An Experience Sampling Method Intervention for Dementia Caregivers: Results of a Randomized Controlled Trial

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Objective: Ecological momentary interventions integrated with real-life assessments using the experience sampling method (ESM) could be promising to effectively support dementia caregivers in daily life. This study reports on the effectiveness of the ESM-based intervention “Partner in Sight.” Design, Setting, Participants: A randomized controlled trial with 76 dementia caregivers was performed. Participants were randomly assigned to the intervention group (“Partner in Sight”: ESM self-monitoring and personalized feedback), the pseudo-intervention group (ESM self-monitoring without feedback), or the control group (usual care). Measurements: Effects were evaluated pre- and postintervention and at 2-month follow-up. Primary outcomes were retrospective measures of caregiver sense of competence and mastery. Secondary outcomes were retrospective measures of depression, anxiety, and perceived stress. Complementary ESM measures of positive and negative affect were collected pre- and postintervention. Results: Both the experimental and pseudo-experimental groups showed an increase in retrospective sense of competence and a decrease in perceived stress at 2-month follow-up. At postintervention, the experimental group showed a decrease in momentary negative affect compared with the pseudo-experimental and control groups. No effects were found for retrospective mastery, depression, anxiety, and momentary positive affect. Conclusions: ESM interventions could be an important asset for increasing caregiver resources and could help caregivers to better adapt and manage difficult situations and to protect against negative emotions. (Am J Geriatr Psychiatry 2018; 26:1231–1243)

Key Words: Dementia, caregiver support, ecological momentary assessment, randomized controlled trial

Highlights
- Ecological momentary interventions, as based on the experience sampling method, contribute to ongoing efforts to enhance the efficacy of caregiver interventions.
- Real-life self-monitoring with and without receiving personalized feedback is effective for increasing caregiver resources and reducing negative feelings.
A focus on positive experiences in caregiver interventions does not lead to increased positive emotions, but rather helps caregivers better regulate negative emotions.

INTRODUCTION

Providing care to a person with dementia can have a substantial impact on the mental and physical health of the caregiver. There is a need for interventions that effectively support caregivers in daily life. Existing psychosocial interventions have demonstrated positive effects on caregiver outcomes, but effects are in general small, and the methodological quality of most studies is limited. Recently, researchers have started to examine the effectiveness of technology-based interventions in providing support and information for caregivers. Rapid technological advances provide new opportunities to extend interventions beyond the clinical setting and 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). So far, EMIs have proven useful in the treatment of various patient groups, including persons with diabetes, asthma, and severe mental illness. However, to the best of our knowledge, no study has yet investigated the potentials and efficacy of EMIs in supporting dementia caregivers.

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), could provide both the caregiver and clinician with detailed information on caregiver well-being. Monitoring caregiver functioning in real life might help clinicians detect at what moments support is most needed, and could help to prevent high levels of burden in a later stage. To this end, EMIs could serve as a useful add-on tool to standard counseling or existing psychological interventions for caregivers of people with dementia, as they reveal fluctuations in caregiver experiences and, therefore, provide a more comprehensive and dynamic view of caregiver functioning. Moreover, the effectiveness of any therapy targeting psychological mechanisms is likely to be greater if delivered in real life, outside the clinician’s office. Additionally, EMIs offer the opportunity to actively involve caregivers in their own empowering process. Self-monitoring may promote awareness of adaptive and dysfunctional patterns of emotions and behavior, and may induce behavioral change accordingly. Caregivers could learn to become more aware of and to engage more in behaviors that elicit positive emotions, such as relaxation and social activities. 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. Positive emotions thus seem to be important facilitators of adaptive coping and could help build enduring personal resources for managing future threats. An increased ability to adapt to the changes that characterize dementia will benefit caregivers in terms of feeling more in control and competent to care.

To ultimately establish behavioral change, personalized feedback on positive affect experience, based on self-monitoring reports and tailored to the specific needs of the caregiver, could be provided. A recent randomized controlled trial in persons with depression demonstrated that adding personalized feedback on positive affect experience resulted in more lasting effects compared with self-monitoring without feedback. Based on this study and the results from a recently performed study on the feasibility of the ESM in caregivers of people with dementia, we developed the EMI program “Partner in Sight” for dementia caregivers.

OBJECTIVES

This study aims to examine the effectiveness of the EMI program “Partner in Sight” in a randomized controlled trial with three arms: ESM self-monitoring, including personalized feedback; ESM self-
monitoring without feedback; and care as usual. Effects were evaluated using retrospective as well as momentary outcome measures to provide both a global and more detailed view of caregiver well-being.\(^8,18\) Primary outcomes were retrospective measures of caregiver sense of competence and mastery. Secondary outcomes were retrospective measures of depressive symptoms, anxiety symptoms, and perceived stress. Momentary outcome measures included levels of positive and negative affect experienced in daily life.

**METHODS**

**Participants and Design**

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 Society. Participants were included if they were a spousal caregiver of a person with dementia, shared a household with the person with dementia, and provided written informed consent. Caregivers with insufficient cognitive abilities to engage in the ESM were excluded from participation. Also, vulnerable caregivers who felt overburdened or had severe health problems causing inability to perform activities of daily living (based on the clinical judgment of a knowledgeable practitioner) were excluded in order to protect them against the time-intensive nature of the ESM and to minimize the drop-out rate.

A single-blinded randomized controlled trial (RCT) was conducted with three treatment arms. Following the baseline assessment, participants were randomly assigned to the intervention, pseudo-intervention, or control group. The intervention group participated in an ESM procedure (ESM self-monitoring for 6 consecutive weeks and three face-to-face feedback sessions with a personal coach [psychologist]). Feedback sessions immediately followed after every 2 weeks of ESM data collection. The feedback was provided both verbally and graphically according to a standardized protocol. During the first feedback session, the module “daily life activities” was discussed with the caregiver, and levels of positive affect in the context of different daily activities were presented (Fig. 1A, B). In the second feedback session, the module “social interactions in daily life” was added, including levels of positive affect in different social contexts. The third feedback session combined both modules. At the end of each session, changes in the level of positive affect over the course of the intervention were evaluated (Fig. 1C). A written copy of the feedback was provided to both the participant and the involved clinician after each session. More detailed information on the content of the feedback sessions is described elsewhere.\(^19\)

The pseudo-intervention group was similar in procedure to the intervention group, except that no

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ESM-derived feedback was provided during the intervention sessions. Alternatively, a semi-structured interview concerning the participant’s well-being during the previous 2 weeks was conducted in order to prevent any effects resulting from different session durations.

**Experience Sampling Methodology**

The ESM was performed according to previous ESM studies. The “PsyMate,” a palmtop, was used to digitally collect momentary assessments and to provide ESM-derived feedback. The feasibility of
the “PsyMate” in caregivers of people with dementia has recently been demonstrated. The “PsyMate” was programmed to generate 10 beeps (sound and vibration) per day at random intervals between 7:30 A.M. and 10:30 P.M. At each beep, participants were asked to complete a brief questionnaire on the screen of the “PsyMate,” including current mood (four positive affect and eight negative affect items), self-esteem (four items), physical well-being (four items), and current context (e.g., social company, activities, location, and important events). A detailed overview of the ESM items and related concepts is presented elsewhere.19

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

The ESM procedure was explained in a 30-minute briefing during the baseline assessment, and a demo questionnaire was presented to ensure that participants understood the questions and device. A process evaluation was performed to assess participants’ general experiences with the ESM procedure and the ESM-derived feedback. These results have been described elsewhere.23

**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), which consists of seven items and reflects caregivers’ feelings of being capable of caring for the person with dementia.24 Total scores range from 7–35. Feelings of mastery were measured with the seven-item Pearlin Mastery Scale.25 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 was used to assess depressive symptoms.26 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. The seven-item anxiety subscale of the Hospital Anxiety and Depression Scale was used to rate the severity of anxiety symptoms in caregivers. Total scores range from 0–21.

Caregiver and care recipient (socio-) demographics, including age, gender, education level, severity of dementia, caregiver hours of contact with and care for the person with dementia, and care recipient hours spent in a dementia daycare setting were obtained during the baseline assessment. The Clinical Dementia Rating Scale was used to rate the severity of dementia on a five-point scale from zero (normal) to three (severe dementia). Additional retrospective measures of quality of the relationship, emotional instability, coping, and neuropsychiatric symptoms in the person with dementia 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. The 12-item neuroticism domain of the NEO Five-Factor Inventory was used to assess emotional instability. The 44-item Utrecht Coping List 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. Neuropsychiatric symptoms in the care recipient were evaluated with the Neuropsychiatric Inventory Questionnaire. Total scores range from 0–36.

ESM measures of momentary positive and negative affect were assessed during a 3-day ESM baseline assessment and 3-day ESM postintervention 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 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 alpha = 0.80 for the mean-centered scores). Responses were rated on seven-point Likert scales (ranging from one [not at all] to seven [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 Kruskal-Wallis tests for continuous variables and \( \chi^2 \) tests for categorical variables. Nonparametric tests were used to account for violation of equality of variances among the three groups. 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, generalized estimated equations for the Gaussian family and identity-link function were specified to yield population average unstandardized regression coefficients (B) and their 95% confidence intervals (CI). Treatment allocation (intervention, pseudo-intervention, control group) was entered as a between-subject factor, time (baseline, postintervention, 2-month follow-up) as a within-subject factor, and their two-way interaction as an additional factor. To account for the correlated data (repeated measures), an unstructured working correlation matrix (R matrix) was specified. Post-hoc analyses were performed to calculate estimated between-group effects. All tests of significance reported mean change and were two-tailed with a minimal alpha set at 0.05.

To examine changes in momentary measures of positive and negative affect between baseline and postintervention assessment for each group, linear mixed models were performed separately for each outcome measure. Linear mixed models 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). Treatment allocation (intervention, pseudo-intervention, control groups), time (baseline, postintervention), and their two-way interaction were entered as fixed factors in the model. The multilevel models for positive and negative affect included a random intercept for subjects and days and a random slope for time. The postestimation command test (providing Wald tests) was used to calculate and compare the effect of time on affect in the different groups. Data from all valid ESM periods, i.e., periods with at least 33% completed reports of the total 30 ESM reports, were included in the analyses.
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 intervention (N = 26), pseudo-intervention (N = 24), or control group (N = 26). Reasons for declining participation are described elsewhere. Of the 76 randomized participants, 64 completed the postintervention assessment (numbers analyzed per group for the primary and secondary outcomes: N = 20 in the intervention, N = 20 in the pseudo-intervention, and N = 24 in the control group) and 61 completed the 2-month follow-up assessment (numbers analyzed per group for the primary and secondary outcomes: N = 19 in the intervention, N = 20 in the pseudo-intervention, and N = 22 in the control group). Figure 2 presents the participant flow throughout the study.

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

Compliance

Of the 50 participants allocated to the intervention or pseudo-intervention group, 39 (78.0%) fully completed the 6-week intervention, including 6 × 3 ESM assessment days and three corresponding face-to-face sessions. The noncompleters (M = 16.1) took care of people with dementia who were spending significantly more hours in a dementia daycare setting compared with the completers (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 intervention and the pseudo-intervention groups 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 (χ²[1] = 0.04, p = 0.85). Feedback sessions lasted significantly longer (M = 89.1 ± 23.1 minutes, range: 45–150 minutes) compared with the pseudo-intervention sessions (M = 57.4 ± 10.7 minutes, range: 30–90 minutes) (t[115] = 9.44, p > 0.001).

Primary Outcomes

A significant overall interaction effect was found 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 (Fig. 3A). SSCQ scores differed between groups at 2-month follow-up: both the intervention and the pseudo-intervention groups had higher SSCQ scores compared with the control group (B = 4.35; 95% CI 1.97–6.73; t[63] = 3.65; p = 0.001; and B = 2.71, 95% CI 0.34–5.09; t[61] = 2.29, p = 0.026, respectively). SSCQ scores of the intervention and pseudo-intervention groups were not different at 2-month follow-up (B = 1.63; 95% CI -0.82, 4.09; t[62] = 1.33; p = 0.188). The overall interaction effect between treatment allocation and time on retrospective feelings of mastery was nonsignificant (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

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 (Fig. 3B). Between-group comparisons demonstrated that the difference in PSS scores became significant at postintervention between the pseudo-intervention and control groups (B = -3.93; 95% CI -7.23, -0.63; t[61] = -2.38; p = 0.020). At 2-month follow-up, both the pseudo-intervention and intervention groups displayed lower perceived stress compared with the control group (B = -4.72; 95% CI -7.86, -1.58; t[60] = -3.01; p = 0.004; and B = -4.65; 95% CI -7.80, -1.50; t[62] = -2.95; p = 0.004, respectively). There was no significant difference in PSS scores between the intervention and pseudo-intervention groups (B = 0.07; 95% CI -3.18, 3.32; t[61] = 0.04; p = 0.967). The overall interaction effects between treatment allocation and time on retrospectively measured symptoms of depression and anxiety were nonsignificant (F[4,59] = 1.82, p = 0.137, and F[4,59] = 1.46, p = 0.226, respectively).

Experience Sampling Method Outcomes

A total of 74 participants collected ESM data during the 3-day ESM baseline assessment, and 62 participants also collected ESM data during the 3-day ESM postintervention assessment. Data from two participants in the ESM baseline assessment and data from two participants in the ESM postintervention assessment were excluded from the analyses for completing fewer than 10 valid reports (less than 33% of the total 30 ESM reports), resulting in a total number of 3007 valid ESM reports for the analyses.

Results of the multilevel regression analyses showed a significant overall interaction effect between treatment allocation and time on momentary negative affect (χ²[2] = 13.00, p = 0.002), indicating
that negative affect scores differed between the three groups over the course of the intervention period. Between-group comparisons revealed that the intervention group experienced lower levels of negative affect at postintervention compared with the pseudo-intervention (B = 0.17, 95% CI 0.05–0.29, standard error = 0.06, z = 2.72, p = 0.007) and control groups (B = 0.21, 95% CI 0.09–0.32, standard error = 0.06,
The pseudo-intervention and control groups did not significantly differ on levels of negative affect over time ($\chi^2[1] = 0.39$, $p = 0.532$). No significant overall interaction effect between treatment allocation and time was found for momentary levels of positive affect ($\chi^2[2] = 2.99$, $p = 0.224$).

**DISCUSSION**

This study examines the effectiveness of an EMI program for supporting caregivers of people with dementia in daily life. Allocation to both the intervention (ESM self-monitoring and feedback) and
pseudo-intervention groups (ESM self-monitoring without feedback) was associated with increased levels of sense of competence and decreased levels of perceived stress after 2 months compared with the usual care group. The difference between the intervention and pseudo-intervention groups was nonsignificant, 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. A recent RCT examining the effectiveness of an EMI in persons with depression yielded comparable results: at 2-month follow-up, both the intervention and pseudo-intervention groups showed a decline in depressive symptoms compared with the control group. However, only in the intervention group did effects persist until the last follow-up 6 months later. This suggests that personalized feedback adds value when it comes to achieving sustainable changes in behavior rather than short-term compensation for deficits. A future study, including longer follow-up assessments, could provide important information on the potential added value of personalized feedback in accomplishing sustainable change.

Differences between groups on sense of competence and perceived stress particularly emerged 2 months after the intervention. Transferring new insights into everyday life and changing behavioral habits might take time, which could explain why effects on these retrospective measures were not yet present at postintervention. However, a follow-up study examining behavioral changes during the EMI in persons with depression showed that participants in both the intervention and pseudo-intervention groups engaged more in social behaviors and less in sedentary behaviors from baseline to postintervention in comparison with the control group. Nevertheless, results illustrated a large heterogeneity in the extent to which individuals showed change in different behaviors over time during the EMI. Individuals may differ in the type of behavioral change they show upon self-monitoring and in the extent to which their daily life behaviors affect their emotional well-being. More research is needed to examine potential behavioral change in the current study and associations with mood and personal resources, such as sense of competence.

Effects on momentary measures of negative affect appeared immediately after the intervention period: caregivers in the intervention group demonstrated lower levels of momentary negative affect compared with the pseudo-intervention and control groups. Contrary to retrospective assessments, momentary assessments provide a more fine-grained view of caregiver functioning and could reveal subtle changes that occur within individuals during or immediately after the intervention. Moreover, ESM allows for capturing in-the-moment experiences that caregivers may not be consciously aware of. It is plausible to assume that the ESM-derived feedback provoked implicit positive effects immediately after the intervention and eventually became explicit to participants after a longer time period. Results of our process evaluation support this idea: several participants reported not being 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 increasing positive caregiver experiences, effects on momentary positive affect did not differ among groups. This finding is in line with the follow-up study of the RCT by Kramer et al., showing that positive affect-focused feedback did not significantly impact daily life positive affect. Our study results suggest that our intervention is a particularly important asset for reducing negative feelings in caregivers and in helping them better adapt to and deal with the daily challenges of dementia. Results highlight that a focus on positive caregiver experiences and caregivers’ ability to cope with the care situation could lead to better adaptation, as evidenced by an increase in sense of competence, and help regulate negative emotions, as proven by a decrease in momentary negative affect and perceived stress. It is plausible to assume that an increase in momentary positive affect is not the mechanism behind the observed increase in sense of competence and decrease in negative affect and perceived stress. Future research is necessary to search for alternative mechanisms by investigating the temporal dynamics of affect and conducting within-person mediation analyses.

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 (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. In our study, caregivers reported relatively high levels of sense of competence and positive affect and low levels of negative affect, which might be specific to caregivers who are not yet facing extreme external demands. Therefore, it remains unknown how the results of this study generalize to a more heterogeneous caregiver population. Furthermore, the study might have been underpowered for detecting smaller treatment effects that may be clinically relevant.49 Second, the possibility cannot be fully excluded that the effects found in the intervention and pseudo-intervention groups are a result of the study procedure, including face-to-face sessions with a coach that might have had a soothing or activating effect. Third, the longer duration of the feedback sessions in the intervention group (approximately 30 minutes per session) may have had an impact on the results. Finally, this study does not report on the size of the EMI effects, as there is currently no consensus in the literature on how to conceptualize and/or calculate effect size measures for multilevel designs.30 A review by Feingold41 showed that formulas used to calculate effect sizes for studies involving multilevel analyses are not conceptually and mathematically equivalent, and none of them expressed the effect size in the same metric deployed in classical analysis, precluding their use in meta-analysis.

Clinical Implications and Future Research

Introducing EMIs in dementia care offers possibilities for bridging the gap between the clinician’s office and the caregiver’s everyday life. This study shows that EMIs, consisting of ESM self-monitoring with and without personalized feedback, may be a useful addition tool for gaining insight into caregivers’ everyday functioning and for increasing caregiver resources that could help caregivers to better adapt and manage difficult situations and protect against negative emotions. Caregivers in our study sample already experienced relatively high levels of sense of competence (SSCQ: $M = 25 \pm 5.2$) and low levels of negative affect ($M = 1.9 \pm 0.9$) at baseline compared with previous studies,14,42,43 but the EMI program proved to be powerful enough to induce significant effects. The study highlights the importance of focusing on positive caregiver experiences to enhance adaptation and reduce negative feelings. Future research into actual changes in daily life behaviors over the course of the current EMI could be useful to better understand the underlying mechanisms that led to the beneficial effects of the current EMI program.

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.

Conclusions

This study demonstrates that EMIs are promising treatments for strengthening dementia caregivers in the caretaking process. However, the application of EMIs in the field of dementia care is still in its infancy. Future research is needed for further fine-tuning and implementation in clinical practice.

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