gevoelens over tijd; mantelzorgers met meer dagelijks gemeten gevoelens van competentie lieten een stabieler patroon van positieve emoties zien. Bovenstaande bevindingen benadrukken dat ESM metingen een waardevolle toevoeging zijn op standaard retrospectieve metingen, aangezien ESM een meer dynamische kijk op het dagelijkse functioneren van mantelzorgers mogelijk maakt.

In **Hoofdstuk 4** werden ESM gegevens afkomstig van de exploratieve studie geanalyseerd om te onderzoeken welke eigenschappen van mantelzorgers hun emotionele reactie beïnvloeden op stressvolle gebeurtenissen in het dagelijks leven. Mantelzorgers met een hoger opleidingsniveau en meer gevoelens van competentie en controle bleken minder negatieve emoties te ervaren tijdens stressvolle momenten. Daarnaast bleken de coping strategieën 'afleiding zoeken', 'sociale steun zoeken', en 'geruststellende en troostende gedachten toelaten' bescherming te bieden tegen stress. Er werden geen effecten gevonden voor leeftijd, geslacht en het aantal uren contact met en zorg voor de persoon met dementie. Deze resultaten suggereren dat persoonlijke capaciteiten van mantelzorgers (zoals coping, gevoelens van competentie en ervaren controle) meer nog dan hun kwetsbaarheden (zoals leeftijd en geslacht) van invloed zijn op hun stressreactie in het dagelijks leven. Het versterken van persoonlijke capaciteiten van de mantelzorger kan een belangrijk speerpunt zijn in toekomstige interventies.

In het tweede deel van dit proefschrift wordt aan de hand van de resultaten van de exploratieve studie de ESM interventie 'Partner in Zicht' verder ontwikkeld. 'Partner in Zicht' is een zes weken durende interventie, bestaande uit ESM self-monitoring en gepersonaliseerde feedback van een coach op dagelijkse situaties die leiden tot positieve gevoelens.

**Hoofdstuk 5** beschrijft de opzet van een gerandomiseerd onderzoek waarin de proceskenmerken en effecten van de ESM interventie 'Partner in Zicht' worden geëvalueerd. Effecten op zowel retrospectieve metingen van gevoelens van competentie, ervaren controle en psychische klachten (stress, depressie en angst) als ESM metingen van positieve en negatieve gevoelens worden hierbij onderzocht. De interventie werd vergeleken met een controle conditie en een pseudo-interventie, bestaande uit ESM monitoring zonder feedback. Op deze manier kon de toegevoegde waarde van de gepersonaliseerde feedback nader worden bekeken.

**Hoofdstuk 6** geeft de resultaten van een procesevaluatie weer om de interne en externe validiteit van de ESM interventie 'Partner in Zicht' te bepalen en belangrijke informatie te verzamelen voor toekomstige implementatie in de klinische praktijk. Het rekruteren van deelnemers verliep moeizamer dan verwacht en resulteerde in een deelnemerspercentage van 31.4%. De werving werd bemoeilijkt doordat veel mantelzorgers aangaven geen behoefte te hebben aan extra steun of de interventie als te tijdrovend en belastend zagen. Over het algemeen waren deelnemers aan 'Partner in Zicht' tevreden met de inhoud en structuur van de interventie. De gepersonaliseerde feedback werd als steun ervaren en vergrootte het inzicht van mantelzorgers in hun gevoelens en gedrag. Mantelzorgers benadrukten het belang van een persoonlijke coach om face-to-face feedback te geven en het toepassen van nieuwe inzichten in het dagelijks leven te stimuleren. Deelnemers gaven aan de interventie als tijdrovend te ervaren met betrekking tot de algehele duur van de interventie en het aantal ESM alerts per dag. Andere suggesties ter verbetering waren om de inhoud van de interventie nog meer toe te spitsen op de individuele situatie van mantelzorgers en om een geavanceerder ESM apparaat te ontwikkelen om de lees- en hoorbaarheid te vergroten voor oudere deelnemers.

**Hoofdstuk 7** behandelt de effectiviteit van de ESM interventie 'Partner in Zicht' voor partners van mensen met dementie. Op de retrospectieve uitkomstmaten werd het volgende gevonden: twee maanden na de interventie ervoeren mantelzorgers in de interventie en pseudo-interventie groep significant meer gevoelens van competentie en minder stress dan deelnemers in de controle groep. Het verschil tussen de interventie en pseudo-interventie groep was niet significant, hetgeen suggereert dat herhaaldelijke ESM metingen in het dagelijks leven op zichzelf al tot een verhoogd zelfbewustzijn leiden. Met betrekking tot de ESM uitkomstmaten, toonden de resultaten een positief effect op negatieve gevoelens van de mantelzorger direct na de interventie: mantelzorgers in de interventie groep ervoeren minder negatieve gevoelens in vergelijking met de pseudo-interventie en controlegroep. Tegen onze verwachting in, werd er geen effect gevonden op ervaren positieve gevoelens. Deze bevindingen impliceren dat de focus van onze interventie op het versterken van positieve ervaringen met name belangrijk is om mantelzorgers te beschermen tegen negatieve gevoelens.

In **Hoofdstuk 9** worden de bevindingen van dit proefschrift samengevat. Daarnaast worden de methodologische aspecten, implicaties voor de klinische praktijk en aanbevelingen voor toekomstig onderzoek besproken.

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## KNOWLEDGE VALORIZATION

The main aim of this thesis was to investigate the application of the experience sampling method (ESM) within an intervention to support spousal caregivers of people with dementia in daily life. In this valorization paragraph, we describe how the obtained knowledge from our research can be made valuable for clinical and societal use.

### Societal relevance

Today, 47 million people live with dementia worldwide. With the numbers of people with dementia expected to double in the next 30 years and predicted costs likely to rise to a trillion dollars by 2018, we are facing one of the biggest global health and social care challenges of our time. There is an urgent need to improve the coverage of health care around the world, for people living with dementia now and those who will be in the future. For this reason, the World Health Organization and the European Union (EU) have indicated that dementia should be regarded as a global public health priority.

Dementia has a considerable impact on the quality of life of persons with dementia as well as on their caregivers. The majority of the people with dementia are living at home and are cared for by their relatives. Providing years of extensive care for a person with dementia is associated with increased levels of stress and a higher risk of developing physical and psychological symptoms, such as stress and anxiety. In the upcoming years, the care for people with dementia will depend even more on informal caregivers, as people with dementia will be urged to live at home for longer periods due to the rising costs of formal care. This calls for psychosocial interventions that effectively support caregivers in daily life and help them endure their care responsibilities for as long as possible.

Recent technological developments provide new opportunities to extend interventions beyond the clinical setting into people's everyday lives. These interventions are also referred to as ecological momentary interventions (EMIs) and reflect a high ecological validity, because they provide real time support in the real world. This thesis described the development and evaluation of the EMI program 'Partner in Sight', which was based on the experience sampling method (ESM). The ESM is an innovative approach that can be used to self-monitor subjective experiences in the flow of daily life and to provide both the caregiver and the health care professional with unique detailed information, which could not have been captured using conventional retrospective methods. Accurate assessment of caregiver functioning is of great importance to provide care more efficiently, at times and in situations when its most needed. This might save costs in the long-term, as caregivers can be prevented from becoming overburdened and institutionalization of the person with dementia can be delayed.

**Target audience**

The findings of this thesis are relevant for caregivers of people with dementia, health care professionals, and policy makers.

Caregivers of people with dementia can benefit from our research as the ESM intervention 'Partner in Sight' effectively increased caregivers' feelings of being capable to care for the person with dementia, and reduced perceived stress and negative feelings. By asking caregivers to monitor their daily functioning, they become more aware of implicit daily patterns of emotions and behavior. Our ESM intervention specifically aimed to give caregivers more insight into those situations that elicit positive emotions, such as relaxation and social activities. Results showed that our focus on empowerment of positive experiences helped to protect caregivers against stress and negative feelings. Existing interventions often put emphasis on negative experiences in order to reduce negative caregiver outcomes, such as stress and feelings of burden. This thesis, however, demonstrates that targeting on positive rather than negative experiences can be beneficial to increase caregiver resources and might be a promising direction in future caregiver interventions.

Dementia health care professionals should consider introducing ESM interventions for informal dementia caregivers in addition to already provided care as usual. This thesis proves that the ESM is a highly feasible method in caregivers of people with dementia and offers new possibilities to tailor interventions more to their personal situations. Previous studies confirmed caregiver interventions to be more effective if they are tailor-made and meet the needs of the caregiver. Moreover, the ESM actively involves caregivers in their own empowering process, which is considered as another important aspect in effective psychosocial interventions. The results of this thesis show that, next to using the ESM as an intervention tool, the ESM can be a valuable tool for assessment and screening in the field of dementia care. For health care professionals, ESM assessments can be a useful complement to standard retrospective questionnaires and clinical interviews, as they take into account fluctuations in caregivers' feelings and provide a more comprehensive and dynamic view of caregiver functioning. The use of the ESM in dementia care, therefore, should be stimulated as it allows for more accurate screening of caregiver functioning and helps health care professionals to detect caregivers that are in need of support.

Our findings could be of great interest to insurance companies and policy makers, given that the future care for persons with dementia will depend increasingly on informal caregivers. When policy makers involved in health care regulations invest in effective caregiver support programs, such as 'Partner in Sight', aimed at strengthening caregivers to continue their care responsibilities for as long as possible, this could contribute to the sustainability of health

care for people with dementia. However, to make this a success, insurance companies and policy makers should be more aware of differences in personal circumstances and should take into account individual needs and wishes when providing support to informal caregivers of people with dementia. To this end, the ESM could offer a valuable contribution.

**Activities and products**

Based on the feasibility results of our exploratory study and evidence from previous research, the EMI program 'Partner in Sight' was developed. The program consists of six weeks of ESM self-monitoring, including personalized feedback from a coach on daily life situations that elicit positive emotions. The program is tailored to the individual situation of the caregiver and stresses the positive aspects of caregiving to strengthen caregivers throughout the caretaking process.

Participants of the study and involved care facilities were updated about the study progress and results through a bi-annual newsletter. Furthermore, results were presented at several national and international congresses, symposia, senior centers, and Alzheimer Cafés. Feedback from informal caregivers, health care professionals, and researchers was taken into consideration throughout the study process.

**Innovation and implementation**

This thesis is the first to present the effects of an ESM intervention to support caregivers of people with dementia. ESM interventions have been successfully implemented in a wide variety of health-related areas. However, the application of the ESM in the field of dementia care is still in its infancy. This thesis, therefore, provides a valuable contribution to our knowledge of delivering caregiver interventions in real life, based on experience sampling techniques. Incorporating ESM interventions in regular health care for dementia caregivers seems to be promising, but the barriers for further implementation should be carefully considered. Future research is essential to make ESM interventions accessible to a wider range of caregivers and more attractive to implement with respect to time and costs.

Within our division 'Cognitive Neuropsychology and Clinical Neuroscience', this was the first project in which we explored the application of the ESM. Throughout the project we closely collaborated with the division of 'Mental Health', who extensively studied the ESM technique in diverse psychiatric populations. With their help, our knowledge about this innovative method has been extended and the method is now being adopted in other research projects with different populations, including persons with acquired brain injuries and persons with mild cognitive impairment.

## DANKWOORD

Ongeloof en trots… dat zijn de gevoelens die overheersen nu ik mijn eigen proefschrift in handen heb. Ongeloof, dat het eindelijk zover is na ruim vier jaar hard werken! Trots, op mezelf én op alle fijne mensen om mij heen die mij de afgelopen jaren ongelofelijk gesteund hebben. Graag wil ik een aantal van jullie persoonlijk bedanken.

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✳

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## THESIS DEFENSES FROM MHENS – SCHOOL FOR MENTAL HEALTH AND NEUROSCIENCE

### 2013

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Hilde Braakman: **Imaging the brain; neuronal correlates of cognitive impairment in children with frontal lobe epilepsy**. Supervisors: Prof.dr. A.P. Aldenkamp / Prof.dr. J.S.H. Vles; Co-Supervisors: Dr.ir. W.H. Backes / Dr. P.A.M. Hofman.

Willem H. van Zwam: **Aneurysmal subarachnoid hemorrhage: imaging strategies and cost-effectiveness aspects in diagnostic work-up and post-therapeutic follow-up.** Supervisors: Prof.dr. J.T. Wilmink / Prof.dr.

J.E. Wildberger; Co-Supervisor: Dr. P.A.M. Hofman.

Klara De Cort: **The Pathogenesis of Panic Disorder.** Supervisors: Prof.dr. I. Myin-Germeys / Prof.dr. E.J.L. Griez; Co-Supervisors: Dr. K.R.J. Schruers / Dr. I. Van Diest, Leuven.

Kim van Wijck: **Mind the Gap; experimental studies on splanchnic hyperfusion and gastrointestinal integrity loss in man**. Supervisors: Prof.dr. W.A. Buurman / Prof.dr. C.H.C. Dejong; Co-Supervisor: Dr. K. Lenaerts.

Yvette Roke: **Antipsychotic-induced hyperprolactinemia in children and adolescents with mainly autism spectrum disorders. Prevalence, symptoms, clinical consequences and genetic risk factors.** Supervisors: Prof.dr. P.N. van Harten / Prof.dr. J.K. Buitelaar (RUN); Co-Supervisor: Dr. A. Boot (UMCG).

Fleur Goezinne: **Retinal detachment surgery: pre and postoperative prognostic factors.** Supervisors: Prof.dr. F. Hendrikse / Prof.dr. C.A.B. Webers; Co-Supervisor: Dr. E.C. La Heij (Amsterdam).

Ralph L.J.G. Maassen: **The Merits of Videolaryngoscopy during Glottic Visualisation for Endotracheal Intubation.** Supervisors: Prof. dr. M. Marcus / Prof.dr. A. van Zundert (University of Queensland).

Maria J. de Sousa Guerreiro: **The role of sensory modality in age-related distraction.** Supervisor: Prof.dr. C.M. van Heugten; Co-Supervisor: Dr. P.W.M. van Gerven.

Ine Rayen: **Effects of developmental fluoxetine exposure on neurobehavioral out-** comes. Supervisor: Prof.dr. H.W.M. Steinbusch; Co-Supervisors: Dr. J.L. Pawluski / Dr. T.D. Charlier (Ohio University, USA).

Nynke M.G. Bodde: **Psychogenic non-epileptic seizures; a separate disorder or part of a continuum?** Supervisors: Prof.dr. R. van Oostenbrugge / Prof.dr. K. Vonck (UZ Gent); Co-Supervisors: Dr. R. Lazeron / Dr. A. de Louw (Epilepsiecentrum Kempenhaeghe, Heeze).

Alejandro M. Gomez: **Novel strategies for making myasthenia less gravis: targeting plasma cells and the neuromuscular junction.** Supervisor: Prof.dr. M.H. De Baets; Co-Supervisors: Dr. M. Losen / Dr. P. Martinez-Martinez.

Mohammad S. Rahnama'i: **Prostaglandins and Phosphodiesterases in the Urinary Bladder Wall.** Supervisors: Prof.dr. Ph. Van Kerrebroeck / Prof.dr. S. de Wachter (Universiteit Antwerpen); Co-Supervisor: Dr. G. van Koeveringe.

Mariken B. de Koning: **Studying biomarkers in populations at genetic and clinical high risk for psychosis.** Supervisors: Prof.dr. T. Amelsvoort / Prof.dr. J. Booij (AMC).

Fabien Boulle: **Epigenetic regulation of BDNF/ TrkB signaling in the pathophysiology and treatment of mood disorders**. Supervisors: Prof.dr. H.W.M. Steinbusch / Prof.dr. L. Lanfumey (Universiteit Parijs); Co-Supervisors: Dr. D. van den Hove / Dr. G. Kenis.

**2014**

Iris Nowak-Maes: **Tinnitus; assessment of quality of life & cost-effectiveness.**
Supervisors: Prof.dr. M. Peters / Prof.dr. B. Kremer; Co-Supervisors: Dr. M. Joore / Dr. L. Anteunis.

Marjolein Huijts: **Cognitive function in patients with cerebral small vessel disease.** Supervisor: Prof.dr. R.J. van Oostenbrugge; Co-Supervisors: Dr. A.A. Duits / Dr. J. Staals.

Markus Gantert: **Fetal inflammatory injury as origin of long term disease: Lessons from animal models.** Supervisors: Prof.dr. B. Kramer / Prof.dr. L. Zimmermann; Co-Supervisor: Dr. A. Gavilanes.

Elke Kuypers: **Fetal development after antenatal exposures: Chorioamnionitis and maternal glucocorticoids.** Supervisors: Prof.dr. B.W. Kramer / Prof.dr. H.W. Steinbusch / Prof. dr. Suhas G. Kallapur (University of Cincinnati, Ohio, USA).

Pieter Kubben: **Ultra low-field strength intraoperative MRI for Glioblastoma Surgery.** Supervisor: Prof.dr. J.J. van Overbeeke; Co-Supervisor: Dr. H. van Santbrink.

Laura Baijens: **Surface electrical stimulation of the neck for oropharyngeal dysphagia in Parkinson's disease: therapeutic aspects and reliability of measurement.** Supervisor: Prof.dr. B. Kremer; Co-Supervisor: Dr. R. Speyer, Townsville.

Janneke Hoeijmakers: **Small fiber neuropathy and sodium channels; a paradigm shift.** Supervisor: Prof.dr. R.J. van Oostenbrugge; Co-Supervisors: Dr. C.G. Faber / Dr. I.S.J. Merkies.

Stephanie Vos: **The Role of biomarkers in preclinical and prodromal Alzheimer's disease.** Supervisor: Prof.dr. F.R. Verhey; Co-Supervisor: Dr. P.J. Visser.

Muriël Doors: **The Value of Optical Coherence Tomography in Anterior Segment Surgery.** Supervisors: Prof.dr. R.M. Nuijts / Prof.dr. C.A. Webers; Co-Supervisor: Dr. T.T.J.M. Berendschot.

Anneke Maas: **Sleep problems in individuals with genetic disorders associated with intellectual disability.** Supervisors: Prof.dr. I. Curfs / Prof.dr. R. Didden.

Sebastiaan van Gorp: **Translational research on spinal cord injury and cell-based therapies; a focus on pain and sensorimotor disturbances.** Supervisors: Prof.dr. B. Joosten / Prof.dr. M. van Kleef; Co-Supervisors: Dr. J. Patijn /Dr. R. Deumens, KU Leuven.

Andrea Sannia: **High risk newborns and brain biochemical monitoring.** Supervisor: Prof. dr. J.S.H. Vles; Co-Supervisors: Dr. D. Gazzolo, Alessandria, Italy / Dr. A.W.D. Gavilanes.

Julie A.D.A. Dela Cruz: **Dopamine mechanisms in learning and memory: Evidence from rodent studies.** Supervisors: Prof.dr. H.W.M. Steinbusch / Prof.dr. R.J. Bodnar, New York; Co-Supervisor: Dr. B.P.F. Rutten.

René Besseling: **Brain wiring and neuronal dynamics; advances in MR imaging of focal epilepsy.** Supervisors: Prof.dr. A.P. Aldenkamp / Prof.dr.ir. W.H. Backes; Co-Supervisor: dr. J.F.A. Jansen.

Maria Quint-Fens: **Long-term care after stroke; development and evaluation of a long-term intervention in primary care**. Supervisors: Prof.dr. J.F.M. Metsemakers / Prof.dr. C.M. van Heugten / Prof.dr. M. Limburg, Almere; Co-Supervisor: dr. G.H.M.I. Beusmans.

Veronique Moulaert: **Life after survival of a cardiac arrest; the heart of the matter.** Supervisors: Prof.dr. J.A. Verbunt / Prof.dr. C.M. van Heugten / Prof.dr. D.T. Wade, Oxford, UK.

Feikje Smeets: **The hallucinatory-delusional state: a crucial connection in the psychosis symptom network.** Supervisor: Prof.dr. J. van Os; Co-Supervisor: Dr. T. Lataster.

Lies Clerx: **Alzheimer's disease through the MR-eye; novel diagnostic markers and the road to clinical implementation".** Supervisor: Prof.dr. F. Verhey; Co-Supervisors: Dr. P.J. Visser / P. Aalten.

Sonny Tan: **The subthalamic nucleus in Parkinson's disease.** Supervisors: Prof.dr. Y. Temel / Prof.dr. H.W.M. Steinbusch / Prof.dr. T. Sharp, Oxford, UK / Prof.dr. V. Visser-Vandewalle, Koln.

Koen van Boxem: **The use of pulsed radiofrequency in the management of chronic lumbosacral radicular pain.** Supervisors: Prof.dr. M. van Kleef / Prof.dr. E.A.J. Joosten; Co-Supervisor: Assoc. Prof.dr. J. van Zundert.

Jérôme Waterval: **Hyperostosis cranialis interna**. Supervisors: Prof.dr. J.J. Manni / Prof.dr. R.J. Stokroos.

Sylvie Kolfschoten-van der Kruijs: **Psychogenic non-epileptic seizures; the identification of neurophysiological correlates.** Supervisors: Prof.dr. A.P. Aldenkamp / Prof.dr. K.E.J. Vonck, Universiteit Gent; Co-Supervisors: Dr. J.F.A. Jansen / Dr. R.H.C. Lazeron, Kempenhaeghe.

Wouter Pluijms: **Spinal cord stimulation and pain relief in painful diabetic: polyneuropathy, a translational approach.** Supervisors: Prof.dr. M. van Kleef / Prof.dr. E.A. Joosten; Co-supervisor: Dr. C.G. Faber.

Ron Handels: **Health technology assessment of diagnostic strategies for Alzheimer's disease.** Supervisors: Prof.dr. F.R.J. Verhey / Prof.dr. J.L. Severens (EUR); Co-Supervisor: Dr. M.A. Joore / Dr. C.A.G. Wolfs.

Evelyn Peelen: **Regulatory T cells in the pathogenesis of Multiple Sclerosis: potential targets for vitamin D therapy.** Supervisors: Prof.dr. R.M.M. Hupperts / Prof.dr. J.W. Cohen Tervaert; Co-Supervisor: Dr. J.G.M.C. Damoiseaux / Dr. M.M.G.L. Thewissen, Diepenbeek.

Reint Jellema: **Cell-based therapy for hypoxic-ischemic injury in the preterm brain.** Supervisors: Prof.dr. B.W.W. Kramer / Prof.dr. H.W.M. Steinbusch; Co-Supervisor: Dr. W.T.V. Germeraad / Dr. P. Andriessen, Veldhoven.

Maria Wertli: **Prognosis of Chronic Clinical Pain Conditions: The Example of Complex Regional Pain Syndrome 1 and Low Back Pain.** Supervisors: Prof.dr. M. van Kleef; Co-Supervisor: Dr. F. Brunner, Zürich / Dr. R. Perez, VUmc.

Dagmar Zeef: **An experimental model of Huntington's disease: Validation & Stimulation.** Supervisors: Prof.dr. Y. Temel / Prof.dr. H.W.M. Steinbusch; Co-supervisor: Dr. A. Jahanshahi.

Jeroen Decoster: **Breaking Down Schizophrenia into phenes, genes and environment.** Supervisors: Prof.dr. I. Myin-Germeys / Prof.dr. M. De Hert, KU Leuven; Co-Supervisor: Dr. R. van Winkel.

Eaja Anindya Sekhar Mukherjee: **Fetal Alcohol Spectrum Disorders: exploring prevention and management.** Supervisor: Prof.dr.

L.M.G. Curfs; Co-Supervisor: Prof. S. Hollins, St. George's University of London, UK.

Catherine van Zelst: **Inside out; On stereotype awareness, childhood trauma and stigma in psychosis.** Supervisors: Prof.dr. Ph. Delespaul / Prof.dr. J. van Os. Ibrahim Tolga Binbay: **Extended Psychosis Phenotype in the Wider Social Environment.** Supervisor: Prof.dr. J. van Os; Co-Supervisor: Dr. M. Drukker.

Frank Van Dael: **OCD matters in psychosis.** Supervisors: Prof.dr. J. van Os / Prof.dr. I. Myin-Germeys.

Pamela Kleikers: **NOXious oxidative stress: from head toe too and back.** Supervisors: Prof.dr. H.H.H.W. Schmidt / Prof.dr. H.W.M. Steinbusch; Co-Supervisor: Dr. B. Janssen.

José Luis Gerardo Nava: **In vitro assay systems in the development of therapeutic interventions strategies for neuroprotection and repair.** Supervisors: Prof.dr.med. J. Weis / Prof.dr. H.W.M. Steinbusch; Co-Supervisor: Dr. G.A. Brook, RWTH Aachen.

Eva Bollen: **Cyclic nucleotide signaling and plasticity.** Supervisors: Prof.dr. H.W.M. Steinbusch / Prof.dr. R. D'Hooge, KU Leuven; Co-Supervisor: Dr. J. Prickaerts.

## 2015

Jessica A. Hartmann: **A good laugh and a long sleep; Insights from prospective and ambulatory assessments about the importance of positive affect and sleep in mental health.** Supervisor: Prof.dr. J. van Os; Co-Supervisors: C.J.P. Simons / Dr. M. Wichers.

Bart Ament: **Frailty in old age; conceptualization and care innovations.** Supervisors: Prof.dr. G.I.J.M. Kempen / Prof.dr. F.R.J. Verhey; Co-Supervisor: Dr. M.E. de Vugt.

Mayke Janssens: **Exploring course and outcome across the psychosis-continuum.** Supervisor: Prof.dr. I. Myin-Germeys; Co-Supervisor: Dr. T. Lataster.

Dennis M.J. Hernau: **Dopayours is not dopamine: genetic, environmental and pathological variations in dopaminergic stress processing.** Supervisor: Prof.dr. I. Myin-Germeys; Co-Supervisors: Prof.dr. F.M. Mottaghy / Dr. D. Collip.

Ingrid M.H. Brands: **The adaptation process after acquired brain injury Pieces of the puzzle**. Supervisors: Prof.dr. C.M. van Heugten / Prof.dr. D.T. Wade, Oxford UK; Co-Supervisors: Dr. S.Z. Stapert / Dr. S. Köhler.

Francesco Risso: **Urinary and salivary S100B monitoring in high risk infants.** Supervisor: Prof.dr. J.S.H. Vles; Co-Supervisors: Dr. D. Gazzolo, Genoa,Italy / Dr. A.W.D. Gavilanes.

Alessandro Borghesi: **Stem and Progenitor Cells in Preterm Infants: Role in the Pathogenesis and Potential for Therapy.** Supervisor: Prof.dr. L. Zimmermann; Prof.dr. B. Kramer; Co-Supervisors: Dr. D. Gazzolo, Genoa,Italy / Dr. A.W.D. Gavilanes.

Claudia Menne-Lothmann: **Affect dynamics; A focus on genes, stress, and an opportunity for change.** Supervisor: Prof.dr. J. van Os; Co-Supervisors: Dr. M. Wichers / Dr. N. Jacobs.

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Martine van Nierop: **Surviving childhood new perspectives on the link between childhood trauma and psychosis.** Supervisors: Prof.dr. I. Myin-Germeys / Prof.dr. J. van Os; Co-Supervisor: Dr. R. van Winkel.

Sylvia Klinkenberg: **VNS in children; more than just seizure reduction.** Supervisors: Prof.dr. J. Vles / Prof.dr. A. Aldenkamp; Co-Supervisor: Dr. H. Majoie.

Anouk Linssen: **Considerations in designing an adult hearing screening programme.** Supervisor: Prof.dr. B. Kremer; Co-Supervisors: Dr. L. Anteunis / Dr. M. Joore.

Janny Hof: **Hearing loss in young children; challenges in assessment and intervention.** Supervisors: Prof.dr. B. Kremer / Prof.dr. R. Stokroos / Prof.dr. P. van Dijk, RUG; Co-Supervisor: Dr. L. Antheunis.

Kimberly Cox-Limpens: **Mechanisms of endogenous brain protection; Clues from the transcriptome.** Supervisors: Prof.dr. J. Vles / Prof.dr. L. Zimmermann; Co-Supervisor: Dr. A. Gavilanes.

Els Vanhoutte: **Peripheral Neuropathy outcome measures; Standardisation (PeriNomS) study part 2: Getting consensus.** Supervisors: Prof.dr. C. Faber / Prof.dr. P. van Doorn; Co-Supervisor: Dr. I. Merkies, Spaarne ziekenhuis Hoofddorp.

Mayienne Bakkers: **Small fibers, big troubles; diagnosis and implications of small fiber neuropathy.** Supervisors: Prof.dr. C. Faber / Prof.dr. M. de Baets; Co-Supervisor: Dr. I. Merkies, Spaarne ziekenhuis Hoofddorp.

Ingrid Kramer: **Zooming into the micro-level of experience: An approach for understanding and treating psychopa-** thology. Supervisor: Prof.dr. J. van Os; Co-Supervisors: Dr. M. Wichers, UMC Groningen / Dr. C. Simons.

Esther Bouman: **Risks and Benefits of Regional Anesthesia in the Perioperative Setting.** Supervisors: Prof.dr. M. van Kleef / Prof.dr. M. Marcus, HMC, Qatar / Prof.dr. E. Joosten; Co-Supervisor: Dr. H. Gramke.

Mark Janssen: **Selective stimulation of the subthalamic nucleus in Parkinson's disease; dream or near future.** Supervisors: Prof.dr. Y. Temel / Prof.dr. V. Visser-Vandewalle, Keulen / Prof.dr. A. Benazzouz, Bordeax, France.

Reina de Kinderen: **Health Technology Assessment in Epilepsy; economic evaluations and preference studies.** Supervisors: Prof.dr. S. Evers / Prof.dr. A. Aldenkamp; Co-Supervisor: Dr. H. Majoie / Dr. D. Postulart, GGZ O-Brabant.

Saskia Ebus: **Interictal epileptiform activity as a marker for clinical outcome.** Supervisors: Prof.dr. A. Aldenkamp / Prof.dr. J. Arends, TUE / Prof.dr. P. Boon, Universiteit Gent, België.

Inge Knuts: **Experimental and clinical studies into determinants of panic severity.** Supervisor: Prof.dr. I. Myin-Germeys; Co-Supervisor: Dr. K. Schruers; Influencing panic.

Nienke Tielemans: **Proactive coping post stroke: The Restored4Stroke Self-Management study.** Supervisors: Prof.dr. C. van Heugten / Prof.dr. J. Visser-Meily, UMC Utrecht; Co-Supervisor: Dr. V. Schepers, UMC Utrecht.

Tom van Zundert: **Improvements Towards Safer Extraglottic Airway Devices.** Supervisors: Prof.dr. A.E.M. Marcus / Prof.dr. W. Buhre / Prof.dr. J.R. Brimacombe, Queensland, Australia / Prof.dr. C.A. Hagberg.

Tijmen van Assen: **Anterior Cutaneous Nerve Entrapment Syndrome Epidemiology and surgical management.** Supervisors: Prof.dr. G.L. Beets / Prof.dr. M. van Kleef / Dr. R.M.H. Roumen / Dr. M.R.M. Scheltinga, MMC Veldhoven.

Rohit Shetty: **Understanding the Clinical, Immunological and Genetic Molecular Mechanisms of Keratoconus.** Supervisors: Prof. dr. R.M.M.A. Nuijts / Prof.dr. C.A.B. Webers.

Christine van der Leeuw: **Blood, bones and brains; peripheral biological endophenotypes and their structural cerebral correlates in psychotic disorder.** Supervisor: Prof.dr. J. van Os; Co-supervisor: Dr. M. Marcelis.

Sanne Peeters: **The Idle Mind Never Rests; functional brain connectivity across the psychosis continuum.** Supervisor: Prof.dr. J. van Os; Co-supervisor: dr. M. Marcelis.

Nick van Goethem: **α7 nicotinic acetylcholine receptors and memory processes: mechanistic and behavioral studies.** Supervisor: Prof.dr. H.W.M. Steinbusch; Co-supervisor: Dr. J. Prickaerts.

Nicole Leibold: **A Breath of fear; a translational approach into the mechanisms of panic.** Supervisor: Prof.dr. H.W.M. Steinbusch; Co-supervisors: Dr. K.R.J. Schruers / Dr. D.L.A. van den Hove.

Renske Hamel: **The course of mild cognitive impairment and the role of comorbidity.** Supervisor: Prof.dr. F.R.J. Verhey; Co-supervisors: Dr. I.H.G.B. Ramakers / Dr. P.J. Visser.

Lucia Speth: **Effects of botulinum toxin A injections and bimanual task-oriented therapy on hand functions and bimanual activities in unilateral Cerebral Palsy.** Supervisors: Prof.dr. J. Vles; Prof.dr. R. Smeets; Co-supervisor: Dr. Y. Janssen-Potten, Adelante Hoensbroek.

Yuan Tian: **The effects of Lutein on the inflammatory pathways in age-related macular degeneration (AMD).** Supervisors: Prof.dr. C. Webers; Prof.dr. A. Kijlstra, WUR; Co-supervisor: Dr. M. Spreeuwenberg; Dr. H. Tange.

Peggy Spauwen: **Cognition and Type 2 diabetes; the interplay of risk factors.** Supervisors: Prof.dr. F. Verhey; Prof.dr. C. Stehouwer; Co-supervisor: Dr. M. van Boxtel

Marc Hilhorst: **Crescentic glomerulonephritis in ANCA associated vasculitis.** Supervisors: Prof.dr. J. Cohen-Tervaert; Co-supervisor: Dr. P. van Paassen

Martin Gevonden: **The odd one out: exploring the nature of the association between minority status and psychosis.** Supervisors: Prof.dr. J-P. Selten; Prof.dr. J. Booij, Uva; Prof.dr. I. Myin-Germeys

Bart Biallosterski: **Structural and functional aspects of sensory-motor Interaction in the urinary bladder.** Supervisors: Prof.dr. Ph. Van Kerrebroeck; Prof.dr. S. De Wachter, UvAntwerpen; Co-supervisors: Dr. G. van Koeveringe; Dr. M. Rahnama'i.

Alexandra König: **The use of information and communication technologies (ICT) for the assessment of patients with Alzheimer's Disease and related disorders.** Supervisors: prof.dr. F. Verhey; prof.dr. Ph. Robert, Nice, Fr; Co-supervisors: dr. P. Aalten; dr. R. David, Nice. Fr.

Michelene Chenault: **Assessing Readiness for Hearing Rehabilitation.** Supervisors: prof. dr. M.P.F. Berger; prof.dr. B. Kremer; Co-supervisor: dr. L.J.C. Anteunis.

Anand Vinekar: **Retinopathy of Prematurity. Recent advances in tele-medicine screening, risk factors and spectral domain optical coherence tomography imaging.** Supervisor: prof.dr. C.A.B. Webers; Co-supervisor: dr. N.J. Bauer

Fleur van Dooren: **Diabetes and Depression: exploring the Interface between Pathophysiological and Psychological factors.** Supervisors: prof.dr. F.R.J. Verhey; prof.dr. J.K.L. Denollet, UvT; prof.dr. F. Pouwer, UvT; Co-supervisor: dr. M.T. Schram.

Gabriëlla Pons van Dijk: **Taekwondo and physical fitness components in middle-aged healthy volunteers; the Sekwondo study.** Supervisors: prof.dr. J. Lodder; prof.dr. H. Kingma; Co-supervisor: dr. A.F. Lenssen.

Yara Pujol López: **Development and psychoneuroimmunological mechanisms in depression.** Supervisor: prof.dr. H.W.M. Steinbusch; Co-supervisors: Dr. G. Kenis; Dr. D. van den Hove; Dr. Aye Mu Myint, München.

Romina Gentier: **UBB⁺¹; an important switch in the onset of Alzheimer's disease.** Supervisors: Prof. H. Steinbusch; Prof. D. Hopkins; Co-supervisor: Dr. F. van Leeuwen.

Sanne Smeets: **Insights into insight: studies on awareness of deficits after acquired brain injury.** Supervisor: Prof. C. van Heugten; Prof. R. Ponds; Co-supervisor: Dr. I. Winkens

Kim Beerhorst: **Bone disease in chronic epilepsy: fit for a fracture.** Supervisor: Prof. A. Aldenkamp; Prof. R. van Oostenbrugge; Co-supervisor: Dr. P. Verschuure.

Alex Zwanenburg: **Cerebral and cardiac signal monitoring in fetal sheep with hypoxic-ischemic encephalopathy.** Supervisor: Prof. T. Delhaas; Prof. B. Kramer; Co-supervisors: Dr. T. Wolfs; Dr. P. Andriessen, MMC.

## 2016

Ismail Sinan Guloksuz: **Biological mechanisms of environmental stressors in psychiatry.** Supervisor: Prof. J. van Os; Co-supervisors: Dr. B. Rutten; Dr. M. Drukker.

Seyed Ehsan Pishva MD: **Environmental Epigenetics in mental health and illness.** Supervisor: Prof.dr. J. van Os; Co-supervisors: Dr. B.P.F. Rutten; Dr. G. Kenis.

Ankie Hamaekers: **Rescue ventilation using expiratory ventilation assistance; innovating while clutching at straws.** Supervisors: Prof.dr. W.F. Buhre; Prof.dr. M. van Kleef.

Rens Evers. **22q11.2 deletion syndrome: intelligence, psychopathology and neurochemistry at adult age.** Supervisors: Prof.dr. L.M.G. Curfs; Prof.dr. T. v. Amelsvoort.

Sarah-Anna Hescham. **Novel insights towards memory restoration.** Supervisor: Prof.dr. Y. Temel; Co-supervisor: Dr. A. Blokland; Dr. A. Jahanshahi.

João P. da Costa Alvares Viegas Nunes. **Insulin receptor sensitization improves affective pathology in various mouse models.** Supervisor: Prof.dr. H.W.M. Steinbusch; Co-supervisors: Dr. K-P. Lesch; Dr. T. Strekalova; Dr.B.H. Cline, Oxford.

Yanny Ying-Yee Cheng. **Clinical Outcomes After Innovative Lamellar Corneal Transplantation Surgery.** Supervisor: Prof.dr. R.M.M.A. Nuijts; Co-supervisor: Dr. J.S.A.G. Schouten.

Oliver Gerlach. **Parkinson's disease, deterioration during hospitalization.** Supervisor: Prof.dr. R. van Oostenbrugge; Co-supervisor: Dr. W. Weber.

Remo Arts. **Intracochlear electrical stimulation to suppress tinnitus.** Supervisor: Prof.dr. R.J. Stokroos; Co-supervisor: Dr. E.L.J. Georg.

Mitchel van Eeden. **The €- Restore-4stroke study: Economic evaluation of stroke care in the Netherlands.** Supervisors: Prof.dr.mr. S.M.A.A. Evers; Prof.dr. C.M. v. Heugten; Co-supervisor: dr. G.A.P. van Mastrigt.

Pim Klarenbeek. **Blood pressure and cerebral small vessel disease.** Supervisor: Prof.dr. R.J. van Oostenbrugge; Co-supervisor: Dr. J. Staals.

Ramona Hohnen. **Peripheral pharmacological targets to modify bladder contractility.** Supervisor: Prof.dr. Ph.E.V. van Kerrebroeck; Co-supervisors: Dr. G.A. van Koeveringe; Dr. M.A. Sahnama'i; Dr. C. Meriaux.

Ersoy Kocabicak. **Deep brain stimulation of the subthalamic nucleus: Clinical and scientific aspects.** Supervisors: Prof.dr. Y. Temel; Prof.dr. K. van Overbeeke; Co-supervisor: Dr. A. Jahanshahi.

Sven Akkerman. **Temporal aspects of cyclic messenger signaling in object recognition memory; a pharmalogical approach.** Supervisor: Prof.dr. H.W.M. Steinbusch; Co-supervisors: dr. J. Prickaerts; dr. A. Blokland.

Anja Moonen. **Emotion and Cognition in Parkinson's disease; etiology and neurobiological mechanisms.** Supervisor: Prof.dr. F.R.J. Verhey; Co-supervisor: dr. A.F.G. Leentjens.

Anna Schüth. **Three-dimensional bladder tissue morphology.** Supervisors: Prof.dr. G.A. van Koeveringe; Prof.dr. M. v. Zandvoort, Aachen; Prof.dr. Ph. V. Kerrebroeck.

Elisabeth van der Ven. **Ethnic minority position as risk indicator for autism-Spectrum and psychotic disorders.** Supervisors: Prof.dr. J.P. Selten; Prof.dr. J. van Os.

Zuzana Kasanova. **Environmental reactivity for better or worse; The impact of stress and reward on neurochemistry, affect and behavior across the psychosis continuum.** Supervisor: Prof.dr. I. Myin-Germeys, KU Leuven/UM; Co-supervisor: dr. D. Collip.

Danielle Lambrechts. **Ketogenic diet therapies; treatment for children and adults with refractory epilepsy.** Supervisors: Prof.dr. H.J.M. Majoie; Prof.dr. J.S.H. Vles; Prof.dr. A.P. Aldenkamp; Co-supervisor: dr. A.J.A. de Louw, Kempenhaghe, Heeze.

Frank van Bussel. **Advanced MRI in diabetes; cerebral biomarkers of cognitive decrements.** Supervisors: Prof.dr.ir. W.H. Backes; Prof.dr. P.A.M. Hofman; Co-supervisor: dr. J.F.A. Jansen.

Lisa Schönfeldt. **Neurostimulation to treat brain injury?** Supervisors: Prof.dr. Y. Temel; Prof.dr. S. Hendrikx, Hasselt; Co-supervisor: dr. A. Jahanshahi.

Rianne Geerlings. **Transition in patients with childhood-onset epilepsy; a long way to adulthood.** Supervisor: Prof.dr. A.P. Aldenkamp; Co-supervisors: dr. A.J.A. de Louw, dr. L.M.C. Gottmer, Kempenhaeghe.

Nele Claes. **B cells as multifactorial players in multiple sclerosis pathogenesis: insights from therapeutics.** Supervisors: Prof.dr. V. Somers, Hasselt; Prof.dr. R. Hupperts; Co-su-

pervisors: Prof.dr. P. Stinissen, dr. J. Fraussen, Hasselt.

Olaf Schijns. **Epilepsy surgery and biomarkers from history to molecular imaging.** Supervisors: Prof.dr. J.J. van Overbeeke; Prof.dr. H. Clustermann, Aachen; Co-supervisors: dr. G. Hoogland; dr. M.J.P. v. Kroonenburgh.

Lizzy Boots. **Balanced and Prepared; development and evaluation of a supportive e-health intervention for caregivers of people with early-stage dementia.** Supervisors: Prof.dr. F.R.J. Verhey; Prof.dr. G.I.J.M. Kempen; Co-supervisor: dr. M.E. de Vugt.

Wouter Donders. **Towards patient-specific (cerebro-) vascular model applications.** Supervisors: Prof.dr. T. Delhaas; Prof.dr.ir. F.N. van de Vosse, TUE; Co-supervisor: dr.ir. W. Huberts.

Sizzle Vanterpool. **The implications of intra-uterine invasion by microbes for placental Pathology and the occurrence of adverse pregnancy outcomes.** Supervisor: Prof.dr. B.W. Kramer. Co-supervisors: dr. J.V. Been, Erasmus MC Rotterdam, dr. U von Rango.

Manuela Heins. **The Relationship between Social Adversity, Psychosis, and Depression across an Individual's Life Span.** Supervisor: Prof.dr. I. Myin-Germeys.

Christianus van Ganzewinkel. **NEONATAL PAIN; Out of Sight, Out of Mind?**

Supervisor: Prof.dr. B.W.W. Kramer; Co-supervisor: dr. P. Andriessen, MMC Veldhoven.

Anne-Hilde Muris. **Hype or hope? Vitamin D in multiple sclerosis; A clinical and immunological perspective.** Supervisor: Prof.dr. R.M.M. Hupperts; Co-supervisor: dr. J.G.M.C. Damoiseaux.

Gerard Bode. **The link between ceramide transporters, innate Immunity and Alzheimer's disease.** Supervisor: Prof.dr. M.H.V. de Baets; Co-supervisors: dr. P. Martinez, dr. M. Losen.

Jo Stevens. **Advanced diagnostics and therapeutics for Alzheimer's disease.** Supervisor: Prof.dr. M. de Baets; Co-supervisors: dr. M. Losen, dr. P. Martinez-Martinez.

Rosan Luijcks. **Stress and pain in muscles and brain; developing psychophysiological paradigms to examine stress and pain interactions.** Supervisors: Prof.dr. J.J. van Os; Prof.dr.ir. H.J. Hermens, UT; Co-supervisor: dr. R. Lousberg.

Harmen Jan van de Haar. **Microvascular and blood-brain barrier dysfunction in Alzheimer's disease.** Supervisor: Prof.dr.ir. W. Backes; Prof.dr. F. Verhey; Co-supervisor: Dr. J. Jansen; Dr.ir. M. v. Osch, LUMC.

Coenraad Itz. **Chronic low back pain, considerations about: Natural Course, Diagnosis, Interventional Treatment and Costs.** Supervisor: Prof.dr. M. van Kleef; Prof.dr. F. Huygen, EUR; Co-supervisor: Dr. B. Ramaekers.

Willemijn Jansen. **The Path of Alzheimer's disease: from neuropathology to clinic.**

Supervisor: Prof.dr. F. Verhey; Co-supervisors: Dr. P.J. Visser; Dr. I. Ramakers.

Ligia dos Santos Mendes Lemes Soares. **Phosphodiesterase inhibitors: a potential therapeutic approach for ischemic cerebral injury.** Supervisor: Prof.dr. H.W.M. Steinbusch; Co-supervisors: Dr. R.M. Weffort de Oliveira, Brazil; Dr. J. Prickaerts

Martijn Broen. **Anxiety and depression in Parkinson's disease.** Supervisor: Prof.dr. R.J.

van Oostenbrugge; Co-supervisors: Dr. A.F.G. Leentjens; Dr. M.L. Kuijf.

Sandra Schipper. **Extrasynaptic receptors as a treatment target in epilepsy.** Supervisor: Prof.dr. J.H.S. Vles; Co-supervisors: Dr. G. Hoogland; Dr. S. Klinkenberg; Dr. M.W. Aalbers, RUG.

João Casaca Carreira. **Making sense of Antisense Oligonucleotides Therapy in Experimental Huntington's disease.** Supervisor: Prof.dr. Y. Temel**;** Co-supervisors: Dr. A. Jahanshahi; Dr. W. van Roon-Mom, LUMC.

Dominique IJff. **Trick or Treat? Cognitive side-effects of antiepileptic treatment.** Supervisors: Prof.dr. A.P. Aldenkamp; Prof.dr. M. Majoie; Co-supervisors: Dr. J. Jansen; Dr. R. Lazeron, Kempenhaeghe.

Alfredo Ramirez. **Neurogenetic approach in neurodegenerative disorders.** Supervisors: Prof.dr. B.P.F. Rutten; Prof.dr. H.W.M. Steinbusch; Prof.dr. M.M. Nöthen, University of Bonn.

Nienke Visser. **Toric Intraocular lenses in cataract surgery.** Supervisor: Prof.dr. R.M.M.A. Nuijts; Co-supervisor: Dr. N.J.C. Bauer.

Jakob Burgstaller. **Prognostic indicators for patients with degenerative lumbar spinal stenosis.** Supervisor: Prof.dr. M. van Kleef; Co-supervisors: Dr. M.M. Wertli, University of Zurich; Dr. H.F. Gramke.

Mark van den Hurk. **Neuronal Identity and Maturation: Insights from the Single-Cell Transcriptome.** Supervisors: Prof.dr. H.W.M. Steinbusch; Prof.dr. B.P.F. Rutten; Co-supervisors: Dr. G. Kenis; Dr. C. Bardy, Adelaide.

Maria Nikiforou. **Prenatal stress and the fetal gut. Potential interventions to prevent adverse outcomes.** Supervisors: Prof.dr. B.W. Kramer; Prof.dr. H.W. Steinbusch; Co-supervisor: Dr. T.G. Wolfs.

Janneke Peijnenborgh. **Assessment of cognition, time perception, and motivation in children.** Supervisors: Prof.dr. J.S.H. Vles; Prof.dr. A.P. Aldenkamp; Co-supervisors: Dr. J. Hendriksen; Dr. P. Hurks.

Joany Millenaar. **Young onset dementia; towards a better understanding of care needs and experiences.** Supervisors: Prof. dr. F. Verhey; Prof.dr. R. Koopmans, RUN; Co-supervisors: Dr. M. de Vugt; Dr. C. Bakker, RUN.

## LIST OF PUBLICATIONS

**Thesis**

**van Knippenberg, R.J.M.**, de Vugt, M.E., Ponds, R.W., Myin-Germeys, I., van Twillert, B., & Verhey, F.R.J. (2016). Dealing with daily challenges in dementia (deal-id study): an experience sampling study to assess caregiver functioning in the flow of daily life. *International Journal of Geriatric Psychiatry,* doi: 10.1002/gps.4552.

**van Knippenberg, R.J.M.**, de Vugt, M.E., Ponds, R.W., Myin-Germeys, I., & Verhey, F.R.J. (2016). 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,* doi: 10.1016/j.jagp.2016.10.015.

**van Knippenberg, R.J.M.**, de Vugt, M.E., Ponds, R.W., Myin-Germeys, I., & Verhey, F.R.J. (2016). Dealing with daily challenges in dementia (deal-id study): effectiveness of the experience sampling method intervention 'Partner in Sight' for spousal caregivers of people with dementia: design of a randomized controlled trial. *BMC Psychiatry,* doi: 10.1186/s12888-016-0834-5.

**van Knippenberg, R.J.M.**, de Vugt, M.E., Ponds, R.W., Verhey, F.R.J., & Myin-Germeys, I. Emotional reactivity to daily life stress in spousal caregivers of people with dementia. *Submitted*.

**van Knippenberg, R.J.M.**, de Vugt, M.E., Smeets, C.M.J., Myin-Germeys, I., Verhey, F.R.J., & Ponds, R.W. Dealing with daily challenges in dementia (deal-id study): process evaluation of the experience sampling method intervention 'Partner in Sight' for spousal caregivers of people with dementia. *Under revision in Aging & Mental Health.*

**van Knippenberg, R.J.M.**, de Vugt, M.E., Ponds, R.W., Myin-Germeys, I., & Verhey, F.R.J. Effectiveness of the experience sampling method intervention 'Partner in Sight' for spousal caregivers of people with dementia: results of a randomized controlled trial. *Submitted.*

**Other**

Boots, L.M.M., de Vugt, M.E., **van Knippenberg, R.J.M.**, Kempen, G.I.J.M., & Verhey, F.R.J. (2014). A systematic review of internet-based supportive interventions for caregivers of patients with dementia. *International Journal of Geriatric Psychiatry, 29(4),* 331-344.

## CURRICULUM VITAE

Rosalie van Knippenberg werd geboren op 9 augustus 1988 te Maasbree. In 2006 behaalde zij haar VWO diploma aan College Den Hulster te Venlo. Hierna studeerde zij psychologie aan de Radboud Universiteit Nijmegen. In het kader van de master neuro- en revalidatiepsychologie liep zij zowel een klinische als wetenschappelijke stage op de afdeling Medische Psychologie van het Zuyderland Medisch Centrum, waarbij ze de Basisaantekening Psychodiagnostiek (BAPD) behaalde. Na afronding van haar master in 2011 (cum laude), vervolgde Rosalie haar klinische werkzaamheden bij het Zuyderland Medisch Centrum tot zij in 2012 de mogelijkheid kreeg om als promovendus te starten bij de afdeling Psychiatrie en Neuropsychologie van de Universiteit Maastricht. Gedurende haar promotietraject werkte zij aan dit proefschrift, vervulde zij onderwijstaken op verschillende faculteiten en was zij actief betrokken bij maatschappelijke projecten van het Alzheimer Centrum Limburg. Momenteel werkt Rosalie als Postdoc onderzoeker bij de afdeling Psychiatrie en Neuropsychologie van de Universiteit Maastricht aan verschillende projecten om de toepassing van de experience sampling methode (ESM) in de klinische praktijk verder uit te breiden. Daarnaast is zij sinds september 2016 werkzaam als psycholoog bij de Zorggroep, waar zij haar passie voor het werken in de ouderenzorg ook in de klinische praktijk inzet.