Deal-iD Study: Dealing with daily challenges in Dementia

A feasibility study of the Experience Sampling Methodology in spousal caregivers of people with dementia

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Background

Lack of ecologically valid and sufficiently detailed information on how caregivers perceive and react on a daily basis to the challenges of dementia

Experience Sampling Method (ESM) momentary assessment in daily life
PsyMate
PsyMate

- ESM-based device
- 10 random beeps per day
- Monitors experiences and behavior of spousal caregivers in daily life
- Morning & evening questionnaire

**Feedback** on daily caregiver functioning:
- mood, burden, activities, events, social situations
PsyMate - Benefits

• Better monitoring of daily caregiver functioning → providing efficient care
• Person-tailored feedback on relevant patterns in daily life → which activities/situations are associated with positive emotions?
• In-depth information on interaction patterns between caregiver and person with dementia
Example of feedback
Feasibility study – background

- ESM has been studied intensively in psychiatric populations
- Introducing ESM in a new field
  - study Fonareva et al. (2012)
  - study Poulin et al. (2010)
- Adapt PsyMate to caregivers of people with dementia and conduct a feasibility study
Feasibility study – objectives

- Examining compliance with the PsyMate
- Examining subjective experiences: difficulty, time burden, overall acceptability
- Examining presence of patterns in daily life
1 Feasibility study - methods

- 31 spousal caregivers of people with dementia
- Introduction session: explanation of study procedure and a 30-minute training session
- ESM period: ESM data collection for 6 consecutive days with PsyMate
- Debriefing session: assessment of general experiences with the PsyMate
Feasibility study - results

- 12 men, 19 women: mean age 70.25 years ($SD$: 6.13 years; range 57-82 years)
- High compliance rate of 78.8% (1466/1860)
- 1 person was noncompliant with ESM
- No fatigue effects: missing data were not associated with number of days in the study
Feasibility study - results

- Positive ratings regarding the difficulty, time burden, interference with daily activities, and overall acceptability
Feasibility study

”I could always express my feelings and thoughts in the PsyMate – it felt like a real buddy”
Feasibility study - results

Type of activities

- Doing nothing: 10%
- Resting: 16%
- Work: 7%
- Household: 8%
- Self care: 8%
- Taking care of partner: 19%
- Relaxation: 7%
- Other: 25%
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Feasibility study - results

Social company

73% of participants reported spending time with their partner, 15% with others, and 4% with family, friends, colleagues, or care professionals.
Feasibility study - results

Location

- At home: 85%
- With family/friends: 7%
- At work: 3%
- Health care setting: 3%
- Public place: 1%
- En route: 1%
① Feasibility study - results
Feasibility study - conclusions

- ESM seems to be a feasible method to gain more insight into daily caregiver functioning and relevant patterns in daily life
- The PsyMate is a feasible and user-friendly device to implement ESM in clinical practice
Next step: intervention study

- Evaluation of the effectiveness of the PsyMate in daily life to increase feelings of competence and control
- 6-week intervention period:
  - ESM data collection with PsyMate
  - Face-to-face feedback every two weeks
- 105 caregivers randomly assigned to 3 treatment arms: 1) intervention group 2) pseudo-intervention group 3) control group
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