Experience sampling in dementia care – an innovative intervention to support caregivers in daily life

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Background
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Caregiver support in daily life
Ecological momentary interventions

Support in clinical setting  Support in daily life
Experience Sampling Method (ESM)

In the moment vs Retrospective

PsyMate

ALZHEIMER
CENTRUM LIMBURG
PsyMate

- Sampling protocol
  - 10 random beeps per day

- ESM daily questionnaire
  - Current subjective experiences (e.g. PA, NA) & context

- ESM evening questionnaire
  - Overall feeling during the day & daily sense of competence

Activity  Company  Location
Focus on positive experiences

- Monitoring caregiver functioning
  - Daily fluctuations
- Person-tailored ESM-derived feedback
  - On positive affect experience
  - Enhance ability to cope with stress
  - Regulate negative feelings
- More positive view on dementia & health\(^1\)

\(^1\)Huber et al. 2011, *BMJ*
Example ESM-derived feedback

- Active relaxation
- Passive relaxation
- Doing nothing
- Self care
- Taking care of partner
- Household activities

Positive affect
(1) Exploratory study

- 31 spousal caregivers of people with dementia
  - 6 days of ESM data collection with PsyMate
- Feasibility and subjective experiences ESM\(^1\)
  - High response rate 78.8%
  - Positive experiences regarding method & device
  - Time-intensive
- Relevant elements intervention
  - Positive relationship sense of competence & positive affect\(^2\)
  - Sense of competence and mastery reduce emotional stress reactivity

\(^1\) Van Knippenberg et al. 2016, *International Journal of Geriatric Psychiatry*

\(^2\) Van Knippenberg et al. accepted for publication, *AJGP*
2) Intervention study

• ESM intervention **Partner in Sight**¹
  • Based on existing intervention in people with depression²
  • 6 weeks, 3 days per week ESM data collection
  • 3 feedback sessions with personal coach = blended approach

• RCT 3 treatment arms
  • Intervention (ESM + feedback), pseudo-intervention (ESM only) & control group (usual care)

• Process & effect evaluation
  • Retrospective sense of competence, mastery, perceived stress, anxiety, depression (pre-, post-intervention, 2 months FU)
  • Momentary PA & NA (pre-, post-intervention)

¹ Van Knippenberg et al. 2016, *BMJ*
² Kramer et al. 2014, *World Psychiatry*
Process evaluation

• Participation rate: 31.4% (76/242)
• Reasons refusal: no need for support, too time-intensive or burdensome, non-familiarity with ICT
• Completion rate: 76.9% (20/26)
• High satisfaction with content and structure
• Feedback increased awareness of own feelings and behavior
• Importance personal coach

1Boots et al. 2013, International Journal of Geriatric Psychiatry
“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”
Effect evaluation
Perceived stress
Momentary negative affect
Conclusion

- ESM is a promising assessment and intervention tool in the field of dementia care
- Barriers to implementation in clinical practice should be carefully considered
- Caregiving is ambivalent process – careful not to tip the balance towards a too positive approach
Thank you!

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